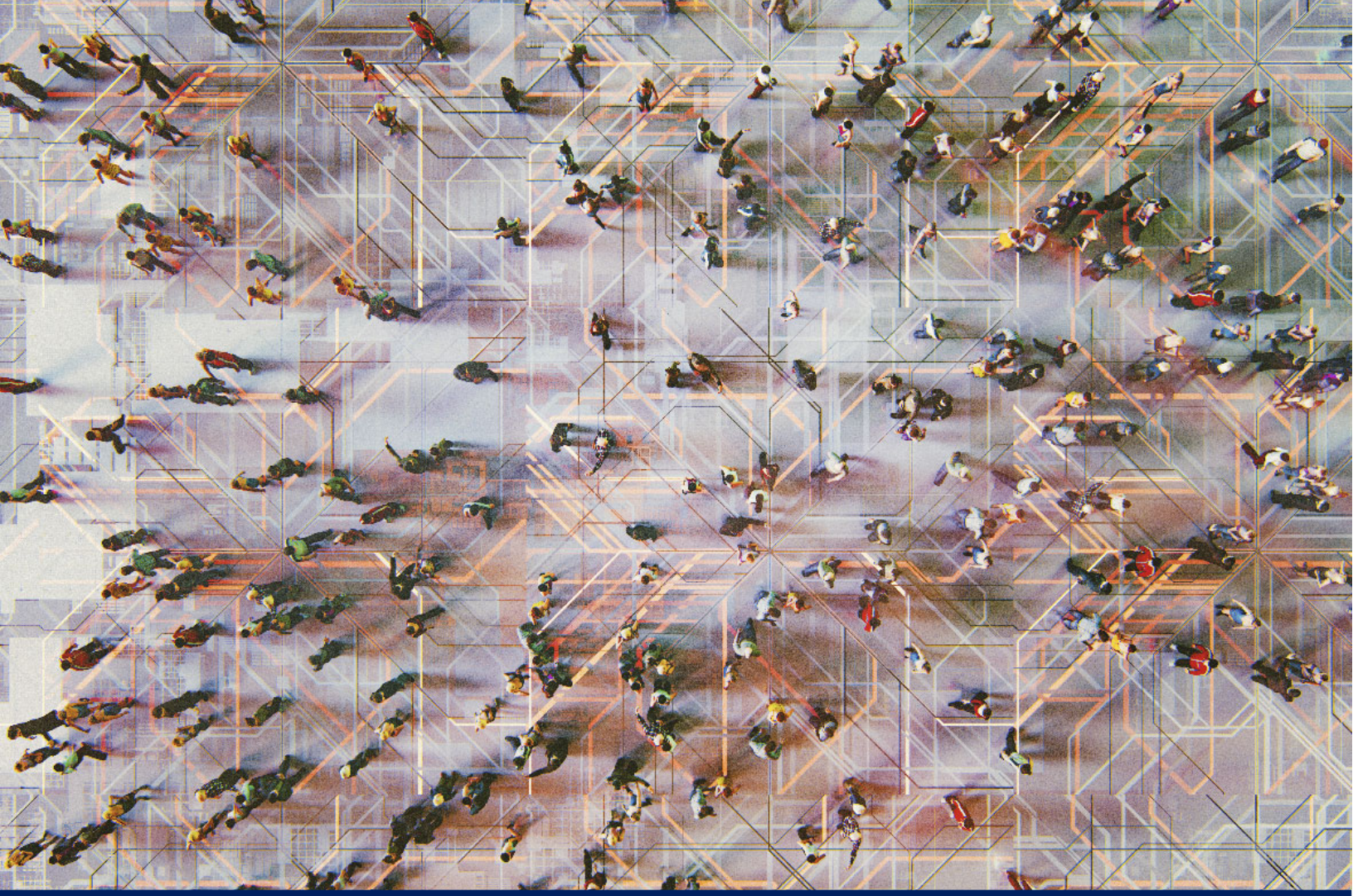

HEALTHCARE LEADERSHIP COUNCIL

DISASTER READINESS AND DATA SHARING INITIATIVE

KEY FINDINGS AND RECOMMENDATIONS REPORT

NOVEMBER 2023

HEALTHCARE LEADERSHIP COUNCIL

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1. Executive Summary

HEALTHCARE LEADERSHIP COUNCIL
DISASTER READINESS AND DATA SHARING INITIATIVE

Effective data sharing is essential for the healthcare sector to deliver care to patients every day, as well as during emergencies, such as natural disasters, infectious disease outbreaks, and cyber incidents. Innovations and lessons observed in data sharing between and among the healthcare sectors and government counterparts at all levels during the COVID-19 pandemic provide an opportunity to quicken progress and gain momentum toward an improved future state. Many public and private partners learned that if systems and processes are not in place prior to a crisis, it is extremely difficult to establish them during a response. **This insight, aligned with the opportunity to build on progress made during the COVID-19 response, led the Healthcare Leadership Council (HLC) to prioritize a Disaster Readiness and Data Sharing Initiative in 2023.**

THE INITIATIVE

INITIATIVE GOALS

This effort sought to 1) collect recommendations on **how to improve data sharing during disasters** and 2) identify **best practices in data exchange** and how to **strengthen adoption of those practices** across the private sector.

INITIATIVE METHODOLOGY

HLC established a Steering Committee comprised of HLC members and an Advisory Committee comprised of non-HLC members with subject matter expertise in data sharing, disaster readiness, and/or healthcare. **HLC interviewed each Steering Committee member and held roundtable discussions for both the Advisory Committee members and government partners** from the Administration for Strategic Preparedness and Response (ASPR), Centers for Disease Control and Prevention (CDC), Centers for Medicare and Medicaid Services (CMS), and the Office of the National Coordinator for Health Information Technology (ONC) to collect recommendations for promising practices, use cases, and commitments.

THE FINDINGS

Through this effort, HLC sought to gather **concrete, actionable commitments the private sector could implement in the short-to-medium term** (one-to-three years). Together, interviewees proposed eight potential commitments for the private sector, and HLC members prioritized three commitments at their September 2023 meeting for further action.

	1	2	3
OBJECTIVE	Support and be a thought partner with ongoing government initiatives related to disaster readiness and data sharing	Focus efforts to promote common data standards for a few core essential elements of information (EEI) relevant to healthcare to reduce reporting burden and improve efficiency	Pre-establish Data Use Agreements (DUA) now to limit administrative burden and increase efficiency for future data sharing requests
COMMITMENT	**Encourage HLC members to support TEFCA, USCDI/USCDI+, HL7 FHIR, and other government priorities**	**Select one-to-three priority emergency and disaster use cases, and for each, define essential elements of information (EEI) and relevant data standards**	**Create a template to more easily establish data use agreements, pre-positioned for disaster response in addition to routine care, among HLC members**
GOALS	✓ *Increase the number of HLC members building TEFCA exchange into their broader exchange efforts* ✓ *Share statement from HLC and members expressing support* ✓ *Invite speaker from ONC to January 2024 meeting*	✓ *Prioritize 1-3 emergencies or disasters and their EEIs* ✓ *Research and agree to common standards/ definitions for selected EEIs* ✓ *Promote EEIs and common standards/ definitions across HLC membership*	✓ *Pulse HLC membership to understand their priorities for inclusion in a DUA template* ✓ *Collect deidentified examples of effective DUAs and best practices* ✓ *Create template DUA aligned to member needs and best practices*

THE NEXT STEPS

HLC members will drive progress towards the three selected initiatives over the next one to three years, forming work groups and reporting on progress at HLC meetings.

