Health Information Technology Advisory Committee™

The Office of the National Coordinator for Health Information Technology

Meeting Notes

HEALTH INFORMATION TECHNOLOGY ADVISORY COMMITTEE (HITAC)

March 10, 2022, 10:00 a.m. – 4:45 p.m. ET

VIRTUAL

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EXECUTIVE SUMMARY

Steve Posnack, the Deputy National Coordinator for Health IT, welcomed everyone to the March 10, 2022, virtual meeting of the HITAC and provided an overview of ONC's recent program updates. The co-chairs of the HITAC, **Denise Webb** and **Aaron Miri**, welcomed members, reviewed the meeting agenda, and presented the minutes from the February 17, 2022, HITAC meeting, which were approved by voice vote. On behalf of the e-Prior Authorization Request for Information Task Force 2022 (ePA RFI TF 2022), **Sheryl Turney** and **Tammy Banks** presented the TF's Final Recommendations. HITAC members submitted feedback and approved the recommendations by a voice vote. **Steven Lane** and **Arien Malec** presented an update from the Interoperability Standards Workgroup (IS WG) and responded to questions from HITAC members. The focus of the second portion of this meeting was a public hearing on Health Equity by Design. A series of panel presentations were given on a variety of topics related to health equity, and HITAC members submitted questions and comments following each panel. No public comments were submitted by phone during the meeting but there were several submitted by email. There was a robust discussion in the public meeting chat via Zoom.

AGENDA

10:00 a.m.	Call to Order/Roll Call
10:05 a.m.	Welcome Remarks
10:15 a.m.	Opening Remarks, Review of Agenda and Approval of February 17, 2022 Meeting Minutes
10:20 a.m.	e-Prior Authorization Request for Information Task Force: HITAC Discussion and Vote
11:00 a.m.	Interoperability Standards Workgroup Update
11:15 a.m.	Break

Health Equity by Design Hearing

11:30 a.m.	Health Equity by Design Hearing Opening Remarks
11:35 a.m.	Framing of the Problem
11:55 a.m.	Discussion
12:05 p.m.	Use of Data: Artificial Intelligence and Machine Learning, Systems Integration, and Interoperability
01:15 p.m.	Discussion
01:30 p.m.	Break
01:45 p.m.	Content and Exchange of Data, Part 1
02:45 p.m.	Discussion
03:00 p.m.	Break
03:10 p.m.	Content and Exchange of Data, Part 2
04:10 p.m.	Discussion
04:30 p.m.	Public Comment
04:45 p.m.	Closing Remarks
04:45 p.m.	Adjourn

CALL TO ORDER/ ROLL CALL

Mike Berry, Designated Federal Officer, Office of the National Coordinator for Health IT (ONC), called the March 10, 2022, meeting to order at 10:00 a.m.

ROLL CALL

Aaron Miri, Baptist Health, Co-Chair
Denise Webb, Individual, Co-Chair
Medell Briggs-Malonson, UCLA Health
Hans Buitendijk, Cerner

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Steven (Ike) Eichner, Texas Department of State Health Services
Cynthia A. Fisher, PatientRightsAdvocate.org
Rajesh Godavarthi, MCG Health, part of the Hearst Health network
Valerie Grey, New York eHealth Collaborative
Jim Jirjis, HCA Healthcare
John Kansky, Indiana Health Information Exchange
Kensaku Kawamoto, University of Utah Health
Steven Lane, Sutter Health
Leslie Lenert, Medical University of South Carolina
Hung S. Luu, Children's Health
Arien Malec, Change Healthcare
Clem McDonald, National Library of Medicine
Aaron Neinstein, UCSF Health
Eliel Oliveira, Dell Medical School, University of Texas at Austin
Brett Oliver, Baptist Health
Raj Ratwani, MedStar Health
Abby Sears, OCHIN
Alexis Snyder, Individual
Fillipe Southerland, Yardi Systems, Inc.
Sheryl Turney, Anthem, Inc.

HITAC MEMBERS NOT IN ATTENDANCE

Lisa Frey, St. Elizabeth Healthcare
Steven Hester, Norton Healthcare
James Pantelas, Individual

FEDERAL REPRESENTATIVES

Thomas Cantilina, Military Health System, Department of Defense (DoD) *(Absent)*
Sanjeev Tandon, Centers for Disease Control and Prevention (CDC) *(standing in for Adi V. Gundlapalli)*
Ram Iyer, Food and Drug Administration (FDA) *(Absent)*
Elaine Hunolt, Department of Veterans Health Affairs *(standing in for Jonathan Nebeker)*
Michelle Schreiber, Centers for Medicare and Medicaid Services *(and Alex Mugge, standing in for Michelle Schreiber after 12 p.m.)*
Ram Sriram, National Institute of Standards and Technology

ONC STAFF

Micky Tripathi, National Coordinator for Health Information Technology
Steve Posnack, Deputy National Coordinator for Health Information Technology
Elise Sweeney Anthony, Executive Director, Office of Policy
Avinash Shanbhag, Executive Director, Office of Technology
Mike Berry, Designated Federal Officer

PRESENTERS

Tammy Banks, Co-Chair of the ePA RFI TF 2022
Eboné Carrington, Manatt Health
Kathleen Blake, American Medical Association
Irene Dankwa-Mullan, IBM Cloud and Cognitive Software
Ziad Obermeyer, University of California Berkeley
Nicol Turner Lee, Brookings Institution
Terri Willits, Anthem Inc.
Denise Hines, Georgia Health Information Network
Dominic Mack, Morehouse School of Medicine
Angela Thomas, MedStar Health
Andrew Hamilton, AllianceChicago

Janet Campbell, Epic
Robert Murry, NextGen Healthcare
Jaffer Traish, findhelp
Carlos Felipe, Unite us
Read Holman, Unite us
Trenor Williams, Socially Determined

WELCOME REMARKS

Steve Posnack, the Deputy National Coordinator for Health IT, welcomed everyone and provided an overview of ONC's recent program updates, including:

- **Sheryl Turney** and **Tammy Banks** will present the recommendations from the Electronic Prior Authorization Request for Information Task Force 2022 (ePA RFI TF 2022) followed by a discussion and HITAC vote. The RFI period is open until March 25, 2022.
- **Steven Lane** and **Arien Malec** will present an update on behalf of the Interoperability Standards Workgroup (IS WG).
- ONC published a Buzz Blog post, "Information Blocking Claims: By the Numbers," which included a Quick Stat visualization and a data set on the information blocking claims received through the Report Information Blocking Portal since April 5, 2021— the applicability date of the information blocking regulations. ONC will continue to provide this information in the future and has shared a variety of resources, which can be found at the healthit.gov website.
- **Micky Tripathi**, the National Coordinator for Health IT, authored an article in HealthAffairs entitled, "Delivering on a Promise of Health Information Technology in 2022."
- The second part of the ONC Annual Meeting will be held on April 13 and 14, 2022, and will feature a variety of dynamic and engaging panel sessions, networking, and exhibits. Related information will be released on the healthit.gov website.
- The next HITAC meeting will also be held on April 13, 2022, and the timing of the meeting will be adjusted to accommodate all attendees who are also attending the ONC Annual Meeting.

OPENING REMARKS, REVIEW OF AGENDA, AND APPROVAL OF FEBRUARY 17, 2022, MEETING MINUTES

Aaron Miri and **Denise Webb**, HITAC co-chairs, welcomed all members and presenters. **Aaron** reviewed the list of planned presentations and added that he was looking forward to the focus on health equity.He also thanked ONC for releasing the Information Blocking information and encouraged everyone to review it. Finally, he reminded members that the electronic health information (EHI) definition is limited right now to the EHI identified by the data elements represented in the United States Core Data for Interoperability (USCDI), but on and after October 6, 2022, the definition of EHI is no longer limited to the EHI identified by the data elements represented in the USCDI.

Denise reviewed the agenda for the meeting and shared procedural information for how the hearing would proceed. She briefly summarized the presentations and acknowledged the presenters.

Aaron invited members to examine the minutes from the February 17, 2022, meeting of the HITAC and called for a motion to approve the minutes. The motion was made by **Medell Briggs-Malonson** and was seconded by **Jim Jirjis.**

The HITAC approved the February 17, 2022, meeting minutes by voice vote. No members

opposed or abstained.

E-PRIOR AUTHORIZATION REQUEST FOR INFORMATION TASK FORCE: HITAC DISCUSSION AND VOTE

Sheryl Turney and **Tammy Banks,** co-chairs of the e-Prior Authorization Request for Information Task Force 2022 (ePA RFI TF 2022), presented the TF's Recommendations Report to the HITAC. **Sheryl** presented an overview of the ePA RFI TF 2022's charge and timeframe, membership, approach to its work and meeting schedule, which were detailed in the ePA RFI TF presentation slides and materials. She then highlighted presentations the TF received from subject matter experts (SMEs) and described the TF's process and workplan.

Sheryl explained that ONC issued a request for information (RFI), published in January 2022, that sought input from the public regarding support for electronic prior authorization (ePA) processes. ONC requested comments on how the ONC Health IT Certification Program could incorporate standards and certification criteria related to electronic prior authorization.

- Task Force Charge: Provide input and recommendations in response to the RFI on Electronic Prior Authorization to inform future rulemaking and other actions in this area.
- Timeframe: Provide recommendations by March 10, 2022.

