

Health Equity by Design (HEBD) Task Force 2024

Hannah Galvin, Task Force Co-Chair Hung Luu, Task Force Co-Chair

December 11, 2024



Call to Order/Roll Call

Seth Pazinski, Designated Federal Officer, ASTP



Health Equity by Design Task Force 2024 Roster

Name	Organization	Name	Organization
Hannah Galvin* (Co-Chair)	Cambridge Health Alliance	Susan M. Jenkins	HHS Assistant Secretary for Planning and Evaluation (ASPE)
Hung S. Luu* (Co-Chair)	Children's Health	Meagan Khau	Centers for Medicare & Medicaid Services (CMS)
Shila Blend*	North Dakota Health Information Network	Kikelomo Oshunkentan*	Pegasystems
Medell Briggs-Malonson*	UCLA Health	Rochelle Prosser*	Orchid Healthcare Solutions
Kristie Clarke	Centers for Disease Control and Prevention (CDC)	Belinda Seto	National Institutes of Health (NIH)
Sooner Davenport	Southern Plains Tribal Health Board	Christopher St. Clair	U.S. Food and Drug Administration (FDA)
Derek De Young*	Epic	Naresh Sundar Rajan*	Neantix Inc.
Sarah DeSilvey*	Gravity Project	Janice Tufte	Hassanah Consulting
Steven Eichner*	Texas Department of State Health Services	Janée Tyus	IMPaCT Care Inc, University of Michigan- Flint and Michigan Health Information Network (MiHIN)
Cynthia Gonzalez	RAND Corporation		



Opening Remarks

Hannah Galvin, Task Force Co-Chair Hung Luu, Task Force Co-Chair



Agenda

2:00 PM Call to Order/Roll Call

 Seth Pazinski, Designated Federal Officer, ASTP

2:05 PM Opening Remarks

- Hannah Galvin, Task Force Co-Chair
- Hung Luu, Task Force Co-Chair

2:15 PM Task Force Framework for Recommendations and Discussion

- Hannah Galvin, Task Force Co-Chair
- Hung Luu, Task Force Co-Chair

2:30 PM Task Force Discussion

- Hannah Galvin, Task Force Co-Chair
- Hung Luu, Task Force Co-Chair

3:20 PM Public Comment

- Seth Pazinski, Designated Federal Officer, ASTP
- 3:25 PM Next Steps
 - Hannah Galvin, Task Force Co-Chair
 - Hung Luu, Task Force Co-Chair

3:30 PM Adjourn

HEBD Task Force Charge

Incorporating HEBD Principles in Health IT

Provide ASTP with recommendations on promising practices, challenges, and resources to support health and human services organizations to incorporate HEBD principles into the design, build, implementation, use, and monitoring of health IT

- The recommendations should include:
 - Considerations that health and human services organizations can use to include HEBD in health IT
 - Recommendations for ASTP on potential next steps to advance the implementation of HEBD principles in the design, build, implementation, use and monitoring of health IT

• Recommendations Due: May 2025



Clarifying Points from the HEBD TF Co-Chairs

- Considerations that health and human services organizations can use to include HEBD in health IT
 - Focus on healthcare delivery organizations that use standards-based health IT, specifically hospitals, clinics, human services COB's (and actors with which they exchange data).
 - Focus on data as foundational to these considerations; specifically:
 - a) HEBD approaches to the capture, use, harmonization, and exchange of health data; and
 - b) Which types of data should be leveraged by health and human services organizations to better promote health equity
 - Highlight existing small-scale implementations for potential expansion
- Recommendations for ASTP on potential next steps to advance the implementation of HEBD principles in the design, build, implementation, use, and monitoring of health IT
 - These recommendations can be focused on the future and going forward
 - Recommendations can relate to coordination, policy, standards, etc.
 - Recommendations can relate both to data strategy as well as wider-scale technology strategy



Example Components of an Informational Resource for Health Organizations

- Summary/Purpose of the Resource
 - Objectives
 - Audience
 - Limitations
- Background
- Explanation of Framework/Themes (or how information is organized)
- Information Organized by Themes
 - Overview
 - Challenges/Opportunities
 - Considerations
 - Resources
- Conclusion

*Examples - list is not comprehensive or exhaustive



What Components should be included in our HEBD Framework?