For additional detail on the information provided in this Executive Summary, please review the full report.

2. Introduction

Initiative Overview

Effective data sharing is essential for the healthcare sector to deliver care to patients every day, as well as during emergencies such as natural disasters, infectious disease outbreaks, and cyber incidents. Innovations and lessons observed in data sharing between and among the healthcare sector and government counterparts at all levels during the COVID-19 pandemic provide an opportunity to quicken progress and gain momentum toward an improved future state. Many public and private partners learned that if systems and processes are not in place prior to a crisis, it is extremely difficult to establish them during a response. This insight, aligned with the opportunity to build on progress made during the COVID-19 response, led the Healthcare Leadership Council (HLC) to prioritize a Disaster Readiness and Data Sharing Initiative in 2023.

This initiative is the first HLC effort to explore the intersection of data sharing and disaster readiness and the unique commitments the private sector can make to drive improvement (see *Appendix A* for a detailed list of HLC initiatives to date related to these topics). Overall, this effort aimed to 1) collect recommendations on how to improve data sharing during disasters and 2) identify best practices in data exchange and how to strengthen adoption of those practices across the private sector. To narrow down what can be a very broad topic, HLC focused this effort on private sector commitments, seeking agreement on what a coalition of private healthcare partners can feasibly achieve in a one-to-three-year time horizon. To meet these goals, HLC held interviews with a Steering Committee comprised of HLC members, government partners from ASPR, CDC, CMS, and ONC, and non-HLC Advisory Committee members with subject matter expertise in data sharing, disaster readiness, and/or healthcare. HLC synthesized the outputs of these interviews to form the key themes and recommendations outlined in this report (see *Appendix B* for a list of interview questions and *Appendix C* for a list of interviewees). The interviews led to eight proposed commitments for the private sector, which were presented to members at the September meeting (see *Appendix F* for full list of commitments). During that meeting, attendees evaluated each commitment according to issue impact and level of effort to determine which proposed commitments should be prioritized first. This evaluation identified three priority commitments for HLC members to adopt moving forward, which this report explores.

3. Current State Findings

Information-Sharing Challenges

While progress improved following the COVID-19 pandemic, significant challenges still exist, many of which have been discussed in detail in previous HLC publications on this topic *(Appendix A)*. Interviewees frequently referenced the following challenges:

1. **Different data needs and data sharing roles** during emergency and disaster depending on the type of healthcare organization
2. **Disparate data requests and reporting systems** from all levels of government and other private sector partners
3. **Data standardization** (through common data elements and standards) **has improved, but still lacks full adoption**

Recent Innovations and Best Practices

For a more detailed summary of Innovations and Best Practices captured during interviews, please reference *Appendix D*. In general, two prominent themes emerged:

Internal (and to some extent, external) data collection, sharing, and reporting improved during the COVID-19 response. Most interviewees shared examples of internal processes that were established or improved during COVID-19 that resulted in better data collection, sharing, and reporting. Many were able to build complementary analytical layers to their proprietary data sets to highlight areas of concern, streamline administrative burden, and target interventions.

Willingness to contribute to data sharing efforts during extreme times of need (as evidenced by COVID-19)
Most interviewees recognized the importance of contributing their organization's data to the overall healthcare picture during an emergency or response. They understood the national imperative to collaborate for the sake of public health and were willing to advocate for increased data sharing and collaboration within their organization. When one organization took the lead in contributing to a data sharing effort, others often followed.

