

## Background

The NYC Pandemic Response Institute is convening a series of multi-sectoral Data Expos to reflect on past data-sharing experiences during emergencies and to consider objectives for future partnerships at various stages of public health emergencies. The first expo, held on February 7, 2024, included stakeholders from academia, government, and business sectors. The focus was on the data available within these sectors and the challenges of sharing data among them. Starting with the second expo, civil society and community leaders—many of whom have already participated in similar data-sharing discussions and indicated they did not need to attend this initial conversation—will also be invited.

## Expo Agenda

The first expo featured a moderated panel discussion and a small-group exercise where participants examined illustrative disaster and emergency scenarios. They explored the partnerships, data sources, data-sharing infrastructure, and collaborations needed to improve understanding and response capabilities across the initial response, expansion, and recovery phases.

## Document Purpose

This document summarizes the day's discussions on past experiences, creative problem-solving, partnership ideas, and next steps to advance these concepts through the Data Expo series. It does not represent any specific perspective or recommendation from PRI. Insights from these discussions will help shape the agendas of upcoming, larger Data Expos, which will involve a wider range of civil society and healthcare partners and lead to PRI's formal recommendations, proposed data projects, and other concrete outcomes.

## Summary of Past Experiences

Participants reflected on past experiences with data sharing during emergencies, and discussed considerations for improved data sharing and collaborative practices:

- **Burdens of data sharing:** issues related to timeliness, adaptability, and the absence of a common framework to support efficient, effective, and compliant data sharing practices among different entities and types of entities.
- **Real-time data reporting:** sharing provisional data with the public in real-time during emergencies (e.g. daily vs. annually), while clearly communicating that the data may be subject to change, has been successful.
- **Data literacy and communication:** variations in levels of data familiarity, data skills, and goals for data use among various stakeholders (primarily government, academia, and business)

representatives), combined with how data is analyzed, who analyzes it, and how data is communicated.

- **Progressively advancing systems:** efforts such as Regional Health Information Organizations (RHIOs) are enabling improvements in data availability and understanding across those partners with access.
- **Transparent communication:** limited understanding about the process for data sharing, who can access data, and how access affected the ability to collaborate.
- **Interoperability hurdles:** differences in data systems across organizations interested in sharing data and lack of interoperability hindered efficient data sharing.

## Data Capacity Building Participant Suggestions

Participants reflected on successes and made suggestions across 5 key themes to develop efficient and effective data sharing capacity within and across sectors before, during, and after emergencies. These suggestions could be implemented or enacted by any entity or sector working with emergency data, whether business, healthcare provider or government. For maximum citywide impact, they require multi-sectoral collaboration and should not be read as the responsibility of any one player. Future data expos will explore these suggestions further to find and solidify activities that will enhance citywide data sharing and capacity.

1. Explore ways to coordinate data collection efforts within and across organizations and sectors
  - a. Streamline data collection approaches to reduce burden on both data collectors and data providers
  - b. Engage potential data sharing entities in data design and collection
  - c. Consider from the start that data may need to be shared and how this could be supported
  - d. Improve upon existing data systems to develop an informative basis for early decision making at the start of emergencies, when less might be known
2. Consider the use of various types of data and sources
  - a. Encourage use of different approaches to data collection, including quantitative, qualitative, and unstructured - understanding challenges involved with each type of collection and analysis
  - b. Utilize data sources beyond traditional health survey data, electronic medical records, and government-based registries to broaden the scope of insights (see Appendix A)
3. Enhance data literacy and data analytic capacity
  - a. Implement workforce development initiatives that invest in training programs on data analysis and data literacy to advance the skill set of personnel involved in data-related tasks and use of data
  - b. Initiate activities to assist in building the general public's data literacy to improve understanding of what data can and cannot tell us during emergencies
  - c. Expand opportunities for cross-agency data analytics engagement to enable effective use of cross-agency data and increase interested parties' awareness of existing activities in this area