Sheryl described 13 recommendations the ePA RFI TF 2022 submitted to the HITAC and summarized their areas of focus. These were detailed in the Recommendations Report document. **Tammy** presented a summary of the topics on which the TF has expanded or provided clarification following their previous presentation to the HITAC. She described specific recommendations within the high-level recommendations to the HITAC, which included:

- Recommendation 1. Suite of Certified Health IT Capabilities to Support the Prior Authorization Workflow
- Recommendation 2. Readiness of Implementation Guides to Support Functional Capabilities
- Recommendation 3. Patient-Centered Inclusion in ePA
- Recommendation 4. Prior Authorization Roadmap to Fast Healthcare Interoperability Resources (FHIR)
- Recommendation 5. Adoption at Scale
- Recommendation 6. Regulatory Coordination
- Recommendation 7. Attachments
- Recommendation 8. Prior Authorization Proving Ground For FHIR
- Recommendation 9. Establishment of an Advisory Process
- Recommendation 10. Accessibility of Health IT for ePA at Scale
- Recommendation 11. Innovation around ePA Integration
- Recommendation 12. Innovation around ePA Bundles
- Recommendation 13. Multi-Stakeholder Engagement

The co-chairs thanked HITAC members for their feedback and ONC for their support. They invited members to share feedback.

Discussion:

- **Arien Malec** thanked the presenters and asked if Recommendation 7, Attachments, were in line with the previous recommendation made to the HITAC by the Intersection of Clinical and Administrative Data Task Force (ICAD TF) to proceed with attachments and then build a roadmap to fully support Fast Healthcare Interoperability Resources (FHIR).
    - **Tammy** responded that the ePA RFI TF 2022 intended to give innovators the flexibility to move from document-based exchange to a data-driven exchange without mandating one way to do so.
    - **Arien** emphasized the idea, originally endorsed by the ICAD TF, that a more flexible standards advancement process is needed for administrative data, similar to what is used for clinical data (where tremendous progress has been made).
    - **Tammy** explained that the ePA RFI TF 2022 wanted to allow innovators to test the ground and bring solutions back to the larger market share to increase capabilities.
- **Aaron Miri** reminded the HITAC members that comments are due by March 25, 2022.
- **Leslie (Les) Lenert** submitted several pieces of feedback, which included:
    - The standards that are developed should provide a clear path forward to the use of transparent artificial intelligence (AI) based approaches that simulate consensus judgment of physicians and experts as to the appropriateness of procedures and treatments. AI methods offer a more robust approach using provider notes and other primary documentation for PA, which reduces work, allows greater flexibility, and improves fairness.
    - Bring the rules to the data rather than the data to the rules for the sake of privacy, better decision support in EHRs, and improved transparency.
    - Rules for approval need to be public, and families should be able to choose insurers based on transparent PA policies.
    - If data for PA is moved to the payers, it should travel on the NHIN architecture. ONC should consider sponsoring a QHIN devoted to PA as a hub to minimize connectivity issues for providers, payers, and patients. There should not be an independent network for PA and the movement of medical data related to it.
    - **Tammy** stated that the ePA RFI TF 2022 determined, through its discussions, that the implementation guides (IGs) that are being developed are focused on the rules related to the data requirements, not the rules PA would have to follow to be approved.
    - **Arien** thanked **Les** for sharing the feedback on the record verbally and in the public chat in Zoom.
    - **Les** thanked the TF for their work, especially around the requirements for patients to have greater visibility in the PA process.
- **Clem McDonald** commented that the TF's suggestions seemed like a lot of work and advised that they should be divided further. He shared his experiences with the development of the attachments process and the United States Core Data for Interoperability (USCDI) work. He worried that members would rotate off the HITAC and TFs before work could be finalized.
    - **Sheryl** agreed with **Clem** but noted that this is why TF work is focused on a roadmap and timeline where things can be implemented in an iterative process based on maturity.

- **Sheryl Turney** highlighted **Alexis Snyder's** comment in the public chat that work might be pushed to the back office and explained that the TF's intent was for patients to be as engaged (or not) as they want in the PA process. Physicians will be able to develop their system to support a patient-centered approach to PA, and the TF agreed that there is a minimum of information that should be made available to the patient but that they should be able to determine how much information they want to receive. There should be coordination around the advanced estimation of benefits (EOB).
  - **Aaron Miri** agreed with other HITAC members' comments about the complexity of the PA process but noted that the TF's recommendations and the RFI will begin to create a roadmap
- **Steven (Ike) Eichner** asked if anything should be done to address constraints on information shared with insurance providers to ensure that only the information necessary for reviewing the PA is shared, not other materials or items retained for different purposes.
  - **Sheryl** responded that the TF addressed his concerns around collecting only the information required for the decision-making process in their recommendations. However, they did not address his concern about materials not being retained.
  - **Steven** stated that information should only be used for the purpose for which it was originally collected and only retained as a matter of record (not re-used inappropriately).
- **Eliel Oliveira** commented that the roadmap, proving ground, and advisory process must be in place before additional work goes forward to support a patient-centered approach that focused on health equity properly.
- **Denise Webb** commented that she participated in the ICAD TF and thanked the ePA RFI TF 2022 for reflecting the ICAD TF's recommendations in 2020.

Aaron called for a motion to adopt the ePA RFI TF 2022 Report and Recommendations and advance them to the National Coordinator for Health IT. The motion was made by **Arien Malec** and was seconded by **Hans Buitendijk.**

The HITAC approved the ePA RFI TF 2022 Report and Recommendations by voice vote. No members opposed or abstained.

INTEROPERABILITY STANDARDS WORKGROUP UPDATE

Steven Lane and **Arien Malec,** co-chairs of the new Interoperability Standards Workgroup (IS WG), explained that the IS WG was chartered to replace the work of the prior United States Core Data for Interoperability Task Force 2021 (USCDI TF 2021) and the Interoperability Standards Priorities Task Force 2021 (ISP TF 2021). **Arien** presented an overview of the IS WG's overarching and specific charges, roster, meeting schedule, and deliverable due dates, detailed in the IS WG Update presentation slides.

Arien described the areas of focus for this iteration of the WG, which runs through June 2022 but could potentially extend its work through the summer into the fall (if requested by ONC). The charges included:

- Overarching charge: Review and provide recommendations on the Draft USCDI Version 3 and other interoperability standards
- Specific charges:
  - Due to the HITAC by April 13, 2022:
    - Evaluate Draft USCDI v3 and provide HITAC with recommendations for:

- 1a - New data classes and elements from Draft USCDI v3
- 1b - Level 2 data classes and elements not included in Draft USCDI v3
- Due June 16, 2022:
  - Identify opportunities to update the ONC Interoperability Standards Advisory (ISA) to address the HITAC priority uses of health IT, including related standards and implementation specifications.

Arien shared a list of specific questions on which ONC requested feedback, detailed in the presentation slides, and included general feedback on Draft Version 3 of the USCDI (Draft USCDI v3) and specific feedback on several existing data elements.

Arien described the work completed by the IS WG following its kick-off meeting on January 25, 2022, and he highlighted the subject matter expert (SME) presentations from the Gender Harmony Project and Project US@, which will inform the WG's work going forward. He encouraged HITAC members to review the transcripts from those meetings or to review the presentation materials linked on the IS WG's webpage. The IS WG discussed the Health Status Data Class at its March 1, 2022, meeting. He summarized the IS WG's remaining work, including general feedback on draft USCDI v3, and noted that the WG had already created a matrix to review these items. He provided a schedule of upcoming meetings and explained that the IS WG would bring its first round of recommendations on Charge 1a and 1b forward for a vote at the April 13, 2022, HITAC meeting. Then, the WG will begin work on Charge 2 (ISA recommendations).

Steven thanked the IS WG members for their dedication and recognized the members who served on previous iterations of the WG. He briefly reviewed the presentations the WG received and highlighted key takeaways and questions that have arisen because of discussions following the presentation. He described the WG's process of reviewing proposed new data elements and data classes for inclusion in the final version USCDI v3 and how they captured discussion around the readiness of each one. He discussed the requests the WG received to add specific data elements and classes, noting that the WG worked to clarify which belong in the USCDI data set and which will belong in the new USCDI+ model that is being developed.

Discussion:

- **Cynthia Fisher** asked if there is a way for patients to change any incorrect information they find in their EHR and noted that physicians and hospitals have reported that it is difficult for them to correct patient data.
  - **Steven Lane** responded that the ability for patients to request amendments or addenda to their record falls under HIPAA, and, though it does not fall under the USCDI, he asked if the IS WG could take up this topic as part of its ISA task.
  - **Arien** agreed that the patient's ability to correct their data is a right under HIPAA, even if it is not honored in practice. He stated that work on patient-generated health data is in scope, including patient self-observation, patient self-assessments, and patient notes. In the public chat, Steve Posnack and Grace Cordovano explained that HL7 is working on using FHIR to support a patient correction process.
  - **Cynthia** emphasized the need to prioritize patients and their care outcomes and make corrections easier at the point of care. Permanence in the patient record should be removed.
  - **Arien** invited **Cynthia** and PatientRightsAdvocate.org to participate in the HL7 process on the FHIR Patient Correction standard.
  - **Cynthia** asked **Arien** to connect offline to ensure that the process is expeditious and efficient to ensure the best outcomes for patients.