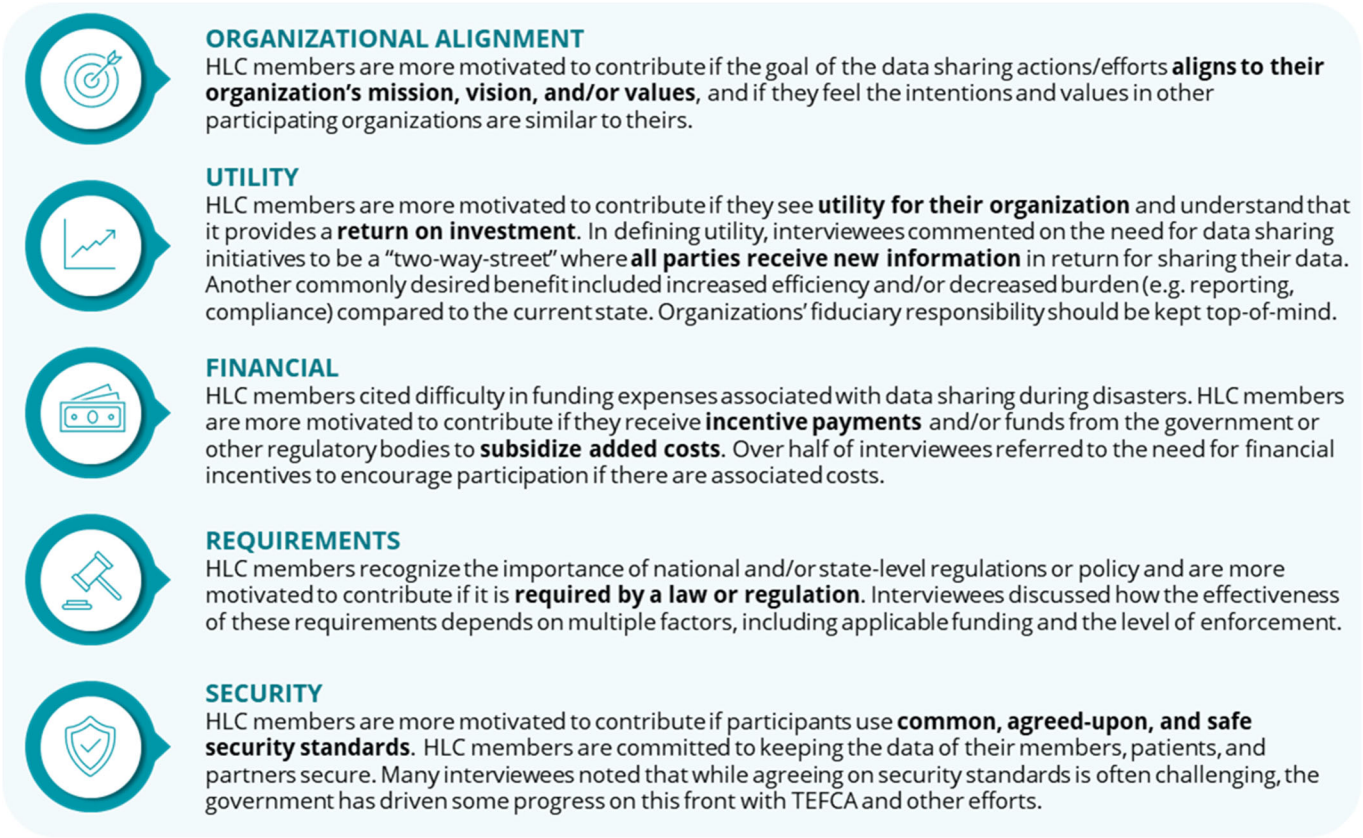
4. Future State Considerations

During HLC's interviews and roundtable discussions, a few central themes appeared in the context of future initiatives to improve disaster readiness and data sharing. Appropriately considering factors discussed in this section, including motivations, business cases, trust, levels of data de-identification and standardization, and relationship with government, will be critical to achieving success with HLC's selected commitments.

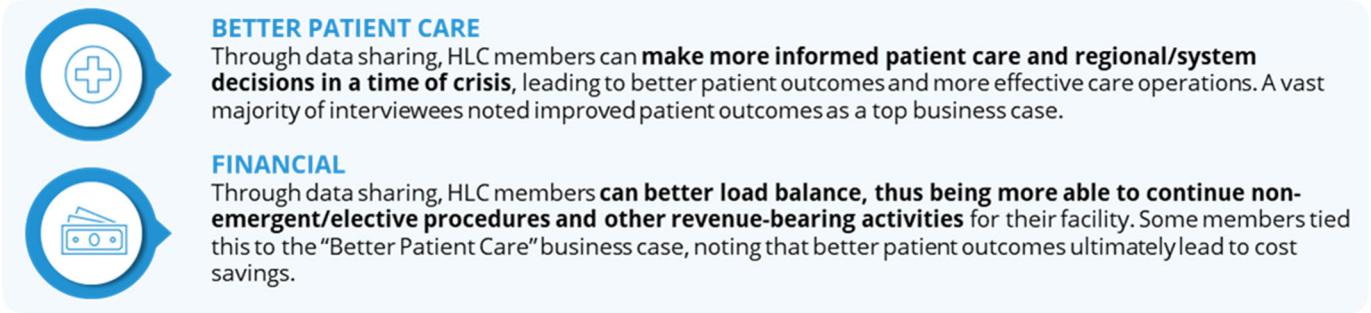
Motivations and Business Case for Improved Data Sharing During Disasters

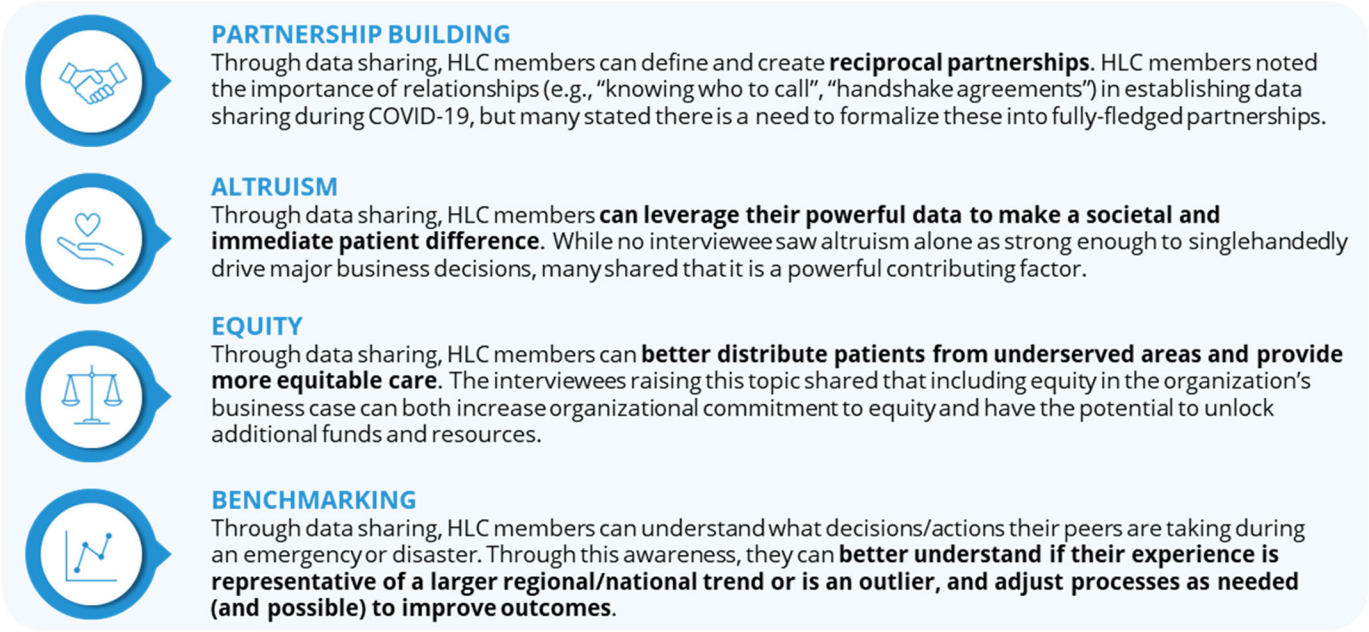
Two interview questions aimed to explore 1) what would motivate an organization to participate in a data sharing or aggregation initiative, and 2) what business cases exist for data sharing in disaster readiness. These motivating factors and business cases should be top-of mind as HLC and the private healthcare sector work to implement commitments. Common themes for motivations and business cases are listed below in order of the frequency they were mentioned.

MOTIVATIONS: What would motivate a private sector organization to contribute to a data sharing initiative?



BUSINESS CASES: What use cases can the private sector adopt to gain buy-in for improved data sharing?





Trust

All prior HLC initiatives related to disaster readiness and/or data sharing highlighted the importance of trust, and this initiative is no exception (*See Appendix A* for a full list of prior efforts). Through an interview question about trust, HLC sought to identify interviewee's priorities when it comes to trust and the characteristics of trusted platforms that currently exist.

