Interagency
Committee on
Disability
Research
icdr.acl.gov

Accessibility and Usability in Health Information Technology:

A Research & Action Conference to Empower People with Disabilities, Older Adults, and Caregivers

Interagency Committee on Assistive Technology
Interagency Committee on Disability Research

Proceedings

September 17-18, 2015

Washington, DC

icdr.acl.gov

Table of Contents

Abbreviation iii

Executive Summary 1

Day 1: Exchanging Perspectives, Identifying Barriers and Facilitators 6

Keynote: Elevating Accessibility and Usability in the Health IT Agenda to Better Meet the Needs of Older Adults, People with Disabilities, and Caregivers 7

Panel 1: Voices and Perspectives of End Users – Needs, Barriers, and Opportunities Associated with Using Health IT Systems and Tools 8

Panel 2: Building Blocks for Accessible and Usable Health IT: Overview of Current Landscape – What Standards and Tools Exist and Where are the Gaps 12

Panel 3: Federal Policy Perspective: Incorporating Accessibility and Usability into Health IT and Electronic Long-Term Services and Supports (eLTSS) Systems and Initiatives – Barriers and Levers of Change 16

Day 2: Advancing Research and Development, Identifying Best Practices, and Building Collaborative Public-Private Partnerships. 23

Keynote: Elevating Accessibility and Usability in the Health IT Agenda 25

Panel 4: R & D Perspectives: What We Know and Need to Know to Drive Accessible Health IT Policy and Practice – Metrics, Data, and Best Practices 26

Panel 5: Industry and Advocacy Perspectives – Next Steps in Creating an Accessible Health IT Ecosystem 31

Appendix A: Small Group Huddles 37

Appendix B: Presentations 43

Appendix C: Resources 45

Appendix D: Speaker and Leadership Biographies 51

Appendix E: Co-Chairs and Steering Committee 64

Appendix F: List of Attendees 66

Appendix G: About the ICDR 68

Abbreviation

ABCD	Asset-Based Community Development
ACA	Affordable Care Act
ACL	Administration for Community Living
ADA	Americans with Disabilities Act
ADL	Activities of daily living
AFB	American Federation for the Blind
AHRQ	Agency for Healthcare Research and Quality
API	Application Programming Interfaces
ASL	American Sign Language
AT	Assistive Technology
ATAG 2.0	Authoring Tool Accessibility Guidelines
CB-LTSS	Community-Based Long-Term Services and Supports
CHOP	The Children's Hospital of Philadelphia
CIO	Chief Information Officer
CITRIS	Center for Information Technology Research in the Interest of Society
CMS	Centers for Medicare and Medicaid Services
DARPA	Defense Advanced Research Projects Agency
DBHi	Department of Biomedical and Health Informatics
DH	Disability and Health
DoD	U.S. Department of Defense
DOJ	U.S. Department of Justice
eHealth	Electronic Health
EHR	Electronic health record
eLTSS	Electronic Long-Term Services and Supports
FDA	U.S. Food and Drug Administration
FITARA	Federal Information Technology Acquisition Reform Act
GPII	Global Public Inclusive Infrastructure
HCBS	Home and Community Based Services
HCI	Human-Computer Interaction
HHS	U.S. Department of Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act
HL/HIT	Health Literacy and Health IT
HP2020	Healthy People 2020
HTML	Hyper Text Markup Language
ICAT	Interagency Committee on Assistive Technology
ICDR	Interagency Committee on Disability Research
ICT	Information and communication technology
ID	Intellectual disability
iOS	iPhone Operating System
IOT	Internet of Things

ISO	International Organization for Standardization
IT	Information Technology
JAWS	Jobs Access with Speech
LTSS	Long-Term Services and Supports
mHealth	Mobile Health
NAC	National Alliance for Caregiving
NCCD	National Center for Cognitive Informatics and Decision Making in Health Care
NIDILRR	National Institute on Disability, Independent Living, and Rehabilitation Research
NIDRR	National Institute on Disability and Rehabilitation Research
NIH	National Institutes of Health
NPRM	Notice of Proposed Rulemaking
NSF	National Science Foundation
OCIO	Office of the Chief Information Officer
ONC	Office of the National Coordinator for Health Information Technology
PCORI	Patient Centered Outcomes Research Institute
PeRC	Pediatrics Research Consortium
PHR	Personal health record
POWERS	Personalized Online Weight and Exercise Response System
RERC	Rehabilitation Engineering Research Center
R&D	Research and Development
ROI	Return on investment
SAR	Socially assistive robotics
SBIR	Small Business Innovation Research
SHARP	Strategic Health IT Advanced Research Projects
SCH	Smart and Connected Health
TEFT	Testing Experience and Functional Tools
TExT-ME	Telehealth Exercise for Monitoring and Evaluation of Home-Based Exercise in People with Neuromuscular Disability
TURF	Task, user, representation, and function
UAAG 2.0	User Agent Accessibility Guidelines
UCD	User-centered design
VA	U.S. Department of Veterans Affairs
VPAT	Voluntary Product Accessibility Template
W3C	World Wide Web Consortium
WAI	Web Accessibility Initiative
WCAG 2.0	Web Content Accessibility Guidelines
Web AIM	Web Accessibility in Mind
WHO	World Health Organization

Executive Summary

On September 17-18, 2015, the Interagency Committee on Assistive Technology (ICAT) of the Interagency Committee on Disability Research (ICDR), National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) conducted a two-day conference, ***Accessibility and Usability in Health Information Technology: A Research and Action Conference to Empower People with Disabilities, Older Adults, and Caregivers***.

The purpose of the conference was to advance the priority of accessibility in health information technology (IT) systems and tools from a compliance-oriented approach toward one that is user-driven, responsive to human-centered consumer experiences, and results in increased patient engagement and improved health and wellness for individuals with disabilities, older adults, and caregivers. Over 35 thought leaders representing users, providers, health IT research and development (R&D), and federal leadership shared their perspectives of current issues and potential levers of change to move the agenda for accessible and usable health IT forward.

Stakeholders representing accessibility and health IT R&D, policy, federal government, industry, providers, aging and disability advocates, individuals with disabilities, older adults, and caregivers exchanged perspectives and identified issues as well as actionable strategies to advance knowledge and practices related to health care methods, models, and tools associated with accessible, interoperable, and person-centered health IT.

Themes

Throughout the two-day conference, the following themes emerged:

Health IT users with disabilities, older adults, and caregivers need to be at the center of health IT development.

- The industry understands Health Insurance Portability and Accountability Act (HIPAA) privacy and security requirements, but generally does not understand the importance of accessibility.
- Healthcare coordination and accuracy of information is essential to the health and well-being of people with disabilities, older adults, and caregivers, making them the “power users” of health IT. Focusing on the majority of users will leave “power users” without access to health IT.
- Most of the IT products are vendor driven instead of user driven.
- There is no such thing as “mostly accessible;” something is either accessible or it is not. For instance, a tool can be completely accessible until a user gets to the “check out” button. If that is not accessible and the user cannot complete the transaction, everything is unusable.
- Accessible solutions can lead to functionality for a broad range of users. For instance, just as curb cuts are useful to a much broader audience than people using wheelchairs, accessible IT solutions can enhance usability and functionality for all users.
- Health IT has the potential to be barrier free and accessible for all people, regardless of physical or mental ability. Accessibility must be built in from the beginning for it be successful.

The federal government is an important lever in promoting accessible and usable health IT.

- The government can help push forward accessible and usable health IT R&D by bringing together industry, academia, usability and accessibility experts, and end-users.

- The Office of the National Coordinator for Health Information Technology (ONC) issued their 2015-2020 Strategic Plan and a National Interoperability Roadmap that provides a framework for health IT to empower individuals, families, and caregivers through improved health management and engagement.
- The Americans with Disabilities Act (ADA) and Section 508 apply to health IT, although they are not consistently enforced and have not been tested in the court system.
- Section 1557 of the Affordable Care Act (ACA) prohibits discrimination based on disability.
- The Federal Information Technology Acquisition Reform Act (FITARA) significantly expands IT decision-making authority (including accessible health IT) to Chief Information Officers (CIO).
- The Federal CIO Council is working to harmonize Section 508 accessibility guidelines.
- Centers for Medicare and Medicaid Services (CMS), National Institutes of Health (NIH), and the U.S. Food and Drug Administration (FDA) could potentially affect accessibility and usability by requiring all providers, drug and device manufacturers, and clinical trial directors to deliver standardized, machine-readable copies of records to patient controlled health information repositories.

Interoperability between health IT systems and applications is an urgent and complex systems integration issue that will require time, money, and talent to fix.

- Health IT and new apps are rapidly emerging, but many operate on different systems so they cannot be shared between platforms.
- Users and advocacy groups described the redundancy of providing health information for every provider, shared potential issues when providers do not have complete information, and expressed the frustration of not being able to access information in one place.
- Application Programming Interfaces (APIs) are potential game changers to health IT. Openly shareable systems allow developers to build upon what already exists without creating an entirely new operating system or device.
- International efforts can be leveraged. The World Wide Web Consortium (W3C) offers free guidelines and tools that can enhance accessibility and interoperability. Apple and IBM are collaborating to create Denmark’s national health IT interoperability standards.
- The International Association of Accessibility Professionals (IAAP) is a group consisting of industry and accessibility experts collaborating to establish standards, accessible products, content, and services.

Collaboration and building on existing solutions can spur more usable, accessible, and frugal health IT development.

- Potential repercussions, if new health IT is not usable or accessible for people with disabilities or older adults, makes this an opportune time for stakeholders to act upon solutions**.**
- Stakeholders are largely unaware of existing expertise and free/affordable APIs, standards, tools, and prototypes.
- Human factors professionals and engineers have varying perspectives that could potentially solve accessibility issues.

Actionable Strategies

Over the two-day conference, presenters and attendees identified the following actionable strategies:

Push forward potential policy levers of change to promote the accessibility and usability agenda.

- Consider how ONC can be a leader in pushing for accessibility and usability, especially at the front-end process.
- Build upon the ONC Roadmap. For example, long-term services and supports (LTSS) for older adults and people with disabilities were not part of the original plan for health IT, but are now increasingly recognized as a part of healthcare.
- Leverage relevant laws and regulations to create fruitful change.
- Build on existing efforts such as the Federal CIO Council and the President's Council of Advisors on Science and Technology.

Strengthen collaboration and partnerships.

- Establish a standard venue for curating policy, R&D, and industry data for study and dissemination. Push solutions into practice.
- Create an easy way for users to identify issues with new technologies.
- Build upon related global efforts such as W3C, the World Health Organization (WHO) conference featuring technology solutions for the aging populations, and the IAAP.
- Establish a disability group, committee, or taskforce that would make recommendations for the next steps in accessible health IT. Membership would include federal agency representatives with disabilities.
- Commit to participating in the ICDR.

Catalyze research and development of accessible and usable health IT.

- Create a business case for accessible health IT.
- Provide designers and vendors with a clarification of expectations or policies. Identify specific technical resources, or help in the evolution of new tools and resources.
- Create testbeds or places where private and public sectors can explore issues and research.
- Consider how to align federal research with industry research pursuits such as Apple's open source platform, and R&D testbeds like Clarix, IBM, Google, and Yahoo.
- Mobile health (mHealth) apps is a rapidly developing market, but many of the developers do not understand accessibility. The Web Accessibility Initiative (WAI) is developing a combined accessibility resource.
- Promote the use of API's to build on what is already available.
- Provide vendors with resources. In the case of safety-enhanced design, W3C could hold workshops or host sessions so companies can understand the requirements.
- Follow the private sector and enable and encourage innovators through events such as "accessibility challenges." A universal design can be built upon for niche audiences.