- d. Implement data quality improvement systems to support the implementation of the corrective actions identified in previous emergencies' after action reports in all sectors of society (government, community, industry, civil society). Enhance partnerships and collaborations across stakeholders, organizations, and sectors
  - e. Engage with cross-sector partners to leverage their expertise, (e.g. industry may have expertise in areas like supply chain management that would be beneficial to other sectors during emergencies)
  - f. Consider establishing a Data Trust (e.g., [Commonwealth Data Trust](#)) to include data from various agencies and organizations (see Appendix B), foster confidence around data access, and ensure security of the information
4. Improve public communication, transparency, and reporting around data
    - a. Engage with partners across sectors to identify different data cadence needs during public health emergencies and how data can support maximum timeliness and transparency
  5. Explore multi-sectoral infrastructure to support expansion of options and opportunities for collaborative data sharing
    - a. **Consider feasibility of centralized data platforms:** create a platform listing available data sources to enhance accessibility and transparency
    - b. **Contemplate common data models:** implement standardized data models to enhance consistency and interoperability across collaborative efforts
    - c. **Create shared and/or published data dictionaries:** develop comprehensive data dictionaries to establish a standardized reference among collaborating entities across stakeholders, organizations, and sectors
    - d. **Create a formal mechanism to facilitate data sharing:** utilize a pre-established mechanism to streamline and facilitate data sharing processes, providing a foundation for collaboration and compliant data sharing practices
    - e. **Design data sharing/data use agreements (DUAs):** formalize legal agreements to delineate the terms and conditions of data sharing

## Ideas for Supporting and Sustaining partnerships and Collaborations

Participants reflected on key partnerships for data sharing before, during, and after emergencies and aligned on the need to build strong relationships across sectors, focus areas, and disciplines proactively (e.g., before an emergency) to leverage varied data sources/types and tap into diverse expertise.

Of note is the critical role of multi-level partnerships - be it among community, government, academia, social service, health facilities, and industry or between city, state, and federal government — before, during, and after emergencies to ensure a coordinated, unified, and informed response.

Such partnerships could facilitate:

- Coordinated legislation and regulations, including national-level data use agreements (DUAs), to

- ensure shared privacy and security protocols for handling/sharing data
- Real-time data sharing
- Resource allocation/resource mapping
- Unified emergency planning
- Collaborative research initiatives
- Joint data analysis
- Unified public communication to ensure the dissemination of accurate and timely information
- Integration of diverse data sources, resources, and expertise
- Harnessing research efforts and data modeling capacity
- Soliciting and appreciating the needs of people and communities who are most impacted
- Building trust
- Identifying and acknowledging the strengths of affected communities that can support resilience
- Amplifying the reach and impact of emergency response strategies

## Next Steps

PRI Data Expo 1 aimed to inform the design and planning of subsequent convenings and form the basis for setting up a data sharing community of practice that will focus on the following:

- Share learnings and document best practices
- Develop case studies for effective data sharing
- Develop a set of data sharing principles to increase multisource data access, effective data use, and data equity
- Develop a framework for effective collaboration to simplify and improve data sharing in the context of emergencies

A planning committee composed of a subset of attendees from this first Data Expo will work on shaping the content and structure of the next Data Expo, which will explore the use of traditional and non-traditional data sources, and opportunities to leverage new types of data during public health emergencies.

This effort will culminate in late 2024 with recommendations for improving data sharing and capacity across NYC society, along with specific projects PRI will undertake toward that goal.

## Appendices

### Appendix A: List of key data sources discussed related to emergency response and management

1. Health data
  - a. Hospitalization data
  - b. Mortality data
  - c. Syndromic surveillance data
  - d. Electronic health records
  - e. EMS data
  - f. Operational data
2. Mobility and transportation data
  - a. Mobility data
  - b. Evacuation zone data
  - c. Transportation data (e.g., MTA, PATH, ferries, bridges)
  - d. Cellular network/geolocation data
3. Community and social data
  - a. 311 data
  - b. Social media data/communication data (e.g., qualitative)
  - c. Anecdotes and lessons learned (e.g., qualitative)
4. Infrastructure and utility data
  - a. Utility and electricity data
  - b. Building residency data
  - c. Inventory data
5. Environmental and geographic data
  - a. Weather modeling data
  - b. Wastewater surveillance data
6. Management and planning data
  - a. Resources needed
  - b. Costs of efforts
7. Support and resource data
  - a. Inventory of aid groups
  - b. Resources and manpower

### Appendix B: Examples of discussed NYC data-sharing infrastructure

- [Open Data Initiative](#)
- [Github](#)