"Data moves at the speed of trust"

In defining trust, an interviewee provided a useful framework for considering different levels of trust when it comes to disaster readiness and data sharing. Any efforts to adopt commitments, build new platforms, or gain buy-in should keep these three dimensions top-of-mind:

1. Trust in the organization receiving the data
2. Trust in the platform/mechanism used to transfer the data
3. Trust that other reputable partners will participate in the exchange

In defining the characteristics of a trusted platform, interviewees provided characteristics of platforms they use, or have used in the past, that they trusted. Key characteristics include:

- **The platform offers value and/or ROI:** Participants are willing to participate in exchange and trust platforms that provide useful information in return for the data shared. *For example, one health system shared they trusted a large clinical insights platform because it offered them better data for their research, which can ultimately lead to more research grants, which isa priority for their organization.*
- **The platform offers optionality regarding data de-identification:** Because capacity and/or willingness to de-identify data differs depending on the organization, participants trust platforms that provide various options to de-identify their data. *For example, one existing platform offers organizations the option to de-identify and structure the data themselves or to allow the third-party organization managing the platform to de-identify the data.*
- **The platform offers the opportunity to exit**: Participants trust platforms that provide the ability to exit if they wish. Reasons for doing this could include security concerns, change in organizational strategy, or competing priorities. Being forced to participate or "locked in" to a platform reduces trust. *For example, one health system shared that they appreciate being able to exit a shared clinical insights platform whenever they choose.*

Scope of Data De-identification

Interviewees differed on the utility of deidentified data. Many stated that sufficient insights can be gleaned through de-identified data, while others shared that identification is needed for true public health decision making in an emergency or disaster. There was a shared sentiment around the need to better understand the roles of the Health Insurance Portability and Accountability

Act (HIPAA) on public health data reporting in the disaster context. In addition, a minority of interviewees shared a concern about the tendency to be over-concerned about privacy and/or over-estimate associated risk. Agreeing to a level of de-identification across a diverse set of healthcare partners will likely prove difficult but will be required to achieve success if building an independent situational analytics platform, according to interviewees.

"It would be foolish to try and create a system that anticipates every type of disease outbreak"

Framing and Prioritizing Emergencies and Disasters

Many interviewees noted the challenge of an All-Hazards approach to this effort, as different emergencies and disasters have different levels of impact and may require different EEIs for effective response. How do we decide which emergencies or disasters are the most important? Many noted that we should try to pick a few use cases and not try to "boil the ocean," as there are hundreds of various scenarios that could be explored. Some interviewees also highlighted "non-traditional" healthcare challenges that can be framed as emergencies and disasters, including rural health disparities, shortages of primary care providers, and an increasing percentage of the population over age 65 that will require increased care.

Data Standardization

Most interviewees noted that while data standards exist and are a step in the right direction (USCDI, USCDI+, HL7 FHIR), they are limited and primarily apply at the provider and/or health system level. While third party aggregation (whether federated or aggregated, owned by the private sector or government) is the "ideal state" according to many interviewees, it will not be possible without agreement and adherence to established data standards. As stated above, different disasters require different EEIs. However, interviewees commonly cited bed occupancy and staffing data as critical across most emergencies and disasters.

Relationship with Government

While HLC focused this effort on commitments and actions the private sector can uniquely make, interviews still touched on existing data sharing challenges between the private and public sector during emergencies and disasters. Common pain points expressed include:

- **Disparate requests:** Interviewees receive differing data requests in differing data standards and formats from various federal, state, and local agencies during emergencies and disasters.
- **Lack of bidirectional information flow:** Interviewees send data to the public sector as requested, but reported challenges in receiving actionable information in return
- **Unclear leadership:** Interviewees recognize that ONC is tapped to lead and coordinate public sector efforts related to interoperability and data sharing, but feel confusion over role and responsibility delineation across ASPR, CDC, CMS, and other federal health agencies, in addition to their state and local counterparts.
- **Lack of funding:** Some interviewees shared that state and local public health lack enough funding to implement large-scale initiatives being proposed at the federal level.

Integration with Larger Policy Efforts

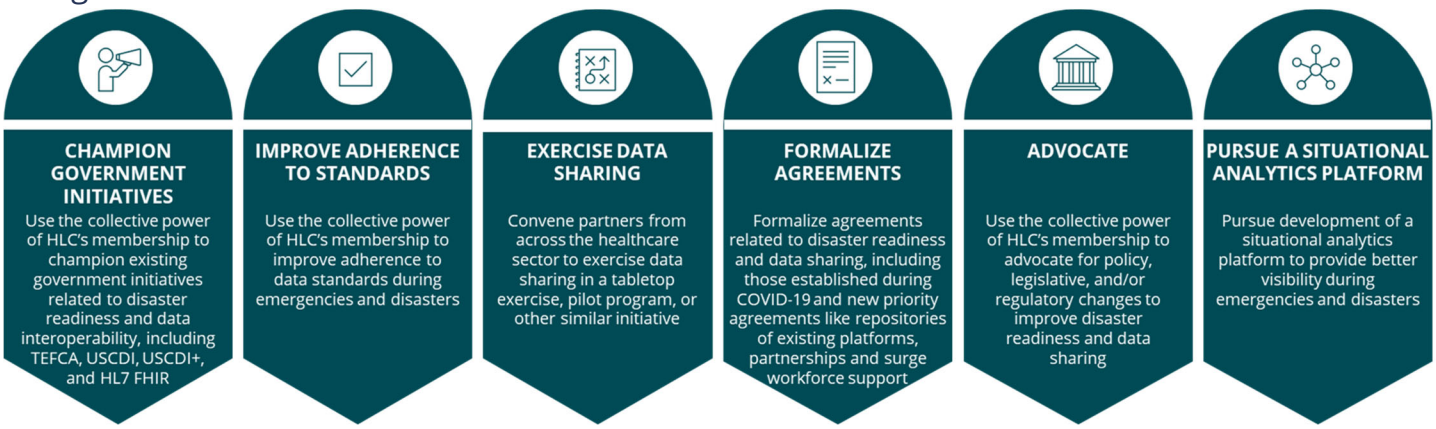
Several interviewees emphasized the bipartisan nature of data sharing and disaster readiness as a key factor to the progress made in the last five-to-ten years. While data sharing can be less divisive than other topics, interviewees also pointed to intersections between the topic and other large pieces of legislation in discussion today and encouraged HLC to try and tie new data sharing and disaster readiness proposals to existing efforts (e.g., Broadband, Infrastructure, Pandemic Preparedness).

"Interoperability is a less-politicized issue than others, and this is beneficial for our Initiative"

5. Potential Areas of Private Sector Commitment

Interviewees spent a majority of their interview time discussing potential areas of private sector commitment. While many unique and creative ideas were posed, the commitments fell into six distinct categories, outlined below.

Categories of Commitment



Proposed Commitments

A full list of the eight commitments raised during the Steering Committee, Advisory Committee, and Government Interviews can be found in *Appendix F*. At the September 2023 meeting, HLC members utilized a prioritization matrix to evaluate the eight commitments against two criteria: level of effort and issue impact (see *Appendix G* for additional detail on the prioritization matrix and evaluation). This activity resulted in three priority commitments, detailed below.