Introduction

Background

The United States is moving rapidly to develop and implement smart, interconnected, health information technology (IT) ecosystems geared to improve both the quality of care and the health of the nation, as well as reduce costs. New health IT such as electronic and personal health records (EHRs/PHRs), mobile and telehealth technology, cloud-based services, medical devices, remote monitoring devices, assistive technologies, and the underlying infrastructure that enables information exchange are revolutionizing health care. Consumers and health care providers increasingly access and use health IT systems and tools to inform decision-making, support coordinated health management, and engage as partners to improve health outcomes. However, to deliver on the promise of health IT for all Americans— including persons with disabilities, older adults, and caregivers— electronic health information must be accessible and usable for providers and consumers alike. Having accurate and accessible health information available when, where, and how it is needed is also pivotal for supporting the new person-centered health paradigm. This state of the science conference centered on advancing the accessible health IT agenda. Facilitated discussions among diverse stakeholder groups identified gaps and barriers, potential synergies, and actionable ideas to move toward a shared culture of inclusion and person-centered care.

Purpose

The purpose of the conference was to advance the priority of accessibility in health IT systems and tools from a compliance-oriented approach toward one that is user-driven, responsive to human-centered consumer experiences, and results in increased patient engagement and improved health and wellness for individuals with disabilities, older adults, and caregivers.

Audience

The audience included accessibility and health IT researchers and developers, policymakers, government and industry representatives, aging and disability advocates, providers, people with disabilities, older adults, and caregivers. This diverse audience of stakeholder groups shared their perspectives, knowledge, priorities, and potential solutions.

Objectives

- To elevate the importance of accessibility and usability in the nation’s health IT agenda in order to better meet the needs of individuals with disabilities, older adults, caregivers, and providers.
- To exchange perspectives among diverse stakeholder groups and identify barriers and potential levers of change for creating an accessible health IT ecosystem.
- To highlight the latest research findings and identify best practices and actionable strategies that advance knowledge about health care methods, models, and tools associated with accessible, interoperable, and person-centered health IT systems.
- To catalyze new research and development initiatives and collaborative partnerships that move the accessible health IT agenda forward to achieving the triple aim of improved patient care, reduced costs, and improved health outcomes for individuals with disabilities, older adults, and caregivers.

Key Terms

Accessibility – ensuring an equivalent user experience for people with disabilities. For the web, it means that people with disabilities can perceive, understand, navigate, and interact with websites and tools, and that they can contribute equally without barriers (World Wide Web Consortium [W3C]).

Usability – designing products to be effective, efficient, and satisfying. Usability is an aspect of human-computer interaction (HCI) research and design (it is much broader than usability testing). The practice of usability is largely about following a user-centered design (UCD) process to create positive user experiences (W3C).

Health IT – the term health information technology (IT) is a broad concept that encompasses an array of technologies to store, share, and analyze health (Office of the National Coordinator for Health Information Technology [ONC]).

Format of this Report

This report contains a summary of proceedings from the ***Accessibility and Usability in Health Information Technology*****:** ***A Research and Action Conference***. Each day began with a welcome and keynote to stimulate the participants' thinking, followed by panels representing the perspectives of the stakeholder groups. Key questions and discussion points that followed presentations are also included to capture the richness of the presentations and stakeholder perspectives. Each day ended with a moderated wrap-up session, also summarized in this report.

The report also contains substantial information intended to provide readers with additional information as they move forward the agenda for more accessible and usable health IT:

- **Appendix A: Small Group Huddles** contains participant input from three roundtable discussions identifying needs and barriers; opportunities and strategies; and roles participants and their agencies might play in advancing suggested solutions.
- **Appendix B: Presentations** contains links to presentations by panelists.
- **Appendix C: Resources** includes links to guidelines; initiatives and projects; organizations, centers and programs; technical accessibility resources tools; and usability resources that were shared at the conference.
- **Appendix D: Speakers and Leadership Biographies** includes information about the presenters.
- **Appendix E: Co-Chairs and Steering Committee** recognizes the co-chairs for the Interagency Committee on Assistive Technology (ICAT), co-chairs for the conference, as well as the steering committee who helped to organize the conference and facilitate discussions.
- **Appendix F: List of Attendees** includes the names, organizations, and contact information of conference attendees.
- **Appendix G: About the ICDR** provides information about the Interagency Committee on Disability Research (ICDR); the ICAT, the standing committee of the ICDR that organized this conference; and how to get involved in its activities.

A website with information about the conference, the agenda, speaker information, and presentations is located at http://icdr.acl.gov/ahit/.

Day 1: Exchanging Perspectives, Identifying Barriers and Facilitators

Welcome and Opening Remarks

Conference co-chair Margaret Campbell, PhD, opened the conference and introduced her fellow co-chairs Kathy McCoy, PhD, and Samantha Meklir. Campbell greeted the participants and thanked the steering committee for their support in planning the conference. Campbell explained that the steering committee designed the conference from the ground up to reflect the importance of bridging aging and disability perspectives on the topic of accessible and usable health information technology (IT). The conference was designed to include five key stakeholder groups: consumers, end-users, and providers; accessibility and usability technical experts; federal policy makers; researchers and developers; and industry representatives and aging and disability advocates.

Campbell noted that this conference was driven by the need to explore accessible and usable health IT solutions in light of the rapidly approaching future of person-centered healthcare. This conference builds upon previous efforts. In 2010, the National Institute on Disability and Rehabilitation Research (NIDRR) in conjunction with Healthy People 2020 (HP2020) and the U.S. Department of Health and Human Services (HHS) Office on Disease Prevention and Health Promotion sponsored the *Stakeholder Forum on Requirements for Accessible Health Information Technology*.

Recently the Office of the National Coordinator for Health Information Technology (ONC) updated the *Federal Health IT Strategic Plan 2015-2020*, with an expanded mission and focus beyond technical aspects of interoperability, including:

- use of health IT by providers, researchers, and individuals to improve health, healthcare, and reduce costs; and
- empowerment of individuals, families, and caregivers through improved health management and engagement.

Sharon Lewis, Principal Deputy Administrator, Administration for Community Living (ACL), expounded on the need for an action-oriented conversation. Lewis charged participants to determine what their agency organization can do to advance the conference goals. Lewis added that the role of individualization in user experience is paramount, especially in terms of usability for long-term services and supports (LTSS). There is a large gap in accessibility for both the aging and disability communities. Getting the right people to the table is an important objective. According to Lewis, accessible health IT is a cornerstone of the Affordable Care Act (ACA). "Health IT has the ability to affect us on a holistic level." The industry needs to be more "person-centered" than "patient-centered" because we are considered "patients" for only a small percentage of our lives. Lewis emphasized that health IT solutions should cater to all walks of life, including people with disabilities and the aging populations.

> *"Government alone cannot solve this problem."*

John Tschida, ICDR Chair and National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Director, opened his remarks with the reason the ICDR brought diverse stakeholders together for this conference. "Government alone cannot solve this problem," Tschida noted. The federal, industry, and advocacy communities must come together to create a concrete plan that is not just aspirational, but actionable. Tschida stated that health IT should be a key part of the ICDR's coordinated research agenda, and considered for their strategic plan, currently being developed. "Technology is ubiquitous, but not designed for people with disabilities," he noted. Tschida closed by encouraging participants in their efforts to move forward on a person-centered action agenda for both research and policy. "We must not simply admire the problem," he added, and welcomed their suggestions for future direction, guidance, and collaboration among stakeholders.

Keynote: Elevating Accessibility and Usability in the Health IT Agenda to Better Meet the Needs of Older Adults, People with Disabilities, and Caregivers

Frank Baitman, *Chief Information Officer, U.S. Department of Health and Human Services (HHS)*

Baitman's background includes work at IBM and the Institute for the Future. He challenged the audience to view health IT in an expansive way, reflecting on the issues people with disabilities now face and the future of healthcare in general. Baitman predicted that, with current developments in genomics, we will not recognize healthcare 20 years from now. Now is the time to consider seriously how to integrate health with technology. "Integrating IT and healthcare is the future," he said.

Stakeholders should make a business case for industry to adopt accessible and usable health IT, at attainable prices. Baitman suggested some key factors to bolster the case that accessibility is good for business.

- The current market for those who use accessible tech is roughly 15 percent of the world's population—nearly 1 billion people with an annual disposable income of $1 trillion.
- A rapidly expanding market includes the aging population with needs for accommodations such as enlarged text.
- By collaborating with people outside of the accessibility community (i.e., the large vendor community), we can bring these demographics to their attention.
- iPhone Operating System (iOS) devices open incredible opportunities to market accessible solutions. For instance, a robust text-to-speech device that used to cost thousands of dollars is now available for a few hundred dollars on an iOS device.
- Building accessibility from the beginning can reduce costs when there are general use applications. Good design requires usability built in from the start.
- Considering accessibility shifts the perspective away from the limitations to personalizing accommodations.

In the past, people with disabilities have had to turn continuously to the Americans with Disabilities Act (ADA) as their only avenue to advocate for accessible health IT. A recent proposed rule, Nondiscrimination in Health Programs and Activities expands on Section 1557 of the Affordable Care Act (ACA). The proposed rule implements prohibitions against discrimination based on race, color, national origin, sex, age, and disability as provided in Section 1557 of the Affordable Care Act. The new rule contains requirements for the provision of auxiliary aids and services, including alternative formats and sign language interpreters and the accessibility of programs offered through electronic and information technology.

Baitman also referenced the Federal CIO Council's efforts to harmonize accessibility based on Section 508 of the Rehabilitation Act of 1973 and encouraged the audience to use those resources.

Key Points from Q&A moderated by **Deborah Kaplan, CIO/HHS**

- The federal appropriations process slows down government investment in accessible health IT research. This keeps federal research from staying on trend with the current market.
- Baitman offered to arrange a conversation between interested conference participants and the HHS Chief Technology Officer, who has not yet focused on accessibility. He went on to suggest that HHS could implement a "design challenge" to get at the technical problems associated with integrating accessibility into health IT systems.
- General use products such as iOS devices are widely adopted and generally more usable than specialized products for users with disabilities. New technologies can track relevant data that can be retained for use in the future. The government needs to create regulation, regarding device use and personal data.
- A big challenge is how to "tag" electronic information to make it accessible in the future. Accessible health IT is only possible with data that can be continuously updated. Technology is temporal. For instance, data developed with outdated technology such as WordPerfect, is no longer readable.
- The federal government does not move quickly. There is a built-in bias to be more intentional to avoid making rash decisions. For example, while Stage 3 of the ONC Strategic Framework Meaningful Use Regulations includes objectives related to patient engagement, Centers for Medicare and Medicaid Services (CMS) is still reluctant to reimburse for health IT services.
- Baitman suggested that to move the needle forward on the accessible health IT issue, there is a need to understand and to pressure the federal government. There is keen competition for ideas, and CMS is a relatively small agency in charge of an $800 billion budget. There is a need to carefully consider the players and how to get their cooperation and collaboration.
- Baitman cited recent legislation that could help advance accessible health IT. He referred to the Federal Information Technology Acquisition Reform Act (FITARA) and the related Title I: Management of Information Technology within Federal Government - (Sec. 101) which would require the heads of all cabinet level federal agencies to ensure that their respective chief information officers (CIO) have a significant role in IT decisions. According to Baitman, this legislation will consolidate authority over all health IT decisions, including accessibility, within the Office of the Chief Information Officer (OCIO), rather than in the appropriation centers.
- Challenge.gov is a potential vehicle for stimulating accessibility solutions. Federal agencies can issue challenges to solve technical problems. Alok Doshi, HHS, offered to help put together a challenge.