Identifying the key pieces that will organize our work:

- TF Charge, Goals, Aims
- Guiding Principles
- Themes
- Considerations



Meeting Objectives

- Describe the draft framework that will be used to guide and organize Task Force's recommendations and workplan
- Discuss any proposed edits to the framework themes/subthemes
- Note some examples for how recommendations can be structured based on the framework themes/subthemes
- Identify any themes/subthemes where the Task Force requests or suggests a presentation by a subject-matter expert (SME) to help the Task Force develop recommendations



Task Force Framework for Recommendations and Discussion

Hannah Galvin, Task Force Co-Chair Hung Luu, Task Force Co-Chair



Framework: Themes and Subthemes

Inclusive Representation

- Diverse participants and users involved in the design
- Diverse community characteristics (socioeconomic, cultural, SDOH) and settings
- Diverse use cases and local needs
- Governance and leadership: diverse demographics and roles
- Need for sustainable workforce

Access

- Infrastructure needs and addressing digital divide
- Interoperability
- Health and HEBD literacy (awareness, training)
- Linguistic, cultural competency, disability access
- Real world testing across diverse use cases
- Address inequitable resources
- Improving access to care

• Privacy

- HIPAA vs. non-HIPAA covered entities
- Data segmentation and consent

Transparency

- Data standardization and collection across different types of data
- Improving data collection and quality
- Important data elements for health equity
- Monitoring, reporting, and analytics

Harm and Bias Prevention

- Addressing systemic and structural (upstream) drivers of health inequities and disparities in health care and outcomes
- Representative data for research and training emerging technologies
- Monitoring for and addressing algorithmic bias

*Adapted from Medell Briggs-Malonson, UCLA Health, Principles of Data Justice



Recommendation Example 1

Theme: Transparency

<u>Subtheme</u>: Data standardization and collection across different types of data <u>Subtheme</u>: Improving data collection and quality

Task Force recognizes the importance of collecting race/ethnicity/language (REL) and sexual orientation/gender identity (SOGI) data to advance health equity. Task Force recommends:

(1) Health and human service agencies use Centers for Disease Control and Prevention (CDC)/Office of Management and Budget (OMB) standards for measures.

(2) ASTP work in coordinating role to align state and federal agencies with CDC/OMB standards.



Recommendation Example 2

Theme: Privacy

<u>Subtheme</u>: Data segmentation and consent Guiding Principles: Promote Trust, Ensure Personal Control

Task Force recognizes that some individuals may have specific considerations for their REL and SOGI data. Task Force recommends:

(1) Health and human services organizations allow patients to indicate if they prefer that their data are not shared in specific circumstances.

(2) ASTP fund ongoing standards development and implementation guidance work related to data segmentation and consent.



Recommendations Structure

	Health Equity by Design Task Force Charge			
HEBD Themes	Incorporate HEBD principles into design, build, implementation, use, and monitoring of health IT (general charge)			
 Inclusive Representation Accessibility 	Health and Human Services Organizations (sub-bullet 1)	ASTP (sub-bullet 2)		
 Privacy Transparency Harm and Bias Prevention 	 [recommendation] [recommendation] [recommendation]	 [recommendation] [recommendation] [recommendation] 		
	Guiding P Include the Diverse Voices of In Improve Personal Health Outco Advance Population Health Equ Ensure Personal Control Design Inclusive Solutions Ensure Accountability and Trans Mitigate Bias and Discrimination Prevent, Reduce, and Remedia Promote Trust	omes uity and Justice sparency n in Health Technologies		

Task Force Discussion

Hannah Galvin, Task Force Co-Chair Hung Luu, Task Force Co-Chair



Discussion Questions

• Any there missing or suggested edits to the framework, themes, or subthemes?

- Are there any themes/subthemes where the Task Force requests or suggests a presentation by a subject-matter expert (SME) to help the Task Force develop recommendations?
 - All presentations to be completed by Mid-February
 - Strategic use of SME perspectives for specific and/or technical considerations



Public Comment

Seth Pazinski, Designated Federal Officer, ASTP



Public Comment

To make a comment please Use the Hand Raise Function

If you are on the phone only, press "*9" to raise your hand

(Once called upon, press **"*6"** to mute/unmute your line)

All public comments will be limited to three minutes

You may also email your public comment to astp-hitac@accelsolutionsllc.com

Written comments will not be read at this time, but they will be delivered to members of the Task Force and made part of the public record



Next Steps

Hannah Galvin, Task Force Co-Chair Hung Luu, Task Force Co-Chair



Meeting Schedule for the Full HITAC

HITAC Meeting Date	Task Force Update	
02/13/2025	Present HEBD Task Force updates to HITAC	
03/20/2025	Present HEBD Task Force updates to HITAC	
04/10/2025	Review draft HEBD Task Force recommendations	
05/08/2025	HITAC vote on final HEBD Task Force recommendations	





Meeting Adjourned