Commitment 1: Champion Government Initiatives			
We heard in interviews…	The government, led by ONC and supported by CDC, ASPR, CMS and others, is spending a lot of time and effort **building infrastructure, standards, and policies to support better data sharing during emergencies and disasters**. While progress has been slow, we should capitalize on current momentum. Primary initiatives mentioned in our interviews included **TEFCA, USCDI/USCDI+, and HL7 FHIR.**		
High-Level Objective	**Support and be a thought partner with ongoing government initiatives related to disaster readiness and data sharing.**		
Commit-ment	**Encourage HLC members to support TEFCA, USCDI/USCDI+, HL7 FHIR, and other government initiatives**		
Goals	*Goal 1*	*Goal 2*	*Goal 3*
	Increase the number of HLC members building TEFCA exchange into their broader exchange efforts by June 2024 *Success Metric: Number of HLC members participating in TEFCA as part of their broader exchange efforts*	**Share a public statement from HLC and from individual members expressing support for TEFCA, USCDI/USCDI+, and/or HL7 FHIR by December 2023** *Success Metric: Statement is released*	**Invite a speaker from ONC to speak at the next HLC meeting in January 2024** *Success metric: Speaker attends meeting*
Suggested Next Steps	✓ Conduct a data call to understand how HLC members participate in priority initiatives (*e.g. TEFCA*) to identify high areas of participation and where gaps exist ✓ HLC members should more broadly participate in efforts oriented around TEFCA and standards, including participating in HL7 FHIR accelerator projects and commenting on suggested	HLC Statement: ✓ Evaluate which government initiatives HLC has already supported, and which initiatives could benefit from a statement ✓ Draft statement and gain approval from membership Individual Member Statement: ✓ Provide sample language and/or examples to members based on HLC statement	✓ Conduct outreach to ONC to determine an appropriate speaker and discussion topic ✓ Confirm speaker

	data elements for USCDI+ when requested by ONC ✓ Encourage members to join QHINs and support knowledge-sharing activities from members who are already committed to QHIN participation		

Commitment 2: Data Standards Use Cases			
We heard in interviews…	1) There are **countless different emergency and disaster scenarios that private healthcare system stakeholders could encounter**. 2) **Data is requested in many different formats and standards** by the private and public sector, **causing confusion, data errors, and high level of effort**.		
High-Level Objective	**Focus efforts to promote common data standards for a few core essential elements of information (EEI) relevant to healthcare to reduce reporting burden and improve efficiency.**		
Commit-ment	Select **one-to-three priority emergency and disaster use cases,** and for each, **define EEIs and data standards**.		
Goals	*Goal 1*	*Goal 2*	*Goal 3*
	Select 1-3 priority emergencies and disaster use cases for healthcare (*e.g., natural disaster, infectious disease, cyber attack*), and select 1-3 common EEIs for each by May 2024 *Success metric: priority use cases and EEIs are selected*	**Conduct research on common standards for selected EEIs and select standards and/or definitions for each by July 2024** *Success metric: Data standards and/or definitions are selected*	**Promote common set of EEIs and data standards with HLC members by August 2024** *Success metric: Data standards and/or definitions communicated to HLC membership*
Suggested Next Steps	✓ Select priority emergencies and disasters and common EEIs for each (*e.g., HLC member discussion at next meeting, consensus on phone call*)	✓ Evaluate existing standards and/or definitions used by existing platforms (reference Appendix E in the report) ✓ Consult with public health to understand their what standards/EEIs they are promoting within their priority initiatives (USCDI/USCDI+) to ensure alignment ✓ Consult with standards SME to determine which standards and/or definitions are most used and effective (ensure alignment with HL7 FHIR)	✓ Share common standards and/or definitions with HLC membership ✓ Promote common standards and/or definitions with stakeholders (e.g., Hill, Administration, other Policymakers)

Commitment 3: Data Use Agreements			
We heard in interviews…	Private healthcare organizations adopted many Data Use Agreements (DUAs) during COVID-19, albeit in an ad-hoc manner as situations required. There is an opportunity now to create more structured and formalized DUAs so infrastructure is already in place when the next emergency or disaster inevitably occurs. HLC has already done great work creating sample interoperability contract language in partnership with the American Health Law Association, and this commitment could build on that work as it relates to DUAs.		
High-Level Objective	**Pre-establish DUAs now to limit administrative burden and increase efficiency for future data sharing requests.**		
Commit-ment	**Create a template to more easily establish data use agreements, pre-positioned for disaster response in addition to routine care, among HLC members.**		
Goals	*Goal 1*	Goals	*Goal 1*
	Understand HLC member priorities for DUA template to form baseline requirements for template creation by January 2024 *Success metric: # of members who submit priorities*	**Gather examples of exemplary DUAs to serve as a model for a template based on the scope level identified in Goal 1 by February 2024** *Success metric: # of example DUAs received*	**Create template DUA based on findings from Goal 2 by April 2024** *Success metric: DUA Template created*
Suggested Next Steps	✓ Pulse HLC membership to understand their priorities for inclusion in a DUA template	✓ Submit a data call for organizations to submit anonymous and/or scrubbed DUAs and to share best practices from their experiences during COVID-19 ✓ Review DUAs to understand common features and pain points ✓ Consult with AHLA to discuss best practices	✓ Use inputs from Goal 2 to draft a template DUA ✓ Circulate template DUA to membership for feedback and review

6. Next Steps for HLC

To meet the initiative's original goals of driving impactful, commitment-based change in the short-to-medium term, it is critical to define, roles, responsibilities, and ownership of each prioritized commitment and sub-goals. For each goal, HLC should:

1. Develop work groups for each commitment area.
2. Break down use cases and outcomes under consideration, including workflows, dataflows, inputs and outputs.
3. Consider adoption strategies: *What is going to make people do this and why?*
4. Define implementation plan and refine suggested success metrics.

Progress towards each goal will be reported to the group at future HLC Meetings. HLC should also plan to monitor industry trends, current events, and membership sentiment in the event that any of the five non-priority initiatives should be reconsidered for prioritization.

On a final note, HLC would like to emphasize the connected nature of these three commitments. While each commitment was detailed in a distinct category for the purpose of specific and actionable goal setting, these commitments are related and can build on each other. For example, there could be potential to use TEFCA data standards (existing or future) as the foundation for a DUA template. Additionally, agreement on a standard definition for a core EEI (Commitment 2) could be incorporated into a DUA template (Commitment 3). HLC plans to leverage this connected nature of the three commitments moving into the next phase of work.