Panel 1: Voices and Perspectives of End Users – Needs, Barriers, and Opportunities Associated with Using Health IT Systems and Tools

Goal: To build awareness and inform other stakeholders – policymakers, researchers, technology developers, industry representatives, and advocacy organizations – of the importance of accessibility and usability in health information technologies from end-user perspectives.

Patients and caregivers have a variety of information needs, including information regarding allergies and health history, family health history, financial options, assistive devices, and treatment options. At any given time, this information should be accessible by patients and their caregivers.

MaryAnn Sterling, *co-founder of Connected Health Resources as well as caregiver and advocate of aging parents*

Sterling opened the panel with some demographics. According to Pew Research, 39% of adults are caregivers equating to 95 million people who are at the front lines of healthcare. She cited a RAND study that calculated the cost of caring for U.S. elderly at $522 billion a year. Patient portals are not user friendly or interoperable, and they vary from provider to provider. Accessibility barriers are not limited to physical access to data or information. An important aspect of accessible health records is making sure they are understandable and usable (i.e., using plain language). While there is a wealth of health information on the Internet, the information is not curated and requires a high level of health literacy to comprehend. Future work should focus on providing the information in a way that the patient and caregiver can understand and use. Making this information more accessible and usable will help breakdown the health care and social services silos.

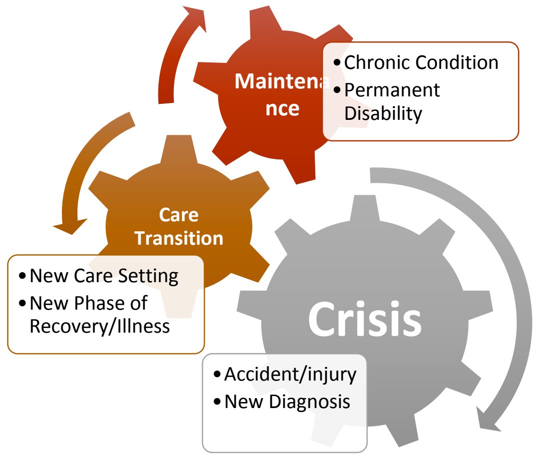

Figure 1: Caregiving Information Cycle

Sterling discussed her model of the caregiving information cycle (see Figure 1). This model identified the information needs of caregivers at different points in time and by different phases of caregiving. Typically, a caregiver is either dealing with a crisis, assisting a loved one through a care transition, or in maintenance mode. Caregivers may experience each phase of this cycle many times over the course of the caregiving journey. Because of this important role, the caregivers should be included in usability testing.

Gail Gibson Hunt, *Co-Founder, CEO and President of the National Alliance for Caregiving (NAC) and Member of the Patient Centered Outcomes Research Institute (PCORI) Board of Commissioners*

The National Alliance for Caregiving (NAC) is a not for profit coalition of 40 organizations representing a virtual network of 90 state coalitions as well as 11 countries. NAC, in conjunction with United Health Care, conducted a survey of 1,000 technology-using caregiving families and published a widely circulated report: *The e-Connected Family Caregiver: Bringing Caregiving into the 21st Century* (2011). The following key findings from this report indicate that the majority of participants would benefit from additional technologies; thus helping to dispel some of the myths surrounding receptivity to technology by older adults.

- 77% of family caregivers thought that additional technologies, such as personal health record (PHR) tracking, would save time;
- 76% believed that additional technologies would make caregiving easier;
- 75% felt that technologies would make the care recipient feel safer; and
- 70% wanted a shared Caregiving Coordination System.

"Caregiving is like an iceberg."

As a follow-up, NAC convened a roundtable in 2014 featuring experts from government, Silicon Valley entrepreneurs, and caregiving advocates and researchers. The purpose of the roundtable was to analyze caregiving and corresponding technology needs, to diagram the family caregiving system which includes the professional healthcare providers and the larger effort of family caregivers, and to reframe the caregiving issues to make technology more useful. Key results of this roundtable, documented in a report, *Catalyzing Technology to Support Family Caregiving* identified the following needs:

- better "concept maps" that include caregiver interactions with the health care system;
- shared language on caregiving;
- new data on caregiving and technology;
- a broad national conversation about health IT and caregiving;
- a stronger business case to encourage providers to use caregiving technologies;
- caregiving coaching to complement the technology; and
- social conversations between families and communities.

John Paré, *Executive Director for Advocacy and Policy, National Federation of the Blind*

According to Paré, vision issues affect a large portion of the U.S. population:

- 1.3 million have blindness
- 3 million have low vision
- 6 million have a visual disability
- 20 million have difficulties seeing
- 20 million use corrective lenses

"Something that is 95% accessible is unacceptable."

Due to the lack of accessible health IT, Paré, as a person who is blind, frequently must give up his privacy and rely on others to read his medication labels or instructions from his doctor. Many people with disabilities live alone; without accessible health IT hardware and software, they run the risk of not being able to take proper care of themselves. Paré stated, "I don't mind being blind. What makes life difficult is inaccessible technology."

Paré also discussed the need for meaningful metrics. For instance, he considers "something that is 95% accessible is unacceptable." We should be striving for standards of 100% accessible.

Jeromie Ballreich, *PhD student in Health Economics at Johns Hopkins University and person with a spinal cord injury*

Ballreich stated that his quadriplegia, which resulted from an accident in 2005, is not his main concern. His biggest challenge is managing the side effects and secondary health conditions, such as poor circulation, paralysis, and lack of feeling that require daily medical care. Ballreich has experienced a number of barriers to accessibility of health records, not just for himself and his caregivers, but also between the multiple providers that he visits. Ballreich believes that ideally, all of his health records should be available online, accessible in one place, and integrated across all hospitals, clinics, healthcare providers, and even pharmacies.

Ballreich currently has multiple records from providers across the country. Since they are not integrated, they are all incomplete. Electronic health records (EHRs) should reflect the *true* health record across all providers, and be accessible and usable to Ballreich, his caregivers, and providers. This would also reduce his time filling out health status forms – there is no need to fill out the same information for each provider. An ideal health record would allow him to view and access reliable information, would be accessible to new providers, and support communication with his providers.

Carol Bradley, *Disability Access/504 Officer for Sutter Health, a large nonprofit health system operating primarily throughout Northern California*

> *Accessibility must be built in from the beginning for it to work successfully.*

Representing the provider perspective, Bradley discussed the importance of incorporating the end users' experience into developing and improving health IT. Health IT has the potential to be barrier free and to allow access for all people, regardless of hardware, software, language, culture, location, or physical or mental ability. Accessibility must be built in from the beginning for it to work successfully.

Sutter Health is a large non-profit health system that intentionally works to build accessibility into their health IT. Sutter Health began the process using Section 508 and the Voluntary Product Accessibility Template (VPAT) checklist for accessibility. They now use Web Content Accessibility Guidelines (WCAG 2.0) as their accessibility standards, but have found there are issues that are not addressed by those standards. This is especially problematic with mobile health apps, a relatively new field. Mobile vendors do not offer products with accessibility and do not understand it. Additionally, much of the content is vendor driven, instead of user driven. Without clear standards for both providers and health IT vendors, there is an ongoing, time-consuming dialogue.

Key Points from Q&A Moderated by **Karl Cooper,** American Association on Health and Disability

- What specific technologies promote patient/caregiver communication?
    - Open Notes is one tool that allows patients and caregivers to communicate with their health care providers.
    - Kiosks in stores and health care providers' offices are becoming much more sophisticated. However, many of them are not accessible.
- Developers end up saying, "This is too complicated. We will come back to it." However, when they come back, it is too late to include accessibility.
- There needs to be measurable, definable quality metrics:
    - The World Health Organization (WHO) is establishing accessibility measures.
    - A cross-disability group could help figure out what needs to be measured and what the measures are.
    - Measures such as "mostly acceptable" do not work. Something is either accessible or it is not. For instance, a tool can be completely accessible until a user gets to the "check out" button. If that is not accessible then the user cannot complete the transaction, therefore making everything unusable.
    - We need to figure out the path to get to accessibility. To be measurable, it needs to be functionally accessible.

- One participant mentioned the Medicare.gov Physician Compare website, which helps beneficiaries find and choose physicians and other health care professionals enrolled in Medicare based on characteristics such as physician specialty, location, type of insurance accepted, and training. Since this capability is required by the ACA to support informed patient decision-making there was a question as to why it does not include information on the accessibility of healthcare facilities and services.
- The public equates the term "accessible" with something being affordable. This is a strong indication that more education is needed to make sure both the public and the health care community understand accessibility means more than affordability. For people with disabilities and sensory impairments, it means that ability to use assistive and health IT technologies when and where they are needed.

Panel 2: Building Blocks for Accessible and Usable Health IT: Overview of Current Landscape – What Standards and Tools Exist and Where are the Gaps

Goal: Build awareness and increase understanding about the current state of the art in accessibility/usability guidelines and tools that could be applied to health IT; and identify some of the barriers and opportunities for closing the gaps in accessible/usable health IT.

Judy Brewer, *Director, Web Accessibility Initiative (WAI), World Wide Web Consortium (W3C)*

The Web Accessibility Initiative (WAI) is an effort to improve the accessibility of websites for people with disabilities. WAI develops internationally recognized guidelines for web accessibility and usability through an open, transparent, multi-stakeholder process. Brewer explained that "both accessibility and usability are important."

Compared to other groups, the health IT community has been slow to adopt accessibility standards. Accessibility exists at multiple levels and includes redundancy of modalities, user interface accessibility, browser accessibility, and content accessibility. Accessibility is not hard. Although system-wide implementation can be, there are many resources designed specifically for use at the development level. Developers should continuously ask themselves if their tools integrate accessibility as much as possible, particularly for mobile devices, and if their content creation tools make it easier to produce accessible content.

Resources exist to make authoring tools, websites, and browsers accessible. Resources available at WAI include:

- Web Content Accessibility Guidelines (WCAG 2.0) to make the content of websites accessible.
- Authoring Tool Accessibility Guidelines (ATAG 2.0) to improve accessible authoring.
- User Agent Accessibility Guidelines (UAAG 2.0) to improve accessibility of browsers.

> ***Resources exist to make authoring tools, websites, and browsers accessible.***

In addition, WAI is developing a combined mobile accessibility resource note. The WAI also offers extensive and freely available educational tools and tutorials, such as Customizable Business Case for Accessibility, Quick Tips, and Web Accessibility Developer Tips. Brewer identified current gaps in accessibility solutions for people with cognitive and learning disabilities and people with low vision. The WAI has task forces examining solutions in these areas.

Brewer wrapped up her presentation with an appeal to developers, government, and industry representatives to let the WAI know how they can help integrate accessibility and health IT.

Muhammed Walji, PhD, *Associate Director, National Center for Cognitive Informatics and Decision Making in Health Care (NCCD) and Associate Dean/Professor, UTHEALTH School of Dentistry*

The National Center for Cognitive Informatics and Decision Making in Health Care (NCCD) was funded by ONC under the Strategic Health IT Advanced Research Projects (SHARP) to support improvements in usability, workflow, and cognitive support for EHR. The center is currently working to define usability on the International Organization for Standardization (ISO) scale: ISO 9241: Ergonomics of Human System Interaction. ISO standards provide standards that measure the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency, and satisfaction within a specified context of use.