- **Denise Webb** noted that this work is under the purview of HIPAA but added that there should be a standard so that corrections to a patient's medical record follow conventions of interoperability.
- **Steven (Ike) Eichner** recognized the need to retain the provenance of old data but emphasized that corrections or updates to a patient record should be presented first.
- **Denise and Arien** agreed that this should be tagged and that there is provenance information in the USCDI. **Arien** shared the U.S. Department of Health and Human Services (HHS) Office for Civil Rights (OCR) guidance on the right to correction in the public chat in Zoom.
- **Cynthia** added that issues around erroneous diagnoses affect patients' billing and often do not realize they are being affected negatively financially. She described how EHRs and patient financial records are interrelated and emphasized that corrections must be approved when discovered.
- **Steven** acknowledged that though this is outside the scope of their USCDI work, the IS WG could discuss it during their upcoming work focusing on the ISA charge.
- **Cynthia Fisher** described how patients often sign away the release of their medical and billing information and responsibility to pay without receiving their documentation. She also highlighted issues patients have reported around their inability to self-pay/pay in cash and added that many have stated that they were not properly informed that insurance could be billed, duplicating their payments. There is no supporting documentation for patients. She asked how patients can have provenance of the terms and conditions of their contractual relationship with their provider.
  - **Arien Malec** responded that OCR is the agency that has the mandate to investigate cases of waste, fraud, and abuse. Legal agreements that a patient signs are part of the designated record set (DRS), and the implementation of the second stage of Information Blocking makes the full DRS electronically available. The full DRS has always been available to patients under the Right of Access in the General Data Protection Regulation (GDPR).
- **Steven (Ike) Eichner** commented that information should not be supplied to an insurance company when a patient self-pays, and there should be a way to get this data back.
- **Denise Webb** thanked the co-chairs for their presentation and the HITAC members for their questions.

BREAK

The HITAC took a short break. **Mike Berry** reconvened the meeting at 11:30 a.m., and **Aaron** and **Denise** welcomed HITAC members, presenters, and the public back to the meeting.

Health Equity by Design Hearing

HEARING OPENING REMARKS

Aaron Miri and **Denise Webb** announced that the second portion of the meeting would be a hearing on the topic of Health Equity by Design. **Aaron** introduced **Micky Tripathi**, the National Coordinator for Health IT, who welcomed the presenters, whose biographies were shared with the HITAC. **Micky** stated that Health Equity by Design is the principle that health should be a core feature of designing health IT

and its implementation, and has been a key feature of his work since he joined the administration. He shared his personal experiences running a non-profit organization in Massachusetts that launched a statewide event notification service to notify providers of encounters that their patients may have had in other settings to improve care management and care coordination. This supported the Medicaid program. He described how they found that the patient matching algorithm used in the state for years was placing too great of an emphasis on patient home address and that housinginsecure patients were not getting the benefit of the coordination to identify encounters across the system. He stated that this was an important lesson about the health equity implications that occur due to the design of a healthcare system.

Micky explained that ONC and HITAC established the goal to improve health equity and related patient care outcomes and invited all attendees to learn from the experts and stakeholders presenting during the hearing. He explained how the presentations were grouped and noted the importance of algorithms and artificial intelligence (AI) in electronic health record systems (EHRs). He thanked the HITAC co-chairs for their leadership and the speakers for taking the time to present to and better inform the HITAC on matters related to health equity.

Denise Webb welcomed the presenters and explained that each would have ten minutes to present their testimony. The March 10, 2022, HITAC meeting transcript captured the entirety of each presentation as text, and all meeting materials are linked below and are available on the healthit.gov website. HITAC members discussed the presentations.

PRESENTATION: FRAMING OF THE PROBLEM

Medell Briggs-Malonson, MD, MPH, MSHS, Chief of Health Equity, Diversity, and Inclusion at UCLA Health and Associate Professor of Emergency Medicine at the David Geffen School of Medicine at UCLA introduced herself, thanked the HITAC for the opportunity to provide testimony, and presented on the topic of framing the problem of Health Equity by Design and shared recommendations on standard frameworks, inclusive design, and accountability, which were included in her presentation slide deck.

Eboné Carrington, MPA, FAB, Managing Director with Manatt Health, introduced herself, thanked the HITAC for the opportunity to provide testimony, and presented on the topic of how innovative health IT policies and standards can advance health equity and shared recommendations on balancing urgency and care to support communities, providers, and drivers of health equity, which were included in her presentation slide deck.

Discussion:

- **Aaron Miri** thanked the presenters for the excellent content of their presentations.
- **Denise Webb** thanked them for clarifying the definition of health equity and noted that the discussion of inclusivity made her think of the use case of the design of the artificial heart, which did not include any women on the design team. This resulted in a design that did not fit in a woman's body. **Medell** agreed that inclusivity is key to the process going forward.
- **Steven (Ike) Eichner** stated that other communities should be considered, including people with rare conditions. He emphasized the need to better leverage technology, data, and non-profit organizations to improve connectivity across provider networks to connect patients to caregivers who can best meet their individual needs.

- **Medell** agreed that individuals who live with rare medical conditions experience different challenges that others who live with more prevalent medical conditions do not. She stated that technology can be leveraged for connectivity and provide greater context around these communities to ensure better health outcomes. Excellence in Health Equity by Design extends to building frameworks and technology systems that benefit unseen and unaccounted for populations and more general populations. She thanked him for his comments.
- **Steven** suggested that a holistic view of improving transportation networks to provide access to care includes ensuring that it is accessible transportation for care and that patients who cannot access a typical vehicle are not left behind.

PRESENTATION: USE OF DATA: ARTIFICIAL INTELLIGENCE AND MACHINE LEARNING, SYSTEMS INTEGRATION, AND INTEROPERABILITY

Kathleen Blake, MD, MPH, Senior Advisor, American Medical Association, introduced herself, thanked the HITAC for the opportunity to provide testimony, and presented on the topics of artificial intelligence and machine learning, systems integration and interoperability shared recommendations on ethics, evidence, and equity, which were included in her presentation slide deck.

Irene Dankwa-Mullan, MD, MPH, Chief Health Equity Officer, Deputy Chief Health Officer IBM Watson Health, introduced herself, thanked the HITAC for the opportunity to provide testimony, and presented on the use of data in artificial intelligence and machine learning (AI/ML), systems integration, and interoperability. She discussed IBM's commitment and efforts to building Health Equity by Design and shared recommendations to the HITAC, which were included in her presentation slide deck.

Ziad Obermeyer, MD, University of California Berkeley**,** introduced himself, thanked the HITAC for the opportunity to provide testimony, and presented on the use of algorithms and AI systems to avoid racial and other biases in healthcare. He discussed three use cases that illuminated algorithms' positive and negative impacts and the need for Health Equity by Design. He shared a link to the following reference document, which contains specific measures that organizations can take to prevent and fix the bias in the algorithms they are using: The Algorithmic Bias Playbook https://www.chicagobooth.edu/research/center-for-applied-artificial-intelligence/research/algorithmic-bias

Nicol Turner Lee, PhD, Senior Fellow in Governance Studies at the Brookings Institution, Director of the Center for Technology Innovation, and Co-Editor-In-Chief of TechTank, introduced herself, thanked the HITAC for the opportunity to provide testimony, and presented an update on recent work on health equity underway at the Brookings Institute. She discussed the focus of her sociological work on the digital divide in the United States, which is related to AI and machine learning algorithmic bias. She explained that Health Equity by Design for health IT is a complex issue to solve and discussed how it intersects with race, technology, social justice, and social determinants of health (SDOH). She shared pragmatic solutions and a link to her recent paper: Algorithmic Bias Detection and Mitigation: Best Practices and Policies to Reduce Consumer Harms https://www.brookings.edu/research/algorithmic-bias-detection-and-mitigation-best-practices-and-policies-to-reduce-consumer-harms/

Terri Willits, MA, IT Strategy & Planning Director, leads the Responsible Artificial Intelligence (AI) program at Anthem, Inc., introduced herself, thanked the HITAC for the opportunity to provide

testimony, and presented an update on recent work on health equity underway at Anthem. She discussed their intentional efforts to focus on Health Equity by Design and responsible AI to create and deploy programs that will address the unmet needs of populations and the root causes of systemic inequalities.

Discussion:

- **Aaron Miri** thanked the presenters for their excellent presentations and added that he would give them a standing ovation.
- **Hung Luu** thanked them for their presentations and commended the panel for their passion. He agreed that AI and machine learning are promising ways to make healthcare more efficient and equitable, though work must be done on the data elements that feed into some algorithms. He recognized the work of the Gender Harmony Project on the capture sex and gender preference information, noting that the current system is too rigid and binary. He stated that the inaccurate capture of data for transitioning patients or those who have undergone gender reassignment surgery could lead to detrimental effects if fed into an algorithm. This creates detrimental effects on vulnerable populations.
    - **Eliel Oliveira** agreed with **Hung's** comments and added that standards around collecting and reporting race and ethnicity data need greater clarity. He discussed the role of genetics in the determination of race and described the use case of a patient diagnosed with rare cancer by IBM Watson due to their self-reported race data. He urged them to consider collecting data on genetics, as well.
    - **Medell Briggs-Malonson** commented that her institution has created more finely tuned race categories to allow patients to self-identify and to allow care providers to better address the issues **Eliel** raised in his comment. She described the various factors at play when capturing these data types to provide the most equitable care while not making assumptions about how a patient's race or ethnicity correlates to their overall health. Continual work is needed to build the best algorithms to lead to greater health equity and do not perpetuate biases.
- **Ziad Obermeyer** agreed with the other commenters' discussions around more intersectional categories but added that most insurance companies do not know anything about the race or ethnicity of the people they cover. He stated that many are afraid to collect this data, as they are afraid that they will be accused of using it improperly, so the government must articulate guidance on the topic. Then, patients can be assured that the collection of this data is meant to reduce healthcare disparities.