7. Appendices

Appendix A: Past HLC Efforts Related to Disaster Readiness and Data Sharing

Date Published	Deliverable/Initiative	Partners/Co-Sponsors
August 2018	Advancing Interoperability and Data Access in the United States Report	Bipartisan Policy Center; University of California, San Francisco (UCSF)
February 2019	Advancing Interoperability, Information Sharing, and Data Access: Improving Health and Healthcare for Americans Report	Bipartisan Policy Center
Summer 2020	HLC Public-Private Partnerships for Disaster Readiness Initiative	Deloitte Consulting
February 2021	HLC/Duke-Margolis Framework for Public-Private Collaboration on Disaster Preparedness and Response	Duke-Margolis Center for Health Policy
Spring 2021	HLC publishes sample interoperability contract language	American Health Law Association, Office of the National Coordinator
November 2021	Opportunities for Private Sector Measures to Inform and Advance Interoperability Policy Report	University of California, San Francisco
May 2023	Updated HLC/Duke-Margolis Framework for Disaster Preparedness and Response	Duke-Margolis Center for Health Policy

Appendix B: List of Interview Questions

Primary questions were asked to all Steering Committee members during interviews and Advisors during Roundtable Sessions. Secondary questions were asked to Steering Committee members during interviews if time allowed and/or if they were pertinent based on the interviewee.

Category	Question Text
Primary Question	What types of data are you currently sharing during emergencies and disasters, and what would you be willing to share in the future (e.g., bed availability, supply chain status, workforce availability)?
Primary Question	Would you be willing to participate in group outsourcing of data to a third-party for readiness and response? For context, HLC/Duke Margolis Framework for Disaster Preparedness and Response recommends that "CMS should consider contracting a third-party entity to support data aggregation and production of real-time 'heat maps' for local and regional situational awareness" • If no, why would you not be willing to share? What are your thoughts on a federated model (similar to FDA Sentinel)? • If yes, how should the data be collected? Who should have access to it? ○ Who would you trust as a third-party aggregator?
Primary Question	What would motivate you to contribute to a private sector data sharing initiative for emergencies and disasters? • What assurances would you need to trust that the data will be protected? • How could data reporting be improved?
Primary Question	Does your organization have any promising practices related to data sharing/interoperability during a recent emergency or disaster (e.g., COVID-19, mPox, Hurricane Maria, wildfires, floods) that could be a model for others?
Primary Question	What do you see as the strongest "business case" for interoperability during disasters?
Primary Question	What commitments do you see as the most feasible and transformative for your organization? For the private sector as a collective group? (Examples already shared include deploying health informaticists during emergencies, developing business cases, committing to TEFCA/USCDI+, supporting regional MOCCs, etc.)
Secondary Question	How do you envision the private sector providing data that are clean, analyzed, and visualized for effective use during an emergency or disaster?
Secondary Question	What are your thoughts on the effectiveness of TEFCA and USCDI/USCDI+ data standards as it relates to better data sharing and interoperability during emergencies and disasters?

	• What commitments can you make as an organization regarding TEFCA, USCDI/USCDI+ data standards, and any other models that may come in the future? • How do you envision them impacting your organization during future emergencies and disasters?
Secondary Question	Are you familiar with the Medical Operations Coordination Cell (MOCC) concept? • If no, explain briefly. *ASPR TRACIE defines MOCCs as: cells often located within emergency operations centers (EOCs) at the sub-state regional, state-wide, and federal regional levels (FEMA/HHS regions) that facilitate patient movement, healthcare staffing, and life-saving resource allocation. The MOCCs rely upon a range of stakeholders to provide the healthcare personnel and data needed to understand current capacity and gaps in the healthcare system and facilitate referrals and load-balancing through patient transfers. Key stakeholder groups include healthcare facilities, emergency medical services (EMS), and supporting SLTT governmental partners.* • Do you see a role for your organization in contributing to/standing up regional structures like MOCCs to improve collaboration in your region? If so, what?
Secondary Question	How does your organization feel about proposed extensions to CMS Conditions of Participation (CoPs) requirements for data reporting? • Do you find these CoPs add additional burden to current reporting efforts?
Secondary Question	What types of data (e.g., reports, specific data elements) do you most frequently share with other organizations during an emergency or disaster? • With what types of organizations do you most frequently share data with? • Is the data you are asked for different than what you track and/or monitor internally?
Secondary Question	How do you communicate with other organizations about the data your organization is able to share during an emergency or disaster?
Secondary Question	What data standards and/or protections do you use?
Secondary Question	Do you have any pre-established data sharing plans and/or clinical/business continuity plans (e.g., a universal data agreement template, Standard Operating Procedures, Continuity of Operations Plans) to use during an emergency or disaster? • During the last time they were utilized, did they work as planned? • Would you be willing to share any of these plans with HLC?
Secondary Question	What are the most common challenges in your organization's or your industry's ability to share data during an emergency or disaster with other organizations? • For reference, challenges highlighted in the updated HLC/Duke Margolis Framework for Disaster Preparedness and Response include 1) slow and manual processes; 2) diverting vital resources and/or adding counterproductive administrative burden; and 3) regulatory reporting burden.

Appendix C: List of Interviewees

Steering Committee Members*

Organization	Name(s)
Ascension	Scott Cormier
Baxter	Heather Knight
Cotiviti	Emad Rizk, Chris Coloian
Elevance	Dr. Marc Overhage
Epic	Dr. Jackie Gerhart, Matt Doyle
IQVIA	Kim Gray
Leidos	Liz Porter, Srini Iyer
Mayo Clinic	Cris Ross
McKesson	Stanton McComb, Fauzea Hussain
Mt. Sinai	Dr. Brendan Carr, Dr. Bruce Darrow, Dr. Carleigh Gustafson
Optum	Neil de Crescenzo, Dr. Kevin Larsen
Oracle	Dr. David Feinberg
Surescripts	Frank Harvey, Max Sow, Andrew Mellin

**HLC Member Pfizer also contributed feedback for the report.*

Advisors

Organization	Name(s)
AdvaMed	Chris White
Aledade	Dr. Farzad Mostashari, Hamiyyet Bilgi
American College of Emergency Physicians (ACEP)	Dr. Kristin McCabe, Dr. Pawan Goyal, Dr. Sandra Schneider, Jeffrey Davis
American Clinical Laboratory Association (ALCA)	Susan Van Meter
American Health Care Association (ACHA)	Dan Schultz, Nisha Hammel
American Hospital Association (AHA)	Stephen Hughes
American Medical Association (AMA)	Todd Askew
American Pharmacists Association (APhA)	Mark Ghobrial
American Public Health Association (APHA)	Donald Hoppert
Association of American Medical Colleges (AAMC)	Tannaz Rasouli, Danielle Turnipseed
Association of Public Health Laboratories (APHL)	Ewa King
Association of State and Territorial Health Officials	Dr. Anne Zink, JT Lane
Audacious Inquiry (PointClickCare Technologies)	Keith Boone
CDC Foundation	Judy Monroe
Council of State and Territorial Epidemiologists (CSTE)	Janet Hamilton
Duke-Margolis Center for Health Policy	Hilary Campbell
Emory University	Dr. Alexander Isakov, Dr. Aneesh Mehta
Federation of American Hospitals	Donald May
Friends of HL7	Janet Marchibroda
GE Healthcare	Jeffrey Terry
Google	Karen DeSalvo
Graphite Health	Dr. Stan Huff
Greater New York Hospital Association	Andrew Dahl
HCA Healthcare	Melissa Harvey
HIMSS	Valerie Rogers
HLN Consulting	Dr. Noam Arzt
Johns Hopkins University	Caitlin Rivers
Kaiser	Dr. Walter Suarez
LabCorp	Dr. Brian Caveney
Mass General Brigham	Dr. Paul Biddinger
Medical College of Georgia, Augusta University	Dr. Amado Alejandro Baez
National Association of Chain Drug Stores (NACDS)	Kevin Nicholson, Bill Tighe
National Association of County and City Health Officials (NACCHO)	Laura Biezadecki
NYC Department of Health and Mental Hygiene	Dr. Mary Foote
NYU Langone/Bellevue Hospital	Dr. Vikramjit Mukherjee
OCHIN	Jennifer Stoll
Sequoia Project	Debbie Condrey
Unaffiliated; Former Deloitte and Kaiser	Dr. Andy Wiesenthal
University of California, San Francisco	Dr. Julia Adler-Milsten
University of Nebraska Medical Center	Dr. James Lawler, Dr. John Lowe
University of Southern California, Schaeffer Center	Dr. Nicole Lurie