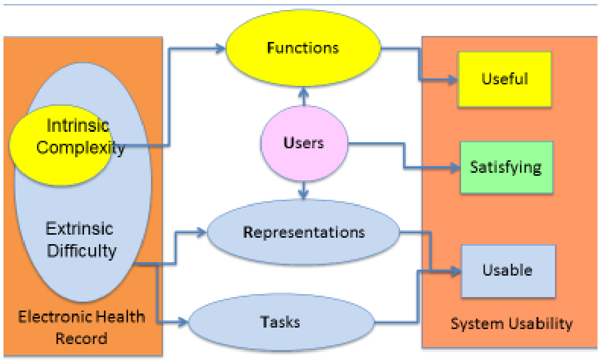

FIGURE 2: TURF FRAMEWORK FOR EHR USABILITY (ZHANG, J., & WALJI, M. F. 2011)

There is a large stimulus for health providers to adopt EHR systems, but culturally, usability is widely overlooked. Usability is defined as “the extent to which a product can be used by specified users to achieve specific goals.” One of the principle barriers to EHR accessibility is the lack of understanding of users and their actions when interacting with a system.

Walji presented the TURF Framework for EHR Usability that defines usability in terms of how useful, satisfying, and usable a system is for intended the users (see Figure 2). TURF provides a set of measures for each of the useful, usable, and satisfying dimensions of usability. TURF stands for task, user, representation, and function, which are the four components that determine the usability of an EHR system.

Walji suggested the following strategies for overcoming the barriers to the usability of EHRs and other health IT:

- Adopt a systems perspective
- Utilize user-centered design methods
- Perform a user analysis
- Create user personas representing all types of users from different backgrounds (including those with varying disabilities)
- Conduct a work domain analysis
- Conduct heuristic evaluations with groups of experts and user-testing with representative users
- Develop use guidelines and inspirational prototypes and make them publically available, such as
    - General Usability Design Principles
    - Safety Enhanced Design Briefs
    - Inspired EHRs: Designing for Clinicians

        - Twinlist: A Multi-Step Interface to Reconcile Medication Lists

Considering diverse user experiences results in more usable products and systems. When evaluating user responses to EHRs, it is important to understand what features consistently receive praise or criticism. Walji acknowledged that usability frameworks should consider accessibility. He observed that developers rarely think to test systems with individuals with disabilities. In fact, many vendors are unaware of the needs and issues people with disabilities or the aging population face when accessing EHRs. “These technology challenges could be built out into user personas, and shared with others,” he noted. As an action step, Walji encouraged the group to share their accessibility experiences and issues directly with vendors and designers.

Janey Barnes, PhD, *Human Factors and Usability Specialist, User-View, Inc.*

Barnes discussed importance of human factors research, defined as the study of how individuals interact with tools and technologies. Theories, models, and information about human performance and interactions can help in the design and development of products and processes. Much of existing health IT is not accessible, requiring developers to attempt remediation with plugins and code supplements. These additions may achieve technical accessibility, but do not take into account usable accessibility. Barnes noted that all developers must adopt a user-centered design approach to combat this issue. She recommended working closely with a human factors specialist or usability expert when designing any type of health IT system (whether or not the target audience is people with disabilities). The needs and workflows of product users need to be intimately understood as usability is a “standard and not in the eye of the beholder.” The ISO 9241 provides standards for a user-centered design process offering guidance for developers to:

> *“All developers must adopt a user-centered design approach.”*

- understand and specify the context of use;
- specify the user and organizational requirements;
- produce design solutions; and
- evaluate designs against requirements.

Barnes identified disconnects between content creators, designers, and coders in developing technology, as well as those who take a “checkbox” approach to technical accessibility instead of considering the process and user accessibility. She identified a number of available resources to consider accessibility from these two perspectives.

Usability Resources include:

- NISTIR 7804
- SHARPC
    - Design Briefs
    - InspiredEHRs.org
- Nielsen's Heuristics
- Gerhardt-Powals’ cognitive engineering principles
- MeasuringUsability.com

Technical accessibility resources include:

- World Wide Web Consortium
- Web Accessibility in Mind (Web AIM)
- International Association of Accessibility Professionals (webinars)
- Contrast checkers
- Automated web checkers

Caitlin Blood, MPH, *Healthy People Communication Fellow, Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services (HHS)*

Coordinated by the HHS Office of Disease Prevention and Health Promotion, Healthy People 2020 (HP2020) is a 10-year national agenda that provides a strategic framework for uniting health promotion and disease prevention in order to improve health equity. “Disability and Health (DH)” and “Health Literacy and Health IT (HL/HIT)” are two of the HP2020’s key topical areas of focus. Each of these two areas, include objectives to eliminate barriers to health care for people with disabilities, and promote health IT to achieve health care equity and improve overall health.

Currently, the HP2020 HL/HIT workgroup is developing the following tools for website developers to help meet these objectives:

- National Quality Website Survey. This is an evaluation instrument to assess health-related websites on six criteria of usability and reliability development requirements: identity, purpose, content development, privacy, user feedback, and content updating. Results from this evaluation emphasize the need for accessible site design, information architecture, and content design.
- Health Literacy Online. This online, research-based set of guidelines provides six strategies for developers to write and design health websites that are accessible to users with limited literacy skills. The second iteration of these guidelines will be released in October 2015. They will focus on broadening access to user-friendly health information and services on the web, while respecting the needs of adults with limited literacy skills and their online behaviors.

Looking ahead, HHS recommends developers consider co-designing health IT tools and systems with intended end users involved throughout the entire process.

Mary Lou Mendez and **Larry Lewis,** *Management Specialists, U.S. Department of Veterans Affairs (VA)*

Mendez asked the audience to consider both consumers and providers who need to use EHR technology. Many of today’s practitioners also have disabilities, and there is a need for interoperable, customizable systems for use by multiple types of end users. Today’s tools do not catch all the accessibility/usability aspects that are needed for these groups. Resources are available, and a number of standards are being developed. However, establishing accessible health IT is not going to be a quick process. While there are resources, standards, and a large number of experts, one of the biggest barriers is the need for “culture change” in how people view disability and the needs of people with disabilities.

Lewis explained the VA’s overall testing process for Section 508 certification of mobile devices. The VA equips employees and veterans with mobile devices in an effort to test everyday device usability. The

VA groups technology development into three main approaches: “native app development” (for iOS or Android); mobile web content development (responsive design-single URL regardless of device); and hybrid app development, which refers to content and information that is developed in HTML5 wrapped in a number of tools so that it can be displayed on iOS or Android devices. With this testing process, the VA specializes in creating and standardizing accessible mobile content. Developers can send locked down versions of their mobile apps to the VA to check for accessible responsive design and hybrid app development. The VA can advise companies on step-by-step remediation for their applications to meet standard accessibility and usability guidelines. In addition, the VA offers classes on what needs to be considered for mobile applications, and an overview of Section 508.

Lewis also highlighted the following common mistakes when creating web content:

- Lack of color contrast
- Forgetting to design for both a Mac and PC
- Not understanding how JAWS reads a display
- Not testing in the right environment (desktop vs. mobile)

However, according to Lewis, the biggest of all challenges is “education” and the lack of a clear understanding of what constitutes accessible technology.

Key Points from Q&A Moderated by **David Baquis,** U.S. Access Board

Society’s cultural perception of people with disabilities needs to change. Often, the needs of people with disabilities and the aging populations are viewed as “separate” from the rest of the society, particularly in the IT and technology fields. A shift in thinking, particularly about accessibility, can only increase with better, usable design. The design process must involve accessibility at every level to ensure quality. Guidelines such as W3C and the VA’s regulations must be adhered to, and can be used for a multitude of digital platforms online and via mobile, including EHRs. Safety-enhanced design is also a popular topic pertaining to accessible health IT.

The focus of usability and accessibility in product creation needs to move from a “point-in-time” evaluation to a process evaluation. Often, vendors will deem a product “accessible” or “usable” after one period of testing, a “point-in-time” evaluation. However, health IT systems are very complex, and the systems can change depending on the user, situation, or task at hand. A quality process evaluation, or testing at different times, with varying scenarios is more likely to lead to a product that is accessible at its conception. Attempting accessibility through back-end plugins or additional code, does not always lead to a fully accessible solution.

Panel 3: Federal Policy Perspective: Incorporating Accessibility and Usability into Health IT and Electronic Long-Term Services and Supports (eLTSS) Systems and Initiatives – Barriers and Levers of Change

Goal: Build awareness and advance knowledge among key stakeholders regarding the current state of policy with respect to accessibility/usability in health IT; and identify potential future policy developments that might positively affect this area.

Amanda Maisels, JD, *Deputy Chief, Disability Rights Section, Civil Rights Division, U.S. Department of Justice (DOJ)*

The U.S. Department of Justice's (DOJ) Disability Rights Sections enforces three titles of the Americans with Disabilities Act (ADA), to ensure equal access and nondiscrimination:

- Title I: Employment (state and local government employers)
- Title II: State and Local Governments (e.g., public schools at all levels, courts, public libraries)
- Title III: Public Accommodations (e.g., private schools at all levels, businesses, museums, restaurants)

The DOJ ensures equal access by publishing technical assistance documents, initiating investigations, filing lawsuits, issuing letters of findings, and rulemaking. DOJ plans to release Title II and Title III Notices of Proposed Rulemaking (NPRM) on Accessibility of Web Information and Services in the near future. Health information technology would fall under these rules. Consumers can at any time make a complaint with the DOJ to help enforce the ADA.

Maisels cited several enforcement cases related to Section 508 accessibility in education technology, public websites, mobile apps, and touchscreen displays. Insurance vendors that are under government contract must comply with ADA, although Maisels is not aware of any awsuits or action against these vendors. Maisels did not rule out DOJ utilizing its own pressure to ensure that the vendors are accessible.

Raja S. Kushalnagar, JD, LLM, PhD, *Assistant Professor, Information and Computing Studies Department, National Institute for the Deaf at Rochester Institute of Technology*

Health records serve multiple owners and customers, including patients, doctors, researchers, and insurers. The law is evolving toward shared custody, shifting away from property law to contract law. The laws that govern the transfer of information from an EHR to PHR might be considered similar to the laws that govern a consumer credit report. Consumers may obtain their PHR information from various sponsoring organizations. With a transfer from an EHR to PHR, the patient owns their health record and their health information.

There are a number of laws that are relevant to the issues of health records:

- Ownership of health records corresponds to various property, contract, and tort laws.
- The Civil Rights Act covers access to health records for non-English speakers.
- The ADA requires health care accessibility for people with disabilities includes accessibility for health care records.

One way to enforce accessibility is to sue; however, there are other market-related levers available to demand accessibility. For instance, when universities refused to purchase Kindles because they did not include a "read aloud" function, Amazon added that function to the device.

Kushalnagar described a few scenarios and high-tech and low-tech solutions:

- If a pharmacy uses old electronic records software that can only print prescriptions in a standard font that is inaccessible to customers with low vision, they can have staff read the information aloud to the customer, print the prescription in a large font, or send the data to the customer's preferred device.