BREAK

The HITAC took a short break. **Mike Berry** reconvened the meeting at 1:45 p.m., and **Aaron** and **Denise** welcomed HITAC members, presenters, and the public back to the meeting.

PRESENTATION: CONTENT AND EXCHANGE OF DATA, PART 1

Denise Hines, DHA, PMP, FHIMSS, Executive Director of the Georgia Health Information Network, (GaHIN) introduced herself, thanked the HITAC for the opportunity to provide testimony and presented ways in which GaHIN is identifying and addressing health equity challenges by screening patients with a questionnaire related to SDOH. She described a number of use cases and shared recommendations for how the HITAC and ONC can address the needs of underserved and underrepresented communities by focusing on health equity and digital access to healthcare

systems.

Dominic Mack, MD, MBA, Professor of Family Medicine at Morehouse School of Medicine, Director of the National Center for Primary Care (NCPC), introduced himself, thanked the HITAC for the opportunity to provide testimony, and presented on the topic of digital health tools and primary care in communities. He described the state of primary care in terms of technology, a community approach and evaluation, tools and resources, his experiences serving on the Board of the GaHIN, and NCPC's and GaHIN's recent work, all of which were detailed in his presentation slide deck.

Angela D. Thomas, DrPH, MPH, MBA, Vice President of Healthcare Delivery Research at MedStar Health Research Institute, introduced herself, thanked the HITAC for the opportunity to provide testimony, and presented her firsthand experiences at Medstar Health with health equity experiences and challenges. She shared recommendations supported by research and described experiences that fell into three categories: data collection, data exchange, and data ethics.

Andrew Hamilton, RN, BSN, MS, Chief Informatics Officer at AllianceChicago, introduced himself, thanked the HITAC for the opportunity to provide testimony, and presented an overview of the Alliance Chicago Network's many efforts to improve individual, community, and public health through innovative Collaboration. He described the plans and initiatives through which AllianceChicago identifies and addresses health disparities and promotes health equity, detailed in his presentation slide deck and testimony.

Discussion:

- **Denise Webb** thanked the presenters and invited HITAC members to engage in a discussion.
- **Eliel Oliveira** highlighted comments from the public chat in Zoom and described how issues related to health equity data and the collection of SDOH data are broader than what is contained in and shared by EHR systems. He described the use case of how the key problem of homelessness is currently dealt with by coalitions and the clinical system in Austin and suggested that there is an opportunity there to expand the view of how to collect and integrate systems to be able to address health equity efficiently.
    - **Denise Webb** responded that state governments often hold data around SDOH and the services individuals receive through government programs. She described her experiences at the Department of Health Services in Wisconsin and explained that they worked to change from a system with a one-on-one focus to a hub-and-spoke focus with the individual at the center. She stated that state government and local county programs that provide services should work with local providers to pull the relevant SDOH and health equity-related data together.
    - **Eliel** responded that different communities have different priorities and problems that can be addressed through the use of SDOH data (e.g., homelessness in Austin, food insecurity in Houston).
- **Dominic Mack** explained that the public and private databases containing information around social determinants are not readily accessible to communities, so the data is not regularly integrated into the EHR. He explained that Medicaid data has a cost that most community-based organizations or grassroots organizations cannot afford, so they cannot access the data about underserved populations. He recommended that ONC and the healthcare community work to find a better way to lower the costs and barriers to integrating that information and make it available back to communities to utilize the information to improve care.

- **Denise** described how Wisconsin has worked to get programs to share data with the statewide health information exchange (HIE) to make it part of the available record. She stated that standards are still needed.
- **Clem McDonald** agreed that HIEs provide a good opportunity to more widely share SDOH data, though he stated that they have been under-supported. He suggested that community organizations that keep track of data around homelessness and other health equity issues could be better integrated into the system.

BREAK

The HITAC took a short break. **Mike Berry** reconvened the meeting at 3:00 p.m., and **Aaron** and **Denise** welcomed HITAC members, presenters, and the public back to the meeting.

PRESENTATION: CONTENT AND EXCHANGE OF DATA, PART 2

Janet Campbell, Software Developer and Vice President of R&D Relations at Epic, introduced herself, thanked the HITAC for the opportunity to provide testimony, and presented Epic's perspective on the opportunities that to better leverage information technology to identify, monitor, and treat disparities that exist in healthcare in the United States. She described Epic's priorities for identifying and treating the disparities of care and outcomes in medicine and healthcare and shared recommendations to the HITAC and ONC, which were detailed in her testimony.

Robert L. Murry, PhD, MD, FAAFP, Chief Medical Officer, NextGen Healthcare, introduced himself, thanked the HITAC for the opportunity to provide testimony, and presented on NextGen's initiatives to address health equity challenges. He shared the recommendations they identified across five areas of success and opportunity, which included health equity data collection, actionable analysis of the data, interoperability of data to promote cooperation and integration of healthcare and social service providers, the special role that HIEs can play this area, and improving overall access to healthcare and technology. These recommendations were detailed in his presentation slide deck and testimony.

Jaffer Traish, Chief Operating Officer of findhelp, introduced himself, thanked the HITAC for the opportunity to provide testimony, and presented on findhelp's work, through a closed-loop referrals system, to connect all people in need with dignity and ease to the programs that serve them. He described how Health Equity by Design is a key part of their mission and how they work toward health equity through social care and government partnerships. He shared recommendations to the HITAC and ONC in his presentation slide deck and testimony.

Carlos Uriarte, JD, Vice President, Regulatory Council, and **Read Holman**, MPH, Policy Director, Government & Regulatory Affairs, of Unite us, introduced themselves, thanked the HITAC for the opportunity to provide testimony, and presented on how Unite us provides services that advance Health Equity by Design by connecting health/clinical and social care. They discussed the gap in care through an end-to-end solution that serves individuals, communities, and populations and shared recommendations to the HITAC and ONC in their presentation slide deck.

Trenor Williams, MD, Co-Founder and CEO of Socially Determined, introduced himself, thanked the HITAC for the opportunity to provide testimony, and presented considerations around creating a more equitable healthcare environment. He described how individual and population-level vulnerabilities can be identified and analyzed at various levels and domains and issues around the visibility of SDOH and social risks/needs. He shared examples of initiatives organizations are undertaking to address these needs and shared recommendations to the HITAC and ONC.

Discussion:

- **Clem McDonald** asked **Trenor Williams** to describe how the products and initiatives he described fit together, interact, and possibly overlap.
    - **Trenor** described how a variety of organizations, including Epic, findhelp, and Unite us, have worked with his organization (Socially Determined) to implement their module.
- **Janet Campbell** commented that because patient needs vary and many of the organizations that serve them are smaller, it is difficult to have one product address them all. Developing interoperable standards for closed-loop referrals and support for social care programs will be key to strengthening the overall health outcomes.
    - **Aaron Miri** added that establishing the Trusted Exchange Framework and Common Agreement (TEFCA) and Qualified Health Information Networks (QHINs) should help augment data flows positively by establishing more networks and referral patterns.
    - **Carlos Uriarte** echoed that national standards will bring everyone together to work in the sandbox that **Trenor** described in his presentation and comments.
- **Steven (Ike) Eichner** commented on the importance of ensuring that patients and their families remain at the center of care and play an active role in looking at the referral process so that it is an action that takes place in conjunction with patients and their families and not for or to them. Patients, especially those with complex medical histories, want to maintain privacy, confidentiality, and control, even while ensuring that their information is interoperable. He suggested a recommendation that ONC create a set of parameters/recommendations that facilitate the sharing of information across the provider continuum that also puts patients and their families in an important central role in managing the process.
    - **Aaron** commented that they are working towards is getting a uniform set of industry-accepted principles and regulations in place.
- **Robert Murry** responded to the previous question about how the presenters and their organizations work together and emphasized the collaboration between the CommonWell Health Alliance, which has worked with service providers and members, to create and deploy a vendor-neutral platform that breaks down the technological and process barriers that inhibit effective health data exchange, and Carequality, an interoperability framework enabling care coordination. He described how interoperability benefits providers and added that ensuring interoperable access to data and networks is key, though additional work is needed.
    - **Aaron Miri** responded that not every vendor "plays in the same sandbox" and that not every provider organization can contribute as much data as the major nationwide networks. In theory, it sounds great, but in practice, it becomes difficult. He encouraged everyone to send data through national networks.
    - **Steven (Ike) Eichner** added that appropriate security and controls must be used when connecting to national networks to ensure that patients/caregivers and family remain at the center of providing access to their own information.
    - **Robert** discussed the proposed standards that will protect patients but noted that they still need work from stakeholders to be adopted.
    - **Aaron** stated that several committees of the HITAC, including the USCDI TF and the IS WG, are working on these topics. They hope to accelerate adoption and to work towards standards maturity.

- **John Kansky** echoed **Clem's** previous comments about how the work fits together and suggested that widening the exchange of health information also widens the definition of healthcare. Therefore, the community-based organizations and intervention systems/their data must also be included in the information exchange circle.
- **Robert** stated that, like utilities, HIEs connect data providers with data consumers, sometimes spontaneously. Coordination at a higher level could ensure that everyone gets connected appropriately.