Government Partners

Organization	Name(s)
ASPR	Sam Imbriale, Kelly Bennett, Sayeedha Uddin
CMS	Dr. Lee Fleisher, Dr. Michelle Schreiber
CDC	Dr. Jennifer Layden, Seth Kroop
ONC	Dr. Micky Tripathi

Appendix D: Innovations and Best Practices

The table below catalogs various innovations and/or best practices that were shared during interviews and roundtable discussions. This list is not meant to be comprehensive or exhaustive, rather it captures insights mentioned in the Initiative interviews and roundtable discussions.

Organization Type	Category for Innovation/ Best Practice	Innovation/Best Practice
Technology Provider	Clinical Innovation	Published research papers in collaboration with large clinical data platforms to share novel insights related to the COVID-19 pandemic
Technology Provider	Clinical Innovation	Added an alert into their clinical workflow that flags when a provider does not have the appropriate training and/or credentials for the current task, and this alert can offer just-in-time training to mitigate risk
Payer	Comms	Funded wireless-enabled vehicles during wildfires in a western state to improve communications during a response
Technology Provider	Data Insights	Created heatmaps showing areas of surge during COVID-19, visualizing where care could be disrupted due to incoming hurricanes in a southern state
Technology Provider	Data Insights	Analyzed prescription needs for a U.S. territory during a hurricane response so first responders could come prepared with appropriate medications
Technology Provider	Data Insights	Leveraged data to highlight where spikes of an unproven COVID-19 alternative therapeutic were being prescribed to add additional supply for patients who needed the medication for non-COVID treatment
Technology Provider	Data Insights	Visualized when providers and/or pharmacies went "offline" due to an emergency or disaster, and then communicated to and re-routed patients to other “online” providers and/or pharmacies
Healthcare Provider	Data Insights	Created a system-wide dashboard that shows bed availability and other core EEIs across multiple disparate EHRs and geographic regions; the dashboard pulls directly and automatically (no administrative burden) from the EHRs every 20 minutes
Various	Data insights	Dashboards from Washington State and the Dominican Republic were referenced as examples of effective and polished situational awareness dashboards
Technology Provider	Increasing Efficiency	Developed a product to remove blank and/or duplicative components of a patient's medical record to allow physicians to more quickly analyze a patient record and provide appropriate care
Healthcare Provider	Models	Served as a pilot for the ASPR-funded Regional Disaster Health Response System, where they developed a color-coded capacity signaling system to better respond to a surge in Pediatric Respiratory Syncytial Virus (RSV)
Industry SME	Models	The Digital Bridge incubator was referenced as a best practice for innovations models.
University	Partner Engagement	Created an "epidemiological intelligence fusion center" to bring partners from the private sector, government, academia, and NGOs together to analyze data and agree on a path forward to gain trust
State	Policy	A northern state used its legislative authority to mandate sharing of bed occupancy data and created a process for integrating with hospitals and health systems to do so
Technology Provider, Healthcare Provider	Standards	The National Healthcare Safety Network (NHSN) and NDMS bed definitions were both referenced as good examples of standards

Appendix E: Existing Platforms Mentioned During Interviews

The below table catalogs various data sharing platforms already in existence across the public and private sector. This list is not meant to be comprehensive or exhaustive, rather it captures those platforms that were mentioned in the Initiative interviews and roundtable discussions.

Platform Name	Platform Sponsor/Host	Public or Private Sector
Truveta	Microsoft	Private
Cosmos	Epic	Private
Emergency Management Data Institute (EMDI)	American College of Emergency Physicians (ACEP)	Private
Long Term Care Data Cooperative	American Health Care Association (AHCA), Institute on Aging	Private
National Emergency Medical Services (EMS) Information System	National Highway Traffic Safety Administration (NHTSA) Office of EMS	Public
ESO	N/A	Private
National Syndromic Surveillance Program (NSSP)	CDC	Public
CDC Immunization Information Systems (IIS)	CDC	Public
CDC National Healthcare Safety Network (NHSN)	CDC	Public

Appendix F: Eight Proposed Commitments from Interviews

1. **Encourage HLC members to support TEFCA, USCDI/USCDI+, HL7 FHIR, and other government priorities**

   Interviewees most frequently proposed commitments that align to, support, and build on existing government efforts related to disaster readiness and improved data sharing, including TEFCA, USCDI/USCDI+, and HL7 FHIR. Those who supported this commitment cautioned against creating something new that would contradict or try to replicate these efforts, and instead championed gaining additional support and participation for these already-existing programs across the healthcare sector.

2. **Select one-to-three priority emergency and disaster use cases, and for each, define essential elements of information (EEI) and data standards**

   Interviewees commented on the broad landscape of emergencies and disasters and shared that HLC should focus on a few specific emergency and disaster use cases that are of high importance to healthcare. For these specific use cases, interviewees suggested mapping out EEIs and standards for dating sharing as a resource for HLC members to utilize during the next emergency and disaster. If selected, HLC and its members should ensure that selected EEIs are aligned to any standards from USCDI+ and/or the Helios HL7 FHIR Accelerator. This commitment could be promoted by the National Institute of Standards and Policy (NIST) or other trusted third-party organizations.

3. **Conduct a data sharing pilot among HLC members within a selected geographic region using a routine data element (e.g., beds)**

   Interviewees posed the idea of a focused data sharing pilot as a commitment for HLC. This pilot could include multiple healthcare partners in a single geographic area, and exercise sharing one specific data element at first to test the current state of data sharing systems and processes. Lessons learned from this pilot could be aggregated and used to implement changes or enhanced data sharing processes for future emergencies and disasters.

4. **Build a list or repository of existing systems and/or platforms currently in place for healthcare data sharing**

   Interviewees shared a desire to compile an aggregated list of existing systems and/or data sharing platforms. By understanding the current landscape of data sharing platforms and systems, interviewees believe they could better see where gaps exist and avoid building efforts that are duplicative. This could also inform future efforts to expand upon existing systems to create a more comprehensive situational analytics platform. See *Appendix E* for a list of existing platforms mentioned throughout the interviews and roundtable discussions.