- A pharmacy with a "telephone automated ordering system" that only provides menus and instructions in English may not be accessible to individuals with deafness/hearing impairments or speakers who do not understand English. The alternative solutions include translations through interpreters, a menu in multiple languages, or automated translation (in the future).
- A deaf patient's English fluency caused him to misunderstand questions in the emergency room. Based on his answers, the staff involuntarily hospitalized him until the psychiatrist arrived the next morning and promptly released him. An accessible EHR could have provided access to the patient's records. Alternatively, to comply with ADA, the hospital could have used a video relay interpreting service.

Jodi G. Daniel, JD, *Director, Office of Policy, Office of the National Coordinator for Health Information Technology (ONC), U.S. Department of Health and Human Services (HHS)*

ONC is the lead agency charged with formulating the federal government's health IT strategy and coordinating federal health IT policies, standards, programs, and investments. Daniel shared a number of useful initiatives and resources developed by ONC.

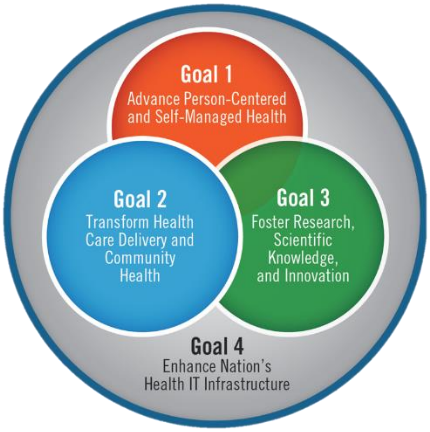

FIGURE 3: ONC 2015-2020 STRATEGIC PLAN GOALS (ONC 2015)

The Federal Health IT Strategic Plan 2015-2020 explains how the federal government intends to apply the effective use of information and technology to help the nation achieve high-quality care, lower costs, a healthy population, and engaged individuals. This plan focuses on advancing health IT innovation and use for a variety of purposes; however, the use of health IT is not in itself an end goal. The work described in this Plan aims to modernize the U.S. health IT infrastructure so that individuals, their providers, and communities can use health IT to achieve health and wellness goals (see Figure 3).

Daniel shared some of ONC's current initiatives and documents that guide and support broad sharing of information and the expanded focus on health IT beyond EHR:

- The Draft National Interoperability Roadmap was published by ONC in January 2015 to guide the nation toward meeting the goal of sharing information more broadly across providers, consumers, and others. The roadmap defines how the government in collaboration with the private sector should approach sharing electronic health information and addresses the collaborative impact of all stakeholders in advancing interoperable health information. (The Final Interoperability Roadmap was released subsequent to the conference in October 2015.)
- The Health IT Certification Program is a voluntary program that sets foundational capabilities, standards, and requirements, so that users have what they need from the technology. The goal is to set standards and criteria to move toward more usable technology. The program also aims to increase transparency around accessibility of health IT to help drive more compliant behavior and advance the product. The ONC Health IT Certification Program does not cover all security

and accessibility for compliance, but are meant to be guidelines. The requirements are continuously updated, and ONC welcomes comment and input regarding how the program could dovetail with other programs, or how they can better issue guidance to users or vendors.
- Electronic Long-Term Services and Supports (eLTSS) Initiative is a community-based initiative designed to identify, evaluate, and harmonize standards needed for the creation, exchange, and re-use of key domains and associated data elements of Community-Based Long-Term Services and Supports (CB-LTSS) person-centered planning, and accessible person-centered service plans that are interoperable and used by providers, beneficiaries, accountable entities, and payers.

Michael R. Smith, MPA, *Director, Division of Community System Transformation, Disabled and Elderly Health Programs Group, Centers for Medicare and Medicaid Services (CMS)*

Smith described two CMS initiatives to support the use of PHRs to deliver person-centered CB-LTSS.

- The Testing Experience and Functional Tools (TEFT) in the Medicaid CB-LTSS Planning and Demonstration Grant Program. The program was created in response to the ACA Section 2701 requirement for HHS to identify and publish initial and voluntary core sets of adult quality measures for adults eligible for Medicaid. Under this program, states were awarded grants to field test a Home and Community Based Services (HCBS) Experience of Care Survey and a set of functional assessment items, demonstrate personal health records, and create a standard electronic LTSS record for Medicaid populations. The benefits of PHRs for LTSS to beneficiaries (and caregivers) include providing standardized information for informed decision-making about care, providing access to a range of personal LTSS and health information that encourage a more active role for the caregiver or beneficiary in managing care, and presenting a way to manage LTSS and healthcare and health services.
- The electronic Long-Term Services and Supports (eLTSS) Initiative, as described by Daniels in the previous presentation, is an ONC-CMS partnership that focuses on identifying and harmonizing electronic standards that will help improve the coordination of health and social services that support an individual’s mental and physical health.

According to Smith, “PHR is where the rubber meets the road.” CMS has identified assessment elements that are interoperable. The user can view the elements of their service plan in order to understand how services are being utilized, talk to people about the coordination of care, and have control over their own services and supports.

> *“PHR is where the rubber meets the road.”*

Caroline Ryan, *Social Science Analyst, Office of Integrated Care Innovations, Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS)*

Ryan explained how ACL both promotes and incorporates accessibility and usability into health IT and eLTSS systems and initiatives. An example is a conference that ACL convened on integrating long-term services and supports and health care delivery through health information technology. The health record should honor and describe the abilities, capabilities, and strengths of the person, and should link to the person’s desired life. This also means that the person and caregiver have access to all information and have the ability to make changes.

Ryan also identified potential ACL funding sources for assistive technology. The Assistive Technology Act of 1998 (AT Act, PL. 108-364) provides all 56 states and territories with financial assistance to support programs designed to maximize the ability of individuals with disabilities to obtain Assistive Technology (AT) devices and services. The Center for Integrated Programs funds state-level activities in state financing, device reutilization, short-term device and device demonstration, as well as state leadership activities.

Key Points from Q&A Moderated by **Samantha Meklir,** ONC

- The Q&A included a discussion about ONC's approach to issue guidelines vs. more actively pursuing requirements to comply with accessibility standards.
- The Blue Button Initiative encourages healthcare providers, insurance companies, labs, and drug stores to make health information actionable for patients. The Blue Button lets patients download their health records online, having more control over their personal health information.
- Maisels clarified that the ADA requirements to make websites accessible also applies to health IT.
- Daniel highlighted the Application Programming Interfaces (API) provisions in the final certification rule. The 2015 Edition includes "application access" certification criteria that require health IT to demonstrate it can provide application access to the Common Clinical Data Set via an API. The API capabilities in the 2015 Edition are included in the 2015 Base EHR definition. In the rule, the Meaningful Use Stage 3 has a requirement for API access to health information by patients. This "frees up" their data so that a patient can use a system that is most usable by their own definition, furthering patient usability and accessibility. For example, the API could send data to a braille reader, a speech to text tool, or system optimized for color blindness.

Wrap-Up Conversation among Key Stakeholders – Identifying Innovative Strategies for Overcoming Accessibility and Policy Barriers

Matthew Quinn, Intel, moderated a final session of day one with three of the day's presenters: **Judy Brewer, Gail Hunt,** and **Michael Smith**

The closing panel felt encouraged by the day's discussion. The panel noted an ever-present need to get systems to work together. As the health industry is "late" to invest in accessible IT strategies, there is opportunity to piggyback on solutions that exist in the private sector. Presenters identified a number of available resources that can facilitate current efforts. Accessibility and usability does not have to start from scratch. Instead, information sharing and dialogue among stakeholders can lead to a stronger and broader utilization of accessible health IT.

All people are users of technology; there should not be the dichotomy of people with disabilities or people without disabilities in the design process. The individual needs to be at the center of development of health IT. The term "accessibility" is not commonly understood, and "accessibility" is not the same as "usability." Both are essential to "meaningful use." This important point was widely endorsed by participants. Accessible solutions need to be useful, delightful, and beautiful. They need to go beyond the needs of the health care industry and medical functionalities, and need to center on the end-users. The ultimate users of health IT have much to contribute to the conversation. If the industry focuses on the “majority” of users, they will neglect the power users – people with disabilities, older adults, and caregivers – who can push technology development that can benefit all users. A place to start is to push for full and consistent health records that are interoperable and sharable across domains. Patients do not want to have to complete the same information for different providers because the system is not interoperable. Providers may not have complete information and for a person with complex care needs, missing information can be critical. As Paré stated, “I don’t mind being blind. I mind inaccessible technology.” Users should not have to depend on others to read information on prescription orders, disclosing personal information. Health IT needs to be very concerned with safety, security, and privacy. It is important that these records contain not only information about chronic conditions, but also the detailed information that may make a difference in care later.

The topic of accessibility and usability of health IT is closely tied to important laws and regulations already in place, such as the ADA, the Civil Rights Act, and the Federal Information Technology Acquisition Reform Act (FITARA), which requires CIOs to thoroughly review their IT investments. These laws have not been meaningfully applied to health IT. This legislation can be leveraged to create fruitful change, move the agenda forward, and shift the field’s perspective on accessibility.

Making the business case that a niche audience, versus the application of “one size fits all,” will be paramount in this field and open the door to a world of innovation. A strong business case for accessibility will help industry understand the value of accessibility and how it helps the business bottom line. Many low-cost solutions exist. For instance, freely-available tools exist to support a business case for web accessibility. There may be an opportunity to establish a friendly forum for businesses to explore new ideas around accessibility and how to build it in so companies can solve this problem together. Government agencies do not always understand the importance of making the business case. One advantage of entering the field a little later than private sector companies is that government and policy can build off their already successful IT approaches. Policymakers have the ability to explain to the private sector how properly accessible health IT can ultimately help their “bottom line.” Even developing an individual use case, or what makes an individual invest in health IT, is important.

Health IT is the curb cut to healthcare. The industry needs to consider the needs of aging people and people with disabilities. Health IT systems have the capacity to educate patients and caregivers in self-management of chronic conditions. However, as with all of health IT, if patients and caregivers do not know these services and tools exist, they cannot access them. The universal design approach will benefit everyone. There is clearly an eagerness to foster collaboration between the accessibility and human factors communities around health care technology.

The following are actionable strategies that were suggested to move the accessible health IT agenda forward:

Push forward potential policy levers of change to promote the accessibility and usability agenda

- Build upon the ONC Roadmap. For example, LTSS were not part of the original plan for health IT, but are now increasingly recognized as a part of healthcare.
- Develop specific guidance on the project management side of health IT and the accessibility field. Standardized monitoring will create true accessibility.
- Leverage important laws and regulations to create fruitful change.

Strengthen collaboration and partnerships

- Establish a disability group, committee, or taskforce. Membership would include federal agency representatives with disabilities. This group could make recommendations for the next steps in accessible health IT.
- Commit to participating in the ICDR, which is a resource in place.

Catalyze research and development of accessible and usable health IT

- Creating a business case for accessible health IT is a paramount step.
- Provide designers and vendors with a clarification of expectations or policies. Identify specific technical resources, or help in the evolution of new tools/resources.
- Application Programming Interfaces (APIs) show great promise as potential game changers to the field. Systems that are openly shareable, allow developers to build upon what already exists to create something new and useful without creating an entirely new operating system or device.
- Provide vendors and designers with resources. In the case of safety-enhanced design, W3C could hold workshops, or invite companies to sessions so they can viscerally understand what these requirements are. This should not be a big mystery for them.
- Follow the private sector’s lead and enable innovators through events such as “accessibility challenges.” A universally designed app can be built upon for niche audiences.