- **Sheryl Turney** thanked all the presenters who spoke at the hearing and emphasized the need for coordination, testing, funding, and working together to ensure that all healthcare business models support services. She explained that the challenges the presenters described made her emotional, due to her personal and family experiences, and she highlighted the need to center around the patient and their viewpoint. She described her family's experiences of being misdiagnosed and having issues updating the EHR and cautioned against some funding and business models that are currently in use. She stated that attributing race, ethnicity, and language data to family members (in modern blended families in the US) in that model needs extra care. Also, she agreed with the importance of the issues brought up earlier related to access to devices. She asked everyone to consider the specific calls to action that would be inspired by the presentations and learnings from the hearing.
- **Janet Campbell** emphasized the need for the accurate collection of data, including but not limited to race, ethnicity, and language. This could include operational procedures and policies, quality reporting, making reported information and processes more transparent, and better using them for decision making.
    - **Carlos Uriarte** suggested ensuring that the right investments are made and the correct incentives are created for those investments to be made, both in the infrastructure that is needed for information sharing, as well as investments back into the communities and the organizations that are providing services.
    - **Read Holman** highlighted questions about who has the power to shape incentives and the role stakeholders play in ensuring that many communities have a voice and are elevated in the process. Governance and standards can be used to uplift marginalized voices.
    - **Jaffer Traish** echoed **Janet's** comments and added that very good data collection and bringing needs-based data to those with the capacity to ensure funding (government, philanthropies, healthcare organizations, etc.) can power better coordination on behalf of patients. He described how the Michael and Susan Bell Foundation is working to remove the barrier of funding from a cross-system care coordination model to incentivize standards, data collection, and care coordination work.
    - **Aaron Miri** thanked everyone for their guidance and referenced the notion that all data is relevant, has a place. He described Epic's Sherlock application that references electronic health information in comments around social determinants.
- **Clem McDonald** commented that, beyond increasing effort and funding, policy issues need to be addressed and discussed how Medicaid could collect some of this data if they were to allow it. He stated that policy changes could improve connections in data sharing and that standards work is also important and must not be done in opposing ways.

PUBLIC COMMENT

Mike Berry opened the meeting for public comment and reminded attendees that written comments could be submitted at ONC-HITAC@accelsolutionsllc.com.

Questions and Comments Received via Telephone
There were no public comments received via telephone.

Questions and Comments Received via Zoom Webinar Chat
Michael Berry: Good morning, and welcome to the March HITAC meeting. Please remember to set your chat to "everyone" so that all participants see your chat. Thanks!

Michael Berry: Today's meeting materials can be found on the HITAC website: https://www.healthit.gov/hitac/events/health-it-advisory-committee-43

Clem McDonald: I am here, Clem

Steven Lane: https://www.healthaffairs.org/do/10.1377/forefront.20220217.71427/

Jim Jirjis: Jim jirjis here

Leslie Lenert: 1.in prior discussions of this issue I have emphasized the importance of ePA being based on application of artificial intelligence methods that simulate human judgments of the appropriateness of care rather than rule based processes, a "brittle" technology from the 1980's. I think this still holds true. Whatever standards are developed should provide a clear path forward to the use of transparent AI approaches that simulate physcian-experts *[sic]* consensus judgment of the appropriateness of procedures and treatments. AI methods offer a most more robust approach that can use provider notes and other primary documentation for PA, reducing work, allowing greater flexibility, and fairness.

Leslie Lenert: 2. Bring the rules to the data rather than the data to the rules. Why? Privacy. HIT certification framework exists. Secondary benefits for better decision support in EHRs. MOST importantly—IMPROVED TRANSPARANCY

Leslie Lenert: Rules for approval need to be public and families should be able to chose insurers based on transparent PA policies.

Leslie Lenert: 3. If we must move data to the payers, data for PA should travel on the NHIN architecture. ONC should consider sponsoring an QHIIN devoted to PA as a hub to minimize connectivity issues for providers, payers, and patients. There should NOT be an independent network for PA and movement of medical data related to it. This activity might be provided long term sustainability to the NHIN.

Arien Malec: As a counterbalance to this, the future of ePA is VBC, with more bundles and more delegation to providers who share risk.

Alexis Snyder: When you discuss the ability of pushing work to back office staff and/or patients we need to make sure that patients are engaged only as much as they would like to be and that we do not create more burden for patients to be the go between

Hans Buitendijk: Da Vinci brings the rules towards the source data that either the source system or an intermediary (e.g., SMART App) can use to gather the data on the provider side.

Hans Buitendijk: Unless the intent is to bring the determination rules to the source as well.

Arien Malec: Strongly endorse — get parts of this over the finish line incrementally.

Sheryl Turney: Thank you Tammy for being such a wonderful co-chair

Steven (Ike) Eichner: The recommendation may address the re-use of data provided for a pre-authorization (e.g., the data should be used for determining authorization and retained for historical purposes. We need to be cognizant of how data collected for a particular pre-authorization is used in the future.

Micky Tripathi: Thank you EPA task force for all of the great work!

Matt Reid: @Steven Eichner, the AMA strongly agrees and has concerns with the potential re-use of patients' data. Data governance and technical protections must be in place to support appropriate data use.

Grace Cordovano: https://build.fhir.org/ig/HL7/fhir-patient-correction/

Steve Posnack: There is some early HL7 FHIR work underway https://build.fhir.org/ig/HL7/fhir-patient-correction/

Steve Posnack: Jinx

Noreen Whysel: It also needs to be on and working/compliant. I have a MyChart account where the redress page is hard to find and when you find it it says to call 555-555-5555. That's not the correct number, btw.

Aaron Miri: Agree with Cynthia point at ensuring patients have the full right to all information including the need to correct any inaccuracies.

Alexis Snyder: I think that the correction of patient EHR is not a part of the scope of this project but something that should be on the agenda for work of ONC for 2022. I have brought up this important topic for need to be worked on in 2022. It can be done, but it is very diffacult *[sic]* for patient, and dangerous when incorrect on many levels and we need a standard improved process moving forward. It is very important that as we expand interoperability that correct information is needed as to not perpetuate incorrect information

Steven Lane: We will consider whether the FHIR work should be identified within the ISA.

Arien Malec: https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/special/healthit/correction.pdf

Alexis Snyder: @Ike, absolutely agree that the corrected Information should be presented first and it can be, there are ways to get this done but again we need standards

Arien Malec: Also note that refusal to comply with the HIPAA right to correction should be reported to OCR for investigation and correction/remedy.

Aaron Miri: @Cynthia - silver lining is that with the October 2022 mandate for the full EHI to be released to the patient on demand and without unreasonable delay - will help to highlight this issue. Certainly as more patients get their full record (note: beyond just whats *[sic]* in the EHR) they will want to correct major defects.   So if nothing else, I hold hope that the transparency driven by law will help all of these issues that have lagged.

Alexis Snyder: Correction of EHR is in the current annual report under topics for consideration to be worked on in 2022

Noreen Whysel: Tag data that is recently added/recently updated and notification to patient/guardian so they can see this is new info about me? Is it right? How do I correct?

Laura Hoffman: Cynthia's comments underscore the importance of ensuring that the ePA processes have ways to filter out self-pay patients and don't have CDS Hooks prematurely pull patient data from the EHR.

Rita Torkzadeh: @Aaron et al. - PGHD may not be considered EHI under current definitions/interpretation in info blocking (e.g. see AHIMA's Defining EHI and the Designated Record Set in an Electronic World report: https://www.ahima.org/media/ztqh1h2q/final-ehi-task-force-report.pdf)

Alexis Snyder: @Noreen, every health system has their own way on how they handle corrections which is why we need a standardized process. For example some systems will only allow for an addendum which is not helpful as it is as the end of the data already seen and may never be read and others will replace the wrong info and pu *[sic]* the wiring info into a historical record for safety so taht *[sic]* it is not seen in the record but can pulled up if there is a question about why it was changed to protect everyone as in the question of malpractice so that records don't get buried

Noreen Whysel: @Alexis exactly

Alexis Snyder: @Noreen I have been pushing this topic since my first day on the HITAC 2 years ago and will continue to try to get it worked on!!

Grace Cordovano: @Alexis, as a patient advocate, would love to learn more about additional ways to support and advance medical record corrections and amendments in additional to the HL7 Patient Empowerment workgroup's efforts and implementation guide that's been crafted.

Alexis Snyder: @Grace-lets connect via linkedin-just sent you request

Steven Lane: @Grace - As a member of the ISWG you are well positioned to champion this area as part of our ISA work starting next month.

Grace Cordovano: @Steven, would be happy and honored to! Let's connect to discuss how to best kick off.

Alexis Snyder: @Steve and @grace would love to be a part of this

Susan Clark: @Grace & @Alexis - I am the Chair for the AHIMA Advocacy & Policy Committee. Health Information Management pros have been handling patient amendments since dawn of records. If you are not already connected with our org, let me know how I can help! I will also put this topic on our March meeting to find out how we are already involved.

Alexis Snyder: @susan would love to connect with your organization

Mark Savage: @Grace, @Steven: Happy to help as well. Been working on patient right to correct/amend since 2013 at the National Partnership for Women & Families.

Grace Cordovano: @Susan, happy to collaborate and contribute in any way possible.

Alexis Snyder: @Grace @Susan @ Eliel I think we have a small work group started

Susan Clark: @Alexis   Love it.