5. **Build a directory of exchange-ready organizations among HLC's membership, including points of contact and relevant data to have on hand when an emergency or disaster occurs**

   Interviewees proposed aggregating a list of relevant organizational information to share in the event of an emergency or disaster. This commitment could include defining the characteristics and qualifications being an "exchange-ready" organization, points-of-contact within the organization, and expectations for when to engage in data exchange. This commitment differs from Commitment #10 (data use agreements) in that it is not a formal agreement, rather a directory of information.

6. **Build a workforce deployment program where health informaticists and other analytics SMEs from member organizations could be deployed to areas and/or organizations of need**

   To meet the challenge of a lack of qualified informaticists and other SMEs to surge quickly and support data sharing needs during a disaster, interviewees posed the idea of workforce deployment agreements. This could include agreements from HLC's members to deploy analytics, information technologists, or other experts to support on-the-ground data collection, analysis, and sharing during an emergency or disaster.

7. **Conduct stress tests to measure capacity to share data in an emergency or disaster, similar to those held in the Financial Services industry**

   Interviewees pointed to a best practice from the Financial Services industry as a potential commitment for private sector partners in the healthcare sector: Stress Testing. Currently, the Federal Reserve conducts annual stress tests on U.S. banks to "assess whether banks are sufficiently capitalized to absorb losses during stressful conditions" (e.g., recession, unemployment, bond market instability).[1] Interviewees as well as third-party research have presented the potential application for stress testing within other sectors, including healthcare.[2,3,4] While the exact mechanisms to conduct the test and what specific capabilities to test would need to be determined, this commitment could elucidate where existing data sharing weaknesses within the healthcare sector exist and thus highlight areas for intervention and improvement.

8. **Begin establishing more data use agreements among HLC members along an agreed-upon set of parameters pre-positioned for disaster response in addition to routine care.**

   Some interviewees expressed a desire to formalize data use agreements made in an ad-hoc manner during COVID-19 and/or desired future data use agreements. This could include formal agreements between specific HLC members, a larger commitment across the entire membership, or templates for establishing future agreements in a more standard and efficient manner.

Several interviewees also raised two commitments that HLC has already supported through their involvement in the Updated HLC/Duke-Margolis Framework for Disaster Preparedness and Response. Please find additional detail on these commitments below.

Advocate for the creation of a public-private coordinating council for healthcare to allow for private sector engagement and improved private-public coordination during an emergency or disaster.

Interviewees commented on the need for healthcare to have a "seat at the table" when it comes to government coordination. This could contribute to better alignment of efforts between the public and private sectors as it relates to disaster readiness and data sharing legislation, policies, and regulations. This could also allow leadership within large healthcare organizations to collaborate and coordinate during crisis situations in a way that avoids anti-trust/anti-collusion concerns. This could be modeled off of structures proposed in the 2021 HLC and Duke-Margolis Report *National Dialogue for Healthcare Innovation: Framework for Private-Public Collaboration on Disaster Preparedness and Response*, including the Critical Infrastructure Partnership Advisory Council (CIPAC), FEMA Voluntary Agreements, HHS Healthcare and Public Health Sector Coordinating Councils (SCC), and/or the CEO-Led Electricity Subsector Coordinating Council (ESCC). Other promising models raised in interviews included the North American Electric Reliability Corporation (NERC) and the Federal Energy Regulatory Commission (FERC).

Pursue a situational analytics platform to collect data from HLC's membership for situational awareness during future emergencies and disasters.

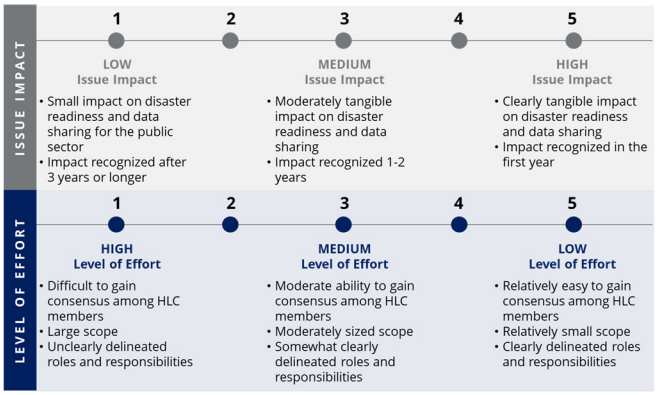
A specific interview question followed up on a recommendation in the HLC/Duke-Margolis Report *Framework for Disaster Preparedness and Response* regarding the feasibility of a situational analytics platform for better data sharing and visibility during

disasters. Opinions on the feasibility and appropriateness of this commitment varied greatly across different HLC members. Still, many interviewees shared the sentiment that working towards a long-term solution such as a shared platform should be the desired future state. As a first step, HLC members could explore building on and/or integrating with an existing aggregation platform (*Appendix E*) or conducting a small pilot to better understand the feasibility of this recommendation.

Appendix G

To facilitate a decision on which commitments to prioritize, HLC members at the Executive Meeting on Patient Safety and Quality utilized a Commitment Prioritization Matrix to **compare the eight proposed commitments across two criteria: impact on disaster readiness and data sharing in the short-to-medium term, and level of effort**.

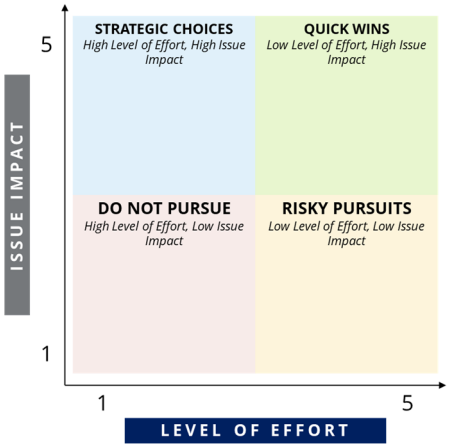
Step 1: Review Evaluation Criteria:



Step 2: Assign each commitment a score of 1-5 for both Level of Effort and Issue Impact using the Evaluation Criteria from Step 1

Commitment #	Issue Impact Score (1-5)	Level of Effort Score (1-5)
1		
2		
3		
4		
5		
6		
7		
8		

Step 3: Plot each Commitment on the Commitments Prioritization Matrix



[1] https://www.federalreserve.gov/supervisionreg/stress-tests-capital-planning.htm
[2] https://www.mckinsey.com/capabilities/risk-and-resilience/our-insights/applying-stress-tests-beyond-banking
[3] https://www.oliverwyman.com/our-expertise/perspectives/health/2021/jan/we-stress-tested-banks-in-2009--we-need-to-do-the-same-thing-now.html
[4] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6265916/