Day 2: Advancing Research and Development, Identifying Best Practices, and Building Collaborative Public-Private Partnerships.

Welcome and Introductions

Kathy McCoy, conference co-chair, opened the second day and shared her observations from the previous day. She noted that rules and standards exist, but people working toward accessibility and people working toward usability do not necessarily communicate.

Users are particularly interested in:

- Ownership of interoperable, full, and consistent health records across various domains.
- Safety, security, and privacy: keeping the aging population and people with disabilities in mind.
- The inefficiencies, fragmentation, and dangers of having to continually provide the same information to each provider.

A major challenge is how to incorporate the needs of power users – people with disabilities and the aging population – as an important and inherent part of the design and development process. Accessibility and usability should be front and center; however, current regulations and guidelines governing accessibility are not strong or clear enough to be enforceable. Both accessibility and usability fields have rich traditions. It is important to bring these two fields together for a cultural change that is attentive to the full user experience.

Tiffani Bright, *Senior Service Fellow, Center for Evidence and Practice Improvement, Agency for Healthcare Research and Quality (AHRQ), U.S. Department of Health and Human Services (HHS)*

Bright shared information about AHRQ's role in building an evidence base to advance the accessibility and usability of health IT. AHRQ's mission is to produce evidence to make health care safer, higher quality, more accessible, equitable, and affordable, and to work within HHS and with other partners to make sure the evidence is understood and used. AHRQ funds over 180 distinct institutions in 46 states and Washington DC, with an investment of $450 million. AHRQ builds the evidence of the health IT impact through research grants (program announcements and requests for applications) and research contracts (demonstration projects and systematic literature reviews).

Bright shared the following evidence of AHRQ's health IT impact:

- Enabling healthcare decision-making through clinical decision support and knowledge management.
- Enabling patient-centered care through health IT grant initiatives.
- Identifying barriers and drivers of health IT use for the elderly, chronically ill, and underserved.
- Designing consumer health IT: a guide for developers and systems designers.

AHRQ has made substantial contributions in developing and disseminating evidence and evidence-based tools demonstrating how health IT can improve the quality of care and patient safety, including health IT strategic planning, and innovative ways to address those evidence needs. Producing future evidence of the impact of health IT on quality of care and patient safety requires understanding how "effectively" to design systems that are more usable and accessible. Bright concluded by describing current and recent health IT research funded by AHRQ that are included on her presentation.

Wendy Nilsen, PhD, *Program Director, Smart and Connected Health Program, National Science Foundation (NSF)*

The Smart and Connected Health (SCH) research areas include digital health information infrastructure; data to knowledge to decision; empowered individuals; and sensors, devices, and robotics. The SCH initiative is in collaboration with a number of NIH institutes: National Cancer Institute, National Human Genome Research Institute, National Institute on Aging, National Institute of Child Health and Human Development, the Office of Behavioral and Social Sciences Research, and the National Institute of Biomedical Imaging and Bioengineering.

In order to empower individuals, their information needs to be accessible and useful. Nilsen shared several existing research projects in this area:

- Computing Robot Motions for Home Healthcare Assistance. Over 10 million Americans currently need assistance with activities of daily living (ADLs), and this number is growing. Robots could empower older adults and individuals needing ADL assistance to remain in their own homes rather than be transferred to costly institutions or nursing homes. New software and algorithms are needed to control home healthcare robots for autonomous, safe assistance with ADLs.
- Use of Gaming Peripherals in Acute Rehabilitation of Balance Following Stroke. Restoration of balance after stroke is a critical determinant of patients' long-term assistive needs. Optimizing use of limited therapy time, particularly in the acute phase shortly after injury, facilitates functional recovery. The high cost of most balance feedback systems limits clinical access and potential for in-home use after discharge.
- SCH EXP: Collaborative Research: A Formalism for Customizing the Control of Assistive Machines. For those with severe upper limb motor impairments, caregivers still help with manipulation tasks like meal preparation or personal hygiene. Robotic arms hold much promise, and this project is customizing control-sharing functions to the user and the task.
- Socially Assistive Human-Machine Interaction for Improved Compliance and Health Outcomes. Socially assistive robotics (SAR) are being tested to improve exercise compliance in post-stroke rehabilitation, physical and cognitive exercise for older adults, and general exercise encouragement.

Nilsen compared health IT research to a marathon that can be easier and faster if people "think about it like a relay race and pass the baton." She encouraged the audience to use the NSF website to see how to partner with NSF and its funded research.

> *"Think about it like a relay race and pass the baton."*

Keynote: Elevating Accessibility and Usability in the Health IT Agenda

Frances West, *Chief Accessibility Officer, IBM*

IBM takes a global perspective as they consider trends driving the need for human centric thinking:

- By 2040, 1.3 billion the world's population (14%) will be age 65 or older.
- 56.7 million people in the U.S. have a disability.
- 65.7 million caregivers (29% of the U.S. adult population) provide care to someone who is ill, aged, or has a disability.

There is a transformational challenge: systems of care, wellness, and support need to come together leveraging technology, data, and expertise to help all people lead healthier and happier lives. IBM considers employees with disabilities to be an asset. West spoke of how accessibility has been a part of 100 years of innovation at IBM, from hiring their first employee with a disability in 1914, to later accomplishments such as the first Braille printer, remote control keyboard, talking typewriter, media captioner, mobile accessibility checker, and workplace accommodation system. To continue to innovate and provide accessible solutions, IBM is pursuing the design and delivery of human-centric solutions that personalize experiences on any device so everyone, regardless of age or ability, has equal access through innovation. They call this "The Market of One."

> *"Accessibility should be a business imperative."*

Unlike many companies, IBM does not locate the accessibility office in legal or human resources. Because they know that accessibility can spawn innovation and advance technology, they locate it in the research department. "It's not about compliance, it's about making the experience better for the individual," West said. Accessibility at its core is about the human experience, and technology should be there to supplement the individuals' wants and needs. When it comes to research and accessibility, there has been very little public-private partnership, and these are issues that need to be collectively addressed.

West shared IBM's pillars of accessibility and examples of their innovations that place the human experience at the center of technology:

- **Risk management to enable web and mobile apps**. IBM Bluemix is a risk management solution to accelerate development, improve testing, and verify the accessibility of content. IBM recently developed two tools as a part of this effort: Digital Content Checker and Automated Accessibility Tester. Both are currently available in beta testing.
- **Human experience to personalize interactions**. With a focus on usability and accessibility Tealeaf is intended to embed accessibility into intuitive commercial offerings with a mobile accessibility check and accessibility overlays that improve the usability of a website. IBM wants to embed accessibility into intuitive commercial offering and the mobile accessibility checker.
- **Inclusive workplace/marketplace to improve employee participation and happiness**. The Accessible Workplace Connection application is a single global accommodation process that helps ensure employees who have disabilities equal opportunity to advance and contribute. This one-stop resource for employees with disabilities and their managers enables accommodations to be delivered, changed, supported, and maintained effectively and efficiently.

West suggested that the government, like any company, needs a roadmap to be successful, and to keep up with the constantly changing technologies. She suggested two YouTube videos that provide the business case for accessibility and usability:

- Inclusion by Design – IBM has made accessibility an integral function of its design thinking, helping designers develop a real empathy for users and deeper understanding of how physical, cognitive, and situational disabilities affect the use of a product. (2:36 minutes, published July 2015)
- IBM Accessibility: Redefining Personalization – IBM designs and delivers human-centric solutions that reduce technology barriers and personalize experiences on any device so everyone, regardless of age or ability, has equal access to the information they need for school, work, and life. (2:33 minutes, published July 2015)

Panel 4: R & D Perspectives: What We Know and Need to Know to Drive Accessible Health IT Policy and Practice – Metrics, Data, and Best Practices

Goal: Build awareness and advance knowledge about the current state of research evidence and funding and identify promising practices for the development and implementation of accessible and usable health IT tools to better support care coordination, promote self-management and better health outcomes for individuals with disabilities, older adults, and caregivers.

Bambang Parmanto, PhD, *Professor, Health Information Management and Biomedical Informatics, University of Pittsburgh*

Parmanto predicted that smartphone apps and wearable devices will become the most important health IT mechanisms. Traditional healthcare, particularly caregiving, can be expensive, and mHealth is increasingly making these services accessible at affordable costs. Parmanto and other investigators created a mobile health systems app called iMHere (see Figure 4). Designed for the aging population and those with chronic conditions and/or disabilities, the goal is to break the common intervention of bringing therapists to consumers' homes to teach them about preventative self-care and monitoring. The current model of iMHere has two interfaces, a consumer side and a clinician side that includes five health sub-apps such as skincare, mental health, and medication. A clinician corresponds with the consumer through photo and chat features.

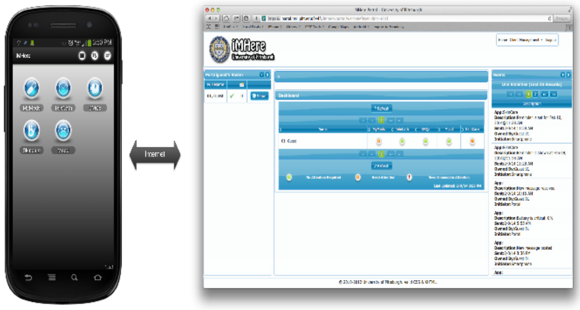

FIGURE 4: IMHERE APP (UNIVERSITY OF PITTSBURG)

In a pilot randomized controlled trial of 23 individuals, Parmanto studied the patient's health, utilization of the technology, independence, quality of life, and mental health. Based only on reduced emergency room visits and hospitalization of $27,000/year per person, this app successfully assisted consumers and kept costs down for emergency medical visits.

Parmanto stressed the need for this type of application to be advanced in usability and accessibility to reach the intended audience effectively. Features such as individualized color contrast, size of text, and pictures are best practices in mHealth. Understanding the mindset of the consumer is imperative. He also suggested measuring task time, and the number of mistakes made while completing a task, to understand usability. Although participants in the pilot study did not report dexterity problems, almost everyone had some kind of impairment. Users also identified important features, such as adding functions to take pictures of needed medication so that they could better manage their prescriptions. The next step is to expand personalization to make the device more accessible. With NIDILRR support, the group is working to expand the 2.0 version to include cloud profiles and personalization.

Madeleine Rothberg, *Senior Subject Matter Expert***,** *National Center for Accessible Media at WGBH*

The Accessible Designs for Personal Health Records Project is a collaborative project with the Department of Biomedical and Health Informatics of the Children's Hospital of Philadelphia (CHOP), and Inglis. This NIDLIRR-funded project investigated how the benefits of emerging medical information technologies can be expanded to fully include people with sensory and mobility disabilities, based on the principles of both accessibility and usability. In their baseline evaluation of three PHRs for accessibility, usability, and feature sets, users found a wide disparity and variability in accessibility, usability, and functionality. They found that a system might be easy to use, but it is inaccessible. On the other hand, another system might be difficult to use, yet be fully accessible. Rothberg noted that most accessibility issues found could be readily addressed—there is simply not widespread knowledge of the appropriate tools and resources among developers. These inconsistencies leave consumers with disabilities using alternative media to access their own medical information.