Susan Clark: Excellent presentation.

Steven Lane: Thank you @Medell for such an excellent introduction and framing.

Kamala Green: Excellent presentation.

Susan Snedaker: Really excellent information and well presented, thank you @Medell!

Aaron Miri: Great job @Medell

Noreen Whysel: Great presentation. Very important language clarification in particular.

Eliel Oliveira: Indeed, great presentation! Thank you.

Steven (Ike) Eichner: Thank you for your presentations!

Medell Briggs-Malonson: Thank you for the kind words. I look forward to our collective work to achieve equity and justice in health intentionally.

Steven Lane: Great to see that a group like Manatt is engaging and leveraging such tremendous expertise in this domain.

Steven (Ike) Eichner: Another aspect of equity is consideration of condition/disease-specific communities, especially in the consideration of rare conditions.

Part of the issue is identifying individuals with rare conditions, especially those that are not regularly tested for as part of newborn screening activities. A second component is linking individuals with rare conditions to appropriate, informed health care providers and support networks, where they exist.

And how are these support networks themselves supported is also something that needs to be considered. Take, for example, conditions with 500 people or less nationwide.

Eliel Oliveira: NY Times article from yesterday highlighting policies that have negatively impacted underserved populations: https://www.nytimes.com/2022/03/09/climate/redlining-racism-air-pollution.html?searchResultPosition=1

Joey Vasquez: Medell, that was a fantastic intro! Thank you so much for clarifying race vs racism as well as the importance of drilling down to actual issues rather than the overarching social determinant driver.

Grace Cordovano: Thank you for such exceptional presentations, insights, and recommendations to advance progress!

Noreen Whysel: Rare conditions: important to recognize that historically studies of rare conditions may overlook conditions that primarily affect minority populations or under-study affects *[sic]* on minority (and female) populations of rare conditions that affect the wider population.

Eliel Oliveira: Terrific presentations!

Susan Snedaker: Thank you for an excellent presentation as well, clear and concise recommendations. Thank you!

Lisa Nicolaou:

Patty Rose:

Kenneth Wilkins:

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Noreen Whysel: Great presentation, Eboné

Joey Vasquez: Great information, Ebone! Thank you.

AJ Chen: To redesign the care delivery with equity in mind, I think the Learning Health Systems vision from NAM/IOM provides a promising technology direction.

Alexis Snyder: +1 to Ike on equity for chronic complex medical issues and rare disease

Noreen Whysel: That makes sense, too, Steven. How to communicate to care providers how certain populations may present during rare and not so rare conditions.

Abby Sears: I agree these are excellent presentations. I also agree that the idea of the Learning health System framework is incredibly important

Eliel Oliveira: +1 @aj

Michael Berry: All presentation materials for today's HITAC and Health Equity By Design Hearing can be found on the HITAC website: https://www.healthit.gov/hitac/events/health-it-advisory-committee-43

Medell Briggs-Malonson: Excellent presentation, Ebone!

AJ Chen: Implementation of health equity requires disease-specific solutions. LHS design will be promising

Aaron Miri: Hope everyone can appreciate the Arthur C Clarke reference w/Hal9000 :-)

Ebone Carrington: Medell, you did an amazing job, thank you for such an informative presentation!

Susan Clark: @Aaron - I am just old enough to know what you are talking about

Heather McComas: @Aaron -- Open the pod bay doors, Hal! :)

Alexis Snyder: Hear Hear to how PCORI has set the example for Patient Engagement

Steven (Ike) Eichner: For these communities, it can be difficult to find local (or even regional) experts. Continuing education can be a challenge for providers. It can take the same amount of time to improve knowledge for a condition that 20% of a provider's has as for 1 percent of the provider's patients.

From a data and perspective, connecting these patient organizations into care delivery and management could be achieved and including patient organizations might be included as data trading partners. Including patient support groups as part of ACOs and other structures may require some change in how these organizations are considered under HIPAA and part of the nation's care delivery network. , .

Susan Clark: Agree about the engagement of an increasing number of entities who are not CEs or BAs under HIPAA. Commission proposed in this act may help explore that if it comes to fruition. https://www.cassidy.senate.gov/newsroom/press-releases/cassidy-baldwin-introduce-legislation-to-begin-modernization-of-health-privacy-laws

Grace Cordovano: Question: RE: "Does it work for my patients?" and an equity standpoint, will all patients have access to data outputs that are generated by AI systems and used to guide care decisions and care coordination?

Alexis Snyder: We cannot ask "does it work for my patients" without asking the patients and caregivers. Work on planning and development need to include patients form the onset

Alexis Snyder: We can not run on assumptions about what works for patients and what patients need and want

Noreen Whysel: +1 Alexis

Grace Cordovano: Agree @Alexis, critically important to ensur *[sic]* patients and primary carepartners are included as stakeholders in translating principles in practice.

Aaron Miri: @Alexis - precisely correct.   Real world example: we have several chronic patients (and patient family members) that are more than happy to brainstorm with us or share their real world stories when they engage with my health system. The direct feedback from the patients across the entire spectrum of care are engaged actively, listened to, etc.   Its amazing just how much the normal general patient wants their local health system to be amazing and they are willing to lend their valuable voice and experiences.   The question is (as you've stated @Alexis) : Are we listening with intent yet?

Jean Ross: Agree! You cannot develop good algorithms for AI from one sided flow of info (provider to provider) that have been shown to hold biases. By including feedback from family caregivers and patients into the medical chart, you will achieve more accurate AI algorithms

Michael Marchant: @all - agree - need to create some intentionality around engaging patients in all processes impacting their care moving forward

Medell Briggs-Malonson: There is an important social justice motto that states "nothing for us without us." Equity cannot be achieved without the voice and input from those that we serve.

Jean Ross:

Aaron Miri: x2 @Medell

Grace Cordovano: X1000 @Medell

Joey Vasquez: YES, Medell!

Mark Savage: Love it, @Medell! And, "If you build it with us, we will already be there."

Alexis Snyder: @JR absolutely- lots of time and money wasted when we get it wrong the first tilmraround *[sic]* by not engaging patients upfront

AJ Chen: We have learned that ML/AI predictions based on EHR data very often fail when being deployed in different hospitals or clinics. This reveals data from underserved and minority groups. Again, this may requires to design continuous learning and improving ML/AI processes on each clinical sites in order to include data of every patient populations in ML training, which a concept from NAM LHS vision

Aaron Miri: Good article talking about synthetic data sets helping to address AI / ML data models: https://www.nature.com/articles/s41551-021-00751-8

Alexis Snyder: Absolutely to bias in EHR snd *[sic]* claims data-this happens all to often and relates back to the conversation on correcting info it EHR and preventing it form happening to begin with!

Eliel Oliveira: @brett, there is a need for an oversight body that can protect IP while making sure the algorithm is ready for wide use.

AJ Chen: @aaron thanks for the great article about Synthetic data. Yes, we need to explore how to use synthetic EHR data to explore ML/AI solutions that are designed with health equity as a quality measurement

Ziad Obermeyer: Link to our 'Algorithmic Bias Playbook': https://www.chicagobooth.edu/research/center-for-applied-artificial-intelligence/research/algorithmic-bias

Eliel Oliveira: Well said @ziad

Hung S. Luu: Race is really a social/political construct and it is more helpful in terms of pathophysiology to focus on geographic descent. Unfortunately, our current health information systems are focused on capturing race as a surrogate for geographic ancestry. Additional, some systems are only capable of accepting a single response for race. This is problematic for mixed race patients. The practical implications of this for example is that a mixed race patient may not be recommended by an algorithm for Factor V Leiden testing to assess for increased risk of clots because they were identified as African American in the data system and their European ancestry was not captured. This is why the algorithms need to be transparent so that unintended bias can be reduced where possible through accurate data capture. At the very least, clinicians who use these algorithms should be informed of the potential blind spots in the system if the bias cannot be eliminated.

Grace Cordovano: @Ziad, from the patient perspective, most patients, if not the majority, do not have access to any of these AI insights as typically the outputs are not documented in clinical notes. From a health equity design perspective, shared decision making persective, *[sic]* trust building, and transparency standpoint, should clinical workflows encourage/require better documentation of leveraging AI/ML insights if they guide patient care?

Steven Lane: @Hung - This, in part, is why we need to move toward more integration of genomic (and multiple -omic) data into our standard healthcare (e.g., EHR) workflows. We hope to address this area as we develop recommendations for the Interop Standards Advisory (ISA) in our Interop Standards WG.

Irene Dankwa-Mullan: @Hung, Race is helpful for identifying racism and bias in health or the healthcare setting or limiting the full range of treatment or interventions needed.

Steven Lane: Why lean exclusively on the social constructs of race when we can increasingly leverage real data regarding genomic differences based on ethnicity/origin and other factors?

Alexis Snyder: @Steven Lane What about when we dont *[sic]* have genomic data on patients who do not know the origin of their birth history

Medell Briggs-Malonson: @Hung, what would be the best approach is to not focus on race or geographic ancestry and build the algorithms to appropriately identify the disease state that it is trying to predict. There are numerous other predictive factors that are far more powerful and accurate than geographic ancestry.

Steven Lane: @Alexis - What about when we don't have a blood pressure or an A1c? We measure it to fill in the blanks in our data.

Alexis Snyder: @Medell agree! Especially when many patients were adopted and may not know their geographic ancestry

Medell Briggs-Malonson: @Grace, there should always be patient-physician/provider/clinician transparency when determining clinical decisions. That should always be a core of high-quality, equitable care.