## Appendix C: List of Attendees

First Name	Last Name	Affiliation	Job Title	Sector
Tara	Abularrage	NYC Pandemic Response Institute	Senior Project Officer	Academia
Shama	Ahuja	NYC Department of Health and Mental Hygiene (DOHMH)	Assistant Commissioner, Bureau of Communicable Diseases (BCD)	Government
Mustafa	Ali	NYC Department of Health and Mental Hygiene (DOHMH)	Director of Technology and Risk Analytics	Government
Adam	Barin	Mayor's Office of Operations	Manager of Strategy and Analytics	Government
Kelly	Bennett	Administration for Strategic Preparedness and Response	Division Director	Government
James	Gibaldi	NYC Economic Developm (EDC)	Asst Vice President	Government
Jeff	Goldsmith	NYC Pandemic Response Institute	Chair, Data Team	Academia
Sean	Haley	CUNY Graduate School of Public Health & Health Policy	Associate Professor	Academia
Debbie	Hernandez	Roche Diagnostic	Scientific Partner Public Health	Business
David	Horrocks	Manager	CEO	Non-Profit / Civil Society
Michael	Jabbour	Microsoft Education	Chief Innovation Officer, Microsoft Education	Business
Jasmine	Jones	NYC Pandemic Response Institute	Program and Operations Manager	Academia
Rainu	Kaushal	Weill Cornell Medicine	Chair of Department of Population health sciences	Academia
Elizabeth	Kelvin	CUNY Graduate School of Public Health & Health Policy Department of Epidemiology/Biostatistics	Associate Professor	Academia
Alyssa	Kumler	NYC Department of Health and Mental Hygiene (DOHMH)	Research Coordinator	Government
Sachi	Kuwabara	HHS Administration for Strategic Preparedness and	Deputy Director, Operational Data and Analytics	Government

First Name	Last Name	Affiliation	Job Title	Sector
		Response (ASPR)		
David	Lee	Public Health Accreditation Board	Sr Director, Product Development & Data Systems	Non-Profit / Civil Society
Deborah	Levine	CUNY Graduate School of Public Health & Health Policy	Dir	Academia
Bashar	Makhay	NYC Pandemic Response Institute	Senior Communications Officer	Academia
Monica	Malowney	NYC Economic Development Corporation (EDC)	VP, Life Sciences and Healthcare	Government
Ingrid	Maurice Knowles	NYC Pandemic Response Institute	Partnerships & Programs Manager	Academia
Meghan	McGinty	Tetra Tech	Senior Executive, Health Emergency Preparedness & Response	Business
Christopher	McLaughlin	CUNY Graduate School of Public Health & Health Policy	Senior Project Officer	Academia
Alberto	Mejia	NYC Pandemic Response Institute	Office Manager	Academia
Samir	Memon	NYC Department of Health and Mental Hygiene (DOHMH)	PRI Coordinator	Government
Melissa	Metz	ICAP at Columbia University	Data Management and Informatics Lead	Academia
Johanna	Miele	NYU Langone	Associate Director	Business
Kathryn	Miller	Bronx Regional Health Information Organization (RHIO)	Chief Operating Officer	Non-Profit / Civil Society
Matthew	Montesano	NYC Department of Health and Mental Hygiene (DOHMH)	Director of Data Communication	Government
Rebecca	Passman	Harlem Children's Zone	Director of Data Science	Non-Profit / Civil Society
Sen	Pei	Columbia University Mailman School of Public Health	Assistant Professor	Academia
Neena	Philip	ICAP at Columbia University	Technical Specialist	Academia
Joey	Platt	ICAP at Columbia University	Senior Project Officer	Academia

First Name	Last Name	Affiliation	Job Title	Sector
Anna	Prince	NYC Emergency Management	Data Analytics Program Manager	Government
Bobby	Rasulnia	Administration for Strategic Preparedness and Response (ASPR)	Chief Analytics Officer	Government
Vasudha	Reddy	NYC Department of Health and Mental Hygiene (DOHMH)	Deputy Director, Bureau of Communicable Diseases	Government
Sarah	Rodriguez	KPMG	Director	Business
Kathryn	Romanchuk	NYU Langone	Emergency Management + Enterprise Resilience (EM+ER) Fellow	Business
Giselle	Routhier	NYU Grossman School of Medicine	Research Assistant Professor	Academia
Suzue	Saito	Columbia University	Assistant Professor of Epidemiology	Academia
Maryanne	Schretzman	Mayor's Office: Center for Innovation through Data intelligence	Executive Director	Government
Zach	Shahn	CUNY Graduate School of Public Health & Health Policy	Assistant Professor	Academia
Jeffrey	Shaman	Columbia University Mailman School of Public Health	Interim Dean of the Climate School	Academia
Joshua	Sidis	EAS-MJ	Founder/Ceo	Business
Matthew	Silverstein	NYC Department of Health and Mental Hygiene (DOHMH)	Director, Strategy & Program Development	Government
Jeanette	Stingone	Columbia University	Assistant Professor	Academia
Daniel	Steinberg	Mayor's Office of Operations	Director	Government
Mitch	Stripling	NYC Pandemic Response Institute	Director	Academia
Gretchen	Van Wye	NYC Department of Health and Mental Hygiene (DOHMH)	Chief Epidemiologist, Deputy Director, Center for Population Health Data Science & AC, Bureau of Vital Statistics	Government