> *There is simply not widespread knowledge of the appropriate accessibility tools and resources among developers.*

After the initial study, the team developed a set of interactive fully usable and accessible PHR prototypes to be tested on a diverse community of end users. With user personalization at the forefront of development, the team used the following methods to capture input from users:

- Semi-structured interviews (16 consumers): Independent living is crucial to users with disabilities to understand what IT features support their independence and medical goals. The most important goal was independence and they identified 22 requirements.
- Web-based survey (150 consumers): Surveys were used to quantify data about what features were crucial to the consumer. These surveys confirmed the importance of the requirements.
- Extensive user testing of a prototype PHR (26 consumers): Task analysis with a diverse group of users with varying disabilities and without determined which tasks the end users perform well, and which tasks need to be enhanced or simplified.

Their findings revealed that many consumers’ needs and ideas for innovation translated well to current government standards, such as meaningful use. They also determined that simplified navigation markup makes a complex site easier to use for assistive technology users.

The next step was to develop the prototype. The hands-on iterative testing helped refine the prototype and improve use and satisfaction. For instance, blind users were able to identify code errors, and deaf users uncovered a need for education materials in American Sign Language (ASL). Rothberg's presentation also provided code samples for icons and text, navigation, and information links.

Rothberg noted that the prototype is freely available to PHR developers to use and adapt. She urged government and those involved in accessible/usable IT to support industry to help them understand that there are readily available solutions for making PHRs accessible.

Dean Karavite, MS, *Lead Human Computer Interaction Specialist, Department of Biomedical and Health Informatics (DBHi), The Children's Hospital of Philadelphia (CHOP)*

Karavite offered a pediatric perspective for improving health outcomes for people with disabilities of all ages. There are about 5.2 million children worldwide who have some type of disability, half of those with a severe disability. Since many may interact with the healthcare system their entire life, they have a unique perspective. Their opinions can greatly inform providers and developers as they deliver care to people with disabilities. With pediatrics, the parent is the caregiver and decision maker necessitating a family-centered approached. For aging adults, the roles are reversed with a similar dynamic for the role of caregivers. Karavite estimated that there are 35 million unpaid family caregivers in the U.S., providing an estimated 40% of long-term care. This number is growing with the average caregiver, a woman in her 40's taking care of one or more parents. There is a resulting negative impact on stress, income, the caregiver's own healthcare and health. The American Academy of Pediatrics has the Bright Futures prevention and health promotion for infants, children, adolescents, and their families. Karavite wondered if it is not time for a similar research-based initiative to promote Bright Futures for Aging Adults.

Karavite recommended both researchers and developers apply data from pediatric learning health systems with interoperable EHR, such as PedsNet, a disease specific-network that has data on over 4.1 million children, when designing health IT systems. He also mentioned the Pediatrics Research Consortium (PeRC), which is managed by the Clinical and Translational Research Center at CHOP. Learning health systems with interoperable EHR can identify certain target populations and provide them with necessary care. In 2004, Karavite and his colleagues began to analyze information from the CHOP EHR and have created wellness registries that allow the identification of children with specific health needs so that they can receive the care they need. These systems can also be applied to identify measurable outcomes for children with disabilities.

David Gustafson, PhD, *Professor, Center for Health Enhancement Systems Studies, University of Wisconsin-Madison*

Elder Tree is an AHRQ-funded collaboration between the Active Aging Research Center at the University of Wisconsin-Madison, the state of Wisconsin, the Wisconsin Institute for Healthy Aging, and local county aging and disability resource centers. Their focus is on aging, but many people who are aging also have disabilities. The goal of Elder Tree is independence by improving transportation, managing medications, reducing loneliness, falls, and caregiver burnout. It was designed with elders for elders and their families, health systems, libraries, congregations, and others. The application works on a tablet, laptop, and desktop.

Traditionally, caregiving assists aging older adults with medical health needs, but does not take into account other aspects of health, such as mental and active wellbeing. To better understand the health priorities of this population, Gustafson and investigators surveyed a group of 300 adults utilizing the Asset-Based Community Development (ABCD) design approach. Identified independent living assets included combating loneliness, participating in local events, managing healthcare and medical information, as well as staying connected with relatives and friends.

Elder Tree is a secure, simplified health app that seeks to meet these needs in an unobtrusive way. Design criteria included:

- Affordability
- Compatibility with assistive technology devices
- Simplified interface (few navigation buttons, large print, color contrast, etc.)
- Minimal typing, reading activities
- Interface for family, friends, and health manager
- GPS and tracking
- Integration between multiple devices (phone, tablet, desktop, etc.)

Gustafson concluded by emphasizing the importance for developers to adopt a broad definition of health to promote wellbeing and quality of life.

James Rimmer, PhD, *Professor, School of Health Professions, Lakeshore Foundation Endowed Chair in Health Promotion, and Rehabilitation Sciences, University of Alabama at Birmingham*

RecTech is a NIDILRR-funded Rehabilitation Engineering Research Center (RERC) focused on expanding new knowledge and research on recreation technology for people with disabilities. While genomics is driving health care in new directions in individual and hyper-customization, the health IT industry should not forget the importance of person-centered health and wellness. This perspective focuses on health promotion concerned with self-care rather than expert care. Rimmer discussed the lack of inclusive, participant-centered health and wellness instruction and data in health IT. People with disabilities, particularly people with intellectual disabilities (ID), are at a greater risk for poor health outcomes, and have less access to fitness programs than the general population. Traditional systems of care are fragmented, uncoordinated, and create obstacles to access resulting in poorer health status and poorer outcomes. For instance, people with obesity often end up with secondary conditions including high blood pressure, diabetes, sleep disorders and gastro-intestinal issues.

With the current rise of Electronic Health (eHealth) and mHealth platforms, such as PHRs and wearable technology designed for patient fitness and health, most of the industry has failed to customize their platforms for people with disabilities, and do not incentivize their use among this demographic. Industry, engineers, and researchers are unaware of the need for accessible health IT, lack incentive to target underrepresented populations, lack funding for inclusion science, and lack knowledge of what others are doing in the accessible fitness space.

RecTech developed the Personal Health Record (PHR-ID) as a telehealth framework intervention to fully integrate individual, environmental, and rehabilitation data for tracking the management of an individual's fitness. The PHR-ID allowed caregivers to view the child's health status, general observations by providers and the caregiver, and the results from the *Special Olympics Healthy Athletes* screenings.

However, their findings indicated that family members of an adult with ID had low interest in accessing the PHR-ID. Only 41% opened it one or more times, and 59% never opened it at all. This supports the need for involving the ultimate user in the design of PHRs.

The Telehealth Exercise Training for Monitoring and Evaluation of Home-Based Exercise in People with Neuromuscular Disability (TExT-ME) is a web-based monitoring system that supports regular communications between clients and facilitators. Another tool, the Personalized Online Weight and Exercise Response System (POWERS) is a community mapping information and communication technology for promoting physical activity for youths with disabilities. It is a web-based intelligent individualized information and communication technology (ICT) system that uses multiple data sets including nontraditional information sources such as social media, Google search interests, and environmental sensor data to lead to improvements in disease surveillance.

During his presentation, Rimmer identified a number of gaps in IT related to people with disabilities:

- eHealth/mHealth platforms are not usable by many people with disabilities.
- Self-monitoring health is key for behavioral change, but there are no wearables (accelerometers) for wheelchair users.
- Industry, engineers, and researchers are unaware of the need for inclusive health IT technologies and there is a lack of incentive or motivation to target underrepresented populations.
- Lack of funding for inclusion science.
- Lack of information on factors such as fitness assessments, heart rate, and gym access.

Key Points from Q&A Moderated by **Tiffani Bright,** AHRQ

- Accessible solutions can lead us to create functionality for a broad range of people. Captioning is an example of a “digital curb cut” used by anyone and everyone.
- There are currently 36,000 mHealth apps, and the number is rapidly growing. The current market caters primarily to medical information and tasks, though there is considerable interest in gearing applications toward caregiving/home-based services.
- Funding sources for these types of projects include NIH, AHRQ, SBIR, and NIDILRR.
- We need to start with the end-user in the community instead of the provider, and personalize tools at that level.
- If we do not bring the right people together, we will never solve the issue.
- What needs to happen to get PHR industry engagement? While the PHR prototype described by Rothberg is in the public domain, many PHR vendors are not interested. Structured negotiations have resulted in some success. While there may be a reluctance to pursue legal action, an approach might be to engage in a discussion to avoid such action.
- Human factors professionals and engineers have varying perspectives that could potentially solve accessibility issues, if brought together. Developers need to break down the testing process and assess application compatibility with the user (however, they interact with the device).

> *If we do not bring the right people together, we’ll never solve the issue.*

- To support these applications, government must work with industry in protecting consumer data and ensuring privacy.

Panel 5: Industry and Advocacy Perspectives – Next Steps in Creating an Accessible Health IT Ecosystem

Goal: Share perspectives and insights from thought leaders in industry and aging and disability advocacy communities regarding the current status, barriers, and promising developments associated with creating an accessible/usable Health IT ecosystem capable of supporting the diverse needs of patients.

Mike Richert, Esq, *Director, Public Policy & Senior Advisor for Strategic Initiatives, American Foundation for the Blind*

As an advocate, Richert challenged the idea that regulating technology stifles innovation. The thought is that any type of regulatory scheme will lock developers in their thinking, but he argued that is not the case. The very basic consideration is whether developers have thought to make the technology accessible in the first place. Richert maintained that there is not a law or regulation that has lost money for a company, nor have they pushed people out of jobs. Current laws and regulations are weak when it comes to accessibility, they are more about compromise than enforcement.

> *Current laws and regulations are weak when it comes to accessibility.*

The next steps in creating accessible products should encompass an examination of accessibility across the board. There needs to be a clear model that not only identifies the problem, but also sets standards to address these problems. Clearer, stronger guidelines and standards will be a great step toward accessibility. Accessibility is not an option. Accessibility should be as central to design as the requirement that the product itself works.

Elaine Blechman, PhD, *Founder & President, Prosocial Applications, Inc; CEO, Smart Health Records, Inc.; Professor Emerita, University of Colorado at Boulder*

Blechman opened with a graphic from the Federal Health IT Strategic Plan (http://healthit.gov) that health IT should be accessible when and where it is needed to improve and protect people's health and wellbeing (see Figure 5). She pointed out that as the health IT moves forward, consumers should be at the center of every health IT system. Consumers need to be the owners of their health information. According to Blechman, 135 million U.S. consumers coping with chronic conditions and disabilities spend 12% or more of their income on unsafe, overpriced, and ineffective healthcare. Hospitals and health systems find it challenging to share information to support clinical care. Sharing and integrating data across EHRs is complex, time consuming, and costly, according to the American Hospital Association.

In 2005, experts were hopeful that better health IT would lower national health spending. However, that interoperability is not yet functioning, and a cost savings has not been realized. Barriers include an insufficient infrastructure, technology challenges such as inconsistent standards and poor usability, and unresolved policy issues such as limited provider resources and inconsistent privacy and security requirements.

The SmartPHR® Health Record Accounts offers patients a singular, comprehensive, and virtual PHR that travels with them through all their healthcare encounters. It is updated and accessed by all their providers instead of being multiple, incomplete EHR records. Patients own this content, and authorized providers can update it when necessary.