Irene Dankwa-Mullan: @Steven, we need to integrate all determinants of health - and social as well as genomic data is fine - but what really drives disparities or inequities are those limited opportunities or access, social factors that have more of an impact on health status and outcomes.

Steven Lane: @Irene - Absolutely!

AJ Chen: @ziad yes, it is critical to have a performance measure for health equity in ML/AI solutions

Alexis Snyder: And lets no forgot the bias that happen with those who live with disabilities as well

Ziad Obermeyer: @Grace, great question. I think it's very hard for patients to make sense of a score without knowing a lot of other contextual information about the population. In our paper https://www.science.org/doi/10.1126/science.aax2342 the doctors had access to the scores, but didn't undo any of the bias. So I don't think it will be a substitute for the health systems and algorithm developers measuring the scores and their relationships to health outcomes at the population level.

Hung S. Luu: Race is important and should continue to be captured, but we need to be aware of the limitations of using race as it pertains to risk of carrier status for particular genes that occur in higher proportions in particular populations as these genes do not always track well with the genes that determine our outward appearance that may identify. I agree with a race neutral approach in the absence of complete data.

Alexis Snyder: +1 to Hung

Ziad Obermeyer: One reason we focus on race in our work is because it is a protected category under the law. So there is a clear legal mechanism for addressing those disparities, which I think can also have positive spillovers into fixing disparities in other (not protected) categories.

Alexis Snyder: @Ziad there is a fine line between fixing disparities and creating more

Noreen Whysel: Again, it's definitions. Perhaps a crosswalk of some sort between the legally defined categories of race and the genetic and lived categories of ethnicity.

Medell Briggs-Malonson: Race is an important category to assess for variations in clinical care delivery, health outcomes, and lived experiences, but it is important not to make assumptions that race leads to specific medical conditions or outcomes. Racism, discrimination, and bias within healthcare and our society leads to adverse medical conditions. This is a very important principle to focus on.

Alexis Snyder: +1 to Medell

Noreen Whysel: +1 Medell and Nicol

Alexis Snyder: Thank you Nicol-terrific presentation!!!!

Robert Gergely MD: Why is Nicole so angry?

Alexis Snyder: She is not angry she is a strong speaker with a passion

Betty Lengyel-Gomez: She's not angry, she's pationate! *[sic]*

Eliel Oliveira: Nicol for president!

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Jean Ross: She's not angry, she's passionate. Hoping Dr G you are showing us an all an example of bias and influences on interpretation of the clinician

Aaron Miri: Dr. Lee is absolutely inspirational.   Wow. She is spot on!

Kimberly Madison: What led you to believe she was angry?

Alexis Snyder: @Robert Gergely- great example of internal bias. Strong woman with a passion is "angry"

Robert Gergely MD: Just my impression.

Irene Dankwa-Mullan: Great ideas and points Nicol! I also like you definition of bias -

Medell Briggs-Malonson: Dr. Lee is a thought leader in this space. Her passion and expertise exudes through her presentation.

Alexis Snyder: Yes it does-awesome

Kenneth Wilkins: ^ compelling discussion above, to mirror the talks — it all points to the urgent need to integrate all potential contributors to health (and, unfortunately given current state of healthcare, health disparities, let alone the legal context); would urge those interested to consider mediation analysis frameworks to frame efforts that try to estimate distinct factors' contributions… as discussed in an epidemiologic journal and its preceding articles / rejoinder: https://pubmed.ncbi.nlm.nih.gov/24887162/ ; in the law scholarship and social science communities the sociopolitical radicalization of certain groups (and underserved populations like those with disabilities and economic disadvantage) is similarly cast and may be of interest to those whose work may not leverage epidemiologic approaches: see, for example: https://www.annualreviews.org/doi/abs/10.1146/annurev-polisci-032015-010015 as well as Dr. Lee's work as she says she'll place a link for… very grateful for her passionate presentation!

Jean Ross: Exclusion of a population I heard a lot today are the family caregivers and the circle of support around patients. Family caregiving can also be culturally constructed

Alexis Snyder: @Jean Ross, agree-caregivers often overlooked

Eliel Oliveira: +1 @jeanross, @alexis

Alexis Snyder: Love Nicol, however lost me a little at "checking a box" we can not "check a box" we have to bring in the lived experience and engage authentically

Grace Cordovano: Thank you for an exceptional presentation! Inspired by your insights and passion!

Amit Trivedi: Thank you, thank you - ONC and panelists for providing this learning opportunity. Very much appreciated.

Patty Rose:

Kenneth Wilkins:

Alexis Snyder: @Nicol last but certainly not least!!!!!!

Joey Vasquez: Thank you Nicol!

Ziad Obermeyer: @Nicol, wonderful presentation - thank you. I particularly appreciated your definition of "similarly situated" people facing different scores depending on race, and the need for litmus tests for bias. It's a perfect way to say it, and parallels civil rights law.

Nicol Turner Lee: Here is the paper that I referenced - https://www.brookings.edu/research/algorithmic-bias-detection-and-mitigation-best-practices-and-policies-to-reduce-consumer-harms/

Aaron Miri: just wow @Nicol.

Jean Ross: Thanks, Nicol!!!!

Medell Briggs-Malonson: Excellent presentation, @Nicol!

Jordan Hefcart: Phenomenal perspective, deep expertise, and unmatched eloquence. Thank you!

Eliel Oliveira: Wow indeed.

Nicol Turner Lee: A chapter on an incentive-based rating system will be released soon. Follow us at Brookings for more information.

Jean Ross: Motivations and incentives are such a great focus to uncover how to get AI/ML to a more functional state!!!

Kiri Bagley: Thank you, Dr. Turner Lee, for sharing your insights and wisdom with all of us today!

Nicol Turner Lee: @Robert - never ever angry; I couldn't see my video so had not idea where I was positioned relative to my screen. My apologies for keeping everyone awake!

Nicol Turner Lee: @Alexis - agreed no box to check, we need more of a collaborative and cooperative framework in design and implementation. Hope that clarifies.

Alexis Snyder: @nicol, I know that's what you meant   just dont *[sic]* like to use a "checklist" as an example

Janet Campbell: To be honest, I'm angry. It's too often that women and especially women of color are judged not on their message but how it's delivered. That's something we can all work together to change, if we confront it honestly in ourselves and hold ourselves accountable.

Ziad Obermeyer: Thanks for the shout-out @Terri! Was such a pleasure to work with you at Anthem.

Alexis Snyder: +1 to Janet

Serena Mack: +1 Janet!

Steven Lane: +3

Nicol Turner Lee: @Alexis, great feedback. We've been experimenting with new language.

Jean Ross: A frustration of mine with payors is realizing the centralized data they get from the health system and not use this data to grown in awareness of how their data could best impact a patient or family. This highlights Nicol's points of incentive because payors incentives focus is on cost saving and reducing costs per member. In the community, there is a lot of mistrust of advice that comes from payors so my hope would be for payors to not take their AI to dictate care to patients but to partner with providers to best suppprt *[sic]* the care team.

Eliel Oliveira:

Susan Snedaker: All of these presenters did a fantastic job talking about AI, many aspects that provided new insights for me. Thank you!

Irene Dankwa-Mullan: A Proposed Framework on Integrating Health Equity and Racial Justice into the Artificial Intelligence Development Lifecycle https://muse.jhu.edu/article/789672 a link to our paper

Carolyn Petersen: +1 Janet

Joey Vasquez: +1 Janet

Alexis Snyder: +1 to Hung

Nicol Turner Lee: @Janet, thanks for bringing up that point up - this is also how bias in machines percolate - "Black woman talks loud = angry." I use this as an example to frame the conversation in the chat dialogue, which is why we have to find frameworks to break these log jams, especially in health care algorithms. These systems are mirroring the behaviors of humans. Teachable moment!

Eliel Oliveira: https://cdebrowser.nci.nih.gov/cdebrowserClient/cdeBrowser.html#/search

Nicol Turner Lee: @Eliel - great points and there is some intersectionality around these variables too.

Kenneth Wilkins: ^to follow up on Eliel's link, for areas more broad than cancer a similar resource (harmonizing with NCI's) can be found under: https://cde.nlm.nih.gov/home

Irene Dankwa-Mullan: @Eliel and @Nicole +1 -

Nicol Turner Lee: @Eliel, I also think that we need to think about these as a continuum of high and low-risk applications. You don't want genetics to become an exclusionary category or foreclosure on algorithmic opportunities.

Eliel Oliveira: @nicol definitely! Patienter-reported, *[sic]* genomics based, clinician captured all matter in different ways. We need standards for many different situations.

AJ Chen: NAM's LHS vision is captured in these NAM reports. It may be a great source to find promising ML/AI solutions regarding health equity. https://nam.edu/programs/value-science-driven-health-care/learning-health-system-series/

Nicol Turner Lee: @Medell - perhaps there should be some additional discussion on racial categories, but there should also be some testing and experimentation. In some instances, there should also be some level of collection with policy guardrails.

Carolyn Petersen: +1 Ziad

Irene Dankwa-Mullan: SO for me, I no longer sit on review panels or research studies that do not integrate the complete etiological context of a patient's lived experience, social needs etc..

Nicol Turner Lee: At Brookings, we have spoken about regulatory safe harbors and sandboxes.

Irene Dankwa-Mullan: Thank you all!

Medell Briggs-Malonson: @Nicol- completely agree! There has to be a clear roadmap for design, implementation, and analysis.

Nicol Turner Lee: Absolutely - such great points.

Nicol Turner Lee: Thanks everyone!

Beth Onofri: is Denise moving through any slides?

Denise Webb: She has no slides except a title slide

Beth Onofri: thank you

Robert Gergely MD: We must have a complete longitudinal medical records.

Robert Gergely MD: Great!

Susan Snedaker: Digital determinants of health an important element of healthcare, thank you

Robert Gergely MD: @susan Snedaker It is extremely important but it changes daily as more and more people are digitally savvy.

Susan Snedaker: More and more are digitally savvy, but the data I've seen doesn't always accurately represent actual access to digital tools for those in lower socio-economic sectors.

Robert Gergely MD:
    For a professional #Telemedicine consultation you need:
    1. Qualified consultant.
    2. Consultant MUST have instant access to patients
       complete medical record.
    3. Documentation for the medical record & medico-
       legal

Abby Sears: We have learned a number of items. The first one is that in many instances because of challenges with connectivity and broad band, patients really need telephonic access. For our aged population, they prefer this modality to care delivery. The patients with English as a second language need embedded interpreter services. Many of our patient have pay as you go phones and this matters a great deal around access. They can't afford to do video so telephonic becomes increasingly important.

Eliel Oliveira: Great slide on LHS

Susan Snedaker: @AbbySears - exactly. Cellphones are pervasive, but do patients have smartphones, enough data minutes for a visit, decent connectivity at their homes and digital literacy to use these health tools. That's one area we're working on in our community.

Robert Gergely MD: Patient Mediated Interoperability

Robert Gergely MD: Great Thank you!

Robert Gergely MD: SDH is dynamic must be evaluated yearly.

Steven Lane: Documentation of SDoH should eventually continuous (and patient-centric), as today we strive to always maintain an accurate and complete Medication List, based on what an individual is

actually taking/using. (Unfortunately even this clear need is not yet supported by the data elements in USCDI, as we discussed at our IDWG this week).

Steven Lane: *ISWG

Steven (Ike) Eichner: From an interoperability perspective, I think it important to enable individuals to supply information when convenient for them (in advance of use). This may mean additional interoperability across systems, outside of the traditional EHR and, potentially, outside (but connected to) traditional healthcare environments.

If relevant information could be assembled by the individual or their family on their schedule and in he comfort of their own home (or other self-selected environment), the quality and completeness of that information may improve. Enabling development of the information outside of an office environment also levels the field in terms of time required for appointments and reducing time burdens, especially during a business day.

Some of the relevant information may be used outside of traditional medicine to apply for a variety of other programs/supports. Having a repository of information already available electronically that an individual could share with the push of a button,, authorizing the

Eliel Oliveira: I say it needs to be realtime. If one becomes unemployed and needs food they can't wait until the next clinical visit to share that they are in need.

Robert Gergely MD: @Steven lane

Eliel Oliveira: @Steven, good points

Steven (Ike) Eichner: sharing of the data would be a significant improvement. The individual's data could easily be augmented with relevant data associated with the individual from other, non-medical resources.

In a real-world example, I have provided core information to 4 or 5 different programs/providers, all related to a particular objective. It would have been a lot easier to send a link to my documentation, granting the program's access to data I'd already stored in a standard format.

Robert Gergely MD: Health Care = Self Care + Medical Care

Susan Clark: @Eliel - agree on the real time. Opportunity to work more with state government on data exchange who are often the keeper of that information. Also statewide social referral tools networks. We can't wait for claims data to get a piece of information.

Lisa Nicolaou:

Steven Lane: SDoH data is particularly personal and warrants particularly strong patient-specified privacy controls - what data to share with what users in what context - not unlike SOGI, substance use, sexual activity and other data classes/elements. In time patients should have the ability to maintain true sovereignty over this data. When patients control the data and its sharing/exchange providers/caregivers will be able to rely on its accuracy and leverage it effectively.

Alexis Snyder: +1 to Steven but add that it does not guarentee *[sic]* the accuracy but does allow for catching errors

Alexis Snyder: As well as whom to share with if incorrect

Lisa Nicolaou: Data sharing will only proceed at the speed of trust; Data governance and stewardship cannot be an afterthought in this process but rather addressed up from if we are going to avoid spending millions on millions of dollars on technology which cannot stand a chance of altering health equity.

Robert Gergely MD: @Steven Lane you are amazing. Can't wait for HIMSS22

Robert Gergely MD: It can NOT continue to complicate HIT any further.

Eliel Oliveira: Great presentation Andrew.

Steven Lane: While transparent health data governance is critical and high priority, it is only a limited substitute for true data self-sovereignty. (Consider to potential of new Web3 approaches such as https://solidproject.org/)

Robert Gergely MD: @Steven Lane or

Robert Gergely MD: https://www.linkedin.com/pulse/patient-mediated-interoperability-robert-gergely-md/

Robert Gergely MD: @Dominic mack I liked your presentation!

Sheryl Turney: @Dominic your points are important and were also brought up during the hearing on Public health data

Robert Gergely MD: Burnout major problem!

Susan Clark: Good point on privacy/trust. Consent management and data segmentation work needs to continue to evolve.

Steven (Ike) Eichner: I think it important that issues be addressed WITH patients/families and providers not BY providers FOR patients/families. Patients and their family members/representative (if the patient is a minor or needs assistance) need to be able to be actively engaged in content creation, review, and control of with whom,, and why, SDOH and other data about the individual is shared.

Alexis Snyder: +1 to Ike-not to, not for, but with!

Robert Barker: National standards that aren't individually changed by states is essential.

Robert Gergely MD: When Medicaid card is issued all this data is collected already.

Alexis Snyder: Also need patient/caregiver input in to care plan format

Steven (Ike) Eichner: Patients' rights to privacy and confidentiality must be respected and appropriate security constrains in place.

It may also be important to remember and consider that asking for some of these details may also be viewed as intrusive. Please remember that people with complex medical needs are still people, with their individual wants and needs, including, in at least some situations to be anonymous.

Alexis Snyder: Telehealth also needs to allow visits when patient is located in different state then provider, Hugh barrier

Alexis Snyder: *huge

Steven (Ike) Eichner: Mr. Traish, thank you for your presentation!

Steven Lane: Great presentation @Jaffer! So nice to see how your company and your peers have evolved to meet the glaring needs in our communities.

Eliel Oliveira:

Medell Briggs-Malonson: @Jaffer, we are excited to deploy Find Help throughout all of the University of CA health systems to directly link our clinical care to social services. Thanks for the great presentation!

Alexis Snyder: Awesome, thanks Jaffer!

Sheryl Turney: @Jaffer important topic you raised and one that should not be allowed to create monopolies

Clem McDonald: In defense of CMS. Medicare and Medicaid data is integrated in the sense that patient records are linked. Researhers *[sic]* can ask for such data but with tight control and they can't get access to individual level data

Clem McDonald: To Jaffer. The idea and the presentation was brilliant. So glad to hear it.

Kenneth Wilkins: +1 @Clem's question *[sic]*

Alexis Snyder: +1to Clem

Denise Webb: Agree @John K

Eliel Oliveira: +1 @johnk

Robert Barker: If the goal is patient centric, we need to have a national standard for consent and state coordination for a national standard fro *[sic]* consent and data to be shared

Aaron Miri: Thank you so much @Sheryl for sharing your personal stories.   Exact reason why this is so important and why we have to get it right.

Joey Vasquez: Sheryl, thank you for sharing your story. I have had some of the same experiences with family members and this is why this work matters.

Eliel Oliveira: @sheryl, I believe real change will happen faster when we move the financial and lobbing levers.

Robert Barker: It is not just collecting data, it is defining needed data. Looking for ONC to help define.

Sheryl Turney: Thank you all for your comments. I want to do more and I'm not sure what that would be.

Janet Campbell: Also, vote.

Medell Briggs-Malonson: The key item is accountability to move this work forward. We have to commit as a country that eliminating health inequities and ensuring optimal health is a human right. Accountability through federal and state policies and incentives is imperative to drive this work forward.

Robert Gergely MD: Thank you all. Great webinar Aaron Miri

Sheryl Turney: Great presentations all

Ryan Argentieri: Thank you everyone for making the time!

Questions and Comments Received via Email
Nicol Turner Lee submitted the following to the record:
Report: Removing Regulatory Barriers to Telehealth Before and After COVID-19. Authored by Nicol Turner Lee, Jack Karsten, and Jordan Roberts. Published in collaboration between The Brookings Institution's Governance Studies program and The John Locke Foundation, Wednesday, May 6, 2019.

Report: Algorithmic Bias Detection and Mitigation: Best Practices and Policies to Reduce Consumer Harms. Authored by Nicol Turner Lee, Paul Resnick, and Genie Barton. Published by The Brookings Institution, Wednesday, May 22, 2019.

FINAL REMARKS

Mike Berry reminded members that the next meeting of the HITAC will be held on April 13, 2022. All materials and testimony from today's meeting would be made available at https://www.healthit.gov/hitac/events/health-it-advisory-committee-43.

Denise and **Aaron** thanked the presenters and everyone for their participation and the robust discussion. **Aaron** noted the impact of the personal stories shared during the meeting and that the impassioned pleas from the presenters are helping make healthcare delivery more equitable.

ADJOURN

The meeting was adjourned at 4:45 p.m. ET.