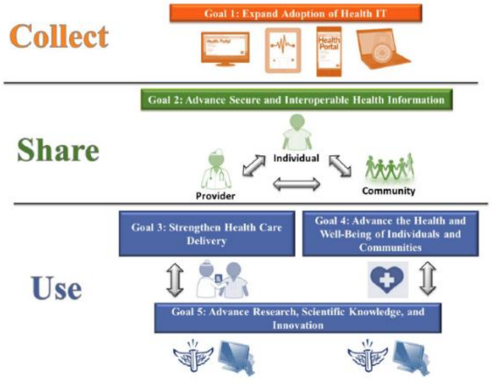

FIGURE 5: FROM THE FEDERAL HEALTH IT STRATEGIC PLAN 2015-2020

Blechman shared some research and policy recommendations on moving forward:

- Commission legal research on consumer ownership of their data.
- Encourage Defense Advanced Research Projects Agency's (DARPA) Brandeis project to pursue innovations in security for storage and transport of consumer-controlled, health information.
- Permit Apple to continue to allow owners of iOS devices to hold the private encryption keys for their mobile health apps.
- Require CMS-funded Medicare and Medicaid providers, NIH-funded clinical trial directors, and U.S. Food and Drug Administration (FDA) evaluated drug and device manufacturers to deliver standardized, machine-readable copies of records to patient-controlled health information repositories.

David Lindeman, PhD, *Director of Health, Center for Information Technology Research in the Interest of Society (CITRIS)*

The Center for Information Technology Research in the Interest of Society (CITRIS) was established to address the most pressing social and environment issues facing California. Initiatives include Sustainable Infrastructures, Connected Communities, People and Robots, and Health. The mission of the Health Initiative is to improve health outcomes and access to cost-effective care through the development and integration of innovative technology in telehealth, sensors, analytics, and mobile devices. This includes projects such as innovations in EHRs and analytics that can become transformative solutions for the future. They are currently using data and data analysis from precision medicine to augment traditional health. One prototype analyzes a range of data from different infrastructures in order to facilitate data sharing and knowledge transfer between researchers and industry. Such tools and enabling technologies spur partnerships and further innovation.

Lindeman noted that the industry involvement is crucial to developing technologies, and many more public/private partnerships are needed. Improved platforms can help them to begin addressing interoperability issues. Engaging end users at the onset will lead to better ideas of what will work.

Kel Smith, *Principal, Anikto, LLC*

With more wearables and devices becoming inter-connected and pervasive, the Internet of Things (IOT) is becoming a reality. Smith stressed the importance of promoting a culture of accessibility and innovation in electronic health. A *Wired* article, *Wearables are totally failing the people who need them most*, laments the fact that wearable health devices such as fitness trackers cut out a large portion of the market that could actually get the most benefit from them. Smith also cited a Journal of American

Medicine article that claimed that the frailest and most vulnerable may be at risk, as more aspects of health care move online. This is partly because "accessibility is often an afterthought, and many people have a very imperfect idea of what makes consumer healthcare technology accessible."

Instead of considering accessibility standards as a barrier, they can be viewed as an opportunity to innovate, and reach more users by making products user friendly for everyone, not just people with disabilities. Developers should focus less on the constraints, and more on the evolution of products. By focusing on this and building in accessibility with everyone in mind, we can "extend human capability by meeting fundamental needs."

> *"By building in accessibility, we can extend human capability by meeting fundamental needs."*

Matthew Ater, *Vice President of Services, Freedom Scientific*

Current standards are a good starting point for designing new technology, but people need to be educated on the standards, and understand them. Ater stressed the importance for developers to be familiar with resources and tools available to build accessibility into products from the beginning, saying, "If we don't think about accessibility from the beginning, it becomes harder to do." It is relatively easy to build accommodations for a person with color-blindness at beginning stages, and this important aspect of design will prevent issues in the future.

Part of the education process must be a true understanding of the user experience from varying disability perspectives. He suggested that developers might have a better understanding of end-user needs when they have their mouse, keyboard, and/or monitor taken away. Another suggestion he offered was to train quality assurance personnel on how to test for accessibility. This helps keep it in the forefront of development, and assures that all products are accessible.

Ater also emphasized advantages of accessible technology in the following examples:

- Because a hospital did not purchase accessible training and technology, they had to provide a full time assistant for an employee.
- A physical therapist who is blind was turned down for employment because the software the practice used was inaccessible.
- Emergency room kiosks that are not accessible require an assistant to use.

He concluded with the need to enforce laws that require accessibility. For instance, the VA and the U.S. Department of Defense (DoD) have the power to push vendors to make things accessible.

Key Points from Q&A Moderated by Robert Jarrin, Qualcomm:

- The FDA requires human factors testing in medical devices. Perhaps there needs to be human factors testing for accessibility.
- At the heart of all of this, accessibility is not an option. We need to take the attitude that accessibility is central, so that if a product works, it works for people with disabilities.
- We should also consider how patients have access to their records collected during clinical trials.
- We need to change the thinking so that developers engage end users from the beginning.

- When considering accessibility, we should also consider how plain language can benefit the multilingual community.
- We should consider how to push vendors, suppliers, and providers to make sure that their products are accessible.

Wrap-Up Conversation – Identifying Innovative Strategies to Promote R&D Investments and Collaborative Public-Private Partnerships that Catalyze Action to Advance Accessible Health IT

Margaret Campbell, conference co-chair moderated a wrap up conversation with **William Peterson,** Executive Director, Office of Accessible Systems and Technology, U.S. Department of Homeland Security (DHS) and conference presenters **David Lindeman** and **Frances West**.

Accessibility first came about as a part of the independent living movement as a pathway to employment. There is a fundamental issue with equity and assistive technology right now. Just as the health industry realized the need for IT in the last few years, there is an opportunity to help the growing health IT industry understand the value of accessibility. The industry should explore more “frugal technology” solutions that draw more people into using them.

> ***Collaboration between industry, research, and government can lead to low cost solutions.***

With so many existing technologies, especially in health IT, there are complex issues with system integration. Solving this problem will take big money, big time, and big talent. Integrating accessibility into the medical field will completely transform the health system. Opportunities for development and innovation can move forward more readily if access is easy and affordable. Collaboration between industry, research, and government can lead to low cost solutions.

The industry inherently understands the importance of Health Insurance Portability and Accountability Act (HIPAA) privacy and security, but is largely unaware of the importance of accessibility. Accessibility and usability should not be afterthoughts, but rather an upfront investment. Inaccessibility and the lack of usability in the health IT field is an ecosystem issue that will not be solved overnight. The solutions involve talent, time, and money, with policy being the primary driver for change.

Government-sponsored research and development (R&D) in accessible health IT does not keep pace with industry R&D that tends to be two to three years ahead of federal funding priorities. Industry cannot wait for the government to catch up. The federal government operates on a five-year funding cycle. By the time a project is completed, it may be years behind the industry. The panel discussed the need to identify ways for the federal government to collaborate with industry. The key is to promote interoperability and connectivity. For instance, Denmark has invested in an effort to create a common EHR interface that will promote interoperability and that others can build upon. Singapore is also moving in the same direction. Another idea was to bring industry together in a friendly forum to collaboratively solve the problem. Even though Microsoft and IBM are competitors, they work with other companies and accessibility organizations to create the International Association of Accessibility Professionals because it is in the best interest of business to establish common standards and approaches.

A number of opportunities for frugal technology development include:

Push forward potential policy levers of change to promote the accessibility and usability agenda

- Use civil rights protections and legislation such as ADA and FITARA to push for equal access.
- Consider how ONC can be a leader in more directly pushing for accessibility and usability for people with disabilities, especially at the front-end of the process.
- Build on existing efforts such as the President's Council of Advisors on Science and Technology.
- Identify ways government can work with industry in an open and fair manner (without showing favoritism).

Strengthen collaboration and partnerships

- Establish a standard venue for curating policy, R&D, and industry data for study and dissemination. Push solutions into practice.
- Consider how to align federal research with industry research pursuits.
- Create an easy way for users to identify issues with new technologies.
- Build upon related global efforts, such as a WHO conference featuring technology solutions for the aging populations.

Catalyze research and development in accessible and usable health IT

- Consider how the Small Business Innovation Research (SBIR) might support more R&D investigator initiated innovation.
- Promote interoperability among platforms.
- Leverage existing resources such as those developed by W3C.
- Support a more synergistic R&D investment in test beds such as Clarix, IBM, Google and Yahoo.
- Utilize Apple's open source iOS platform to spur future development of mobile apps including mHealth apps.
- Promote the use of API to build on top of what is already available, without recreating the entire EHR. SMART Health IT is one example.
- Collect data to fine tune the methodology on current devices in order to translate the findings for commercial use.
- Create testbeds, or places where private and public sectors can jointly explore issues and research.
- Sponsor initiatives that invite industry and research to come together, such as hackathons, or opportunities for researchers from industry to work in the academic environment.

Next Steps

Kristi Wilson Hill, PhD, *ICDR Interim Executive Director and Deputy Director, National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS)*

Hill complimented the participants and presenters for meeting the goals and objectives of the meeting with an informative and enlightening two-day conference. The ICDR wanted to serve as a bridging point for the various stakeholders and for the intersection between aging and disability. Hill thanked the co-chairs and steering committee for putting together a conference with a full spectrum of perspectives.

The ICDR envisioned this as interactive and engaging for the full audience to synthesize thinking. Along with suggestions for incremental steps to move forward, she felt energized by the discussions, and encouraged the audience to think big.

A proceedings document will follow this meeting, and there is discussion about preparing an article for submission to a journal. As the interim ICDR Executive Director, Hill hopes to keep the momentum going, and the conference proceedings will inform further action by the ICDR. Hill thanked the organizers and participants for their enthusiastic commitment to making health IT more accessible for people with disabilities, older adults, and their caregivers.

Appendix A: Small Group Huddles

Small Group Huddle Discussion 1: Elevating Accessibility and Usability in Health Information Technology to Meet the Needs of People with Disabilities, Older Adults, and Caregivers

The first small group huddle followed a keynote presentation and end-user perspectives panel on how to elevate accessibility and usability in health IT to better meet the needs of people with disabilities, older adults, and caregivers. Participants spent a few minutes organizing their thoughts on three questions. Next, they discussed their responses and selected the most promising 1-2 ideas to share.

1. What specific needs and barriers associated with accessible/usable health IT discussed so far by the keynote speaker and end users do you think are most important to address in the near term (next 2 years) and beyond?
    - Individuals and caregivers are not active in the design process and usability testing.
    - Laws and regulations are needed to ensure personal ownership or access to all healthcare.
    - The lack of uniform accessibility standards for websites, systems, and tools. There is a lack of transparency of accessibility testing.
    - Measurable requirements for accessibility that are built into the quality measures that are actually enforced at the level that is adequately required for EHR.
    - Education. Business and providers do not perceive incentives for accessibility. A return on investment (ROI) should provide a rationale for accessibility.
    - There needs to be a focus on plain language and interoperability.
    - Off-the-shelf health IT is often not accessible and vendors have little incentive to address accessibility.
    - Security and privacy.
    - Consumers do not have ownership investment in their EHR.

2. What opportunities or promising strategies discussed so far, or drawn from your own experience, do you believe could best respond to these needs and barriers?
    - Encourage industry leadership and collaboration between advocates and researchers.
    - Engage stakeholders in IT development and strategic planning: include individuals earlier in the process.
    - Test iOS for accessibility; connecting on perspective side government can facilitate connectivity and standards.
    - There needs to be a coordinated federal acquisition strategy.
    - Develop uniform standards for accessible websites, systems, and tools.
    - Build accessibility metrics into the standards.
    - Require that third party software is accessible.
    - Develop tools to make 508 adherence easier (importing alternate text).
    - Develop a strategy to encourage vendors.
    - Market opportunities as a result of an open sharing of results of accessibility testing.

- Any time there is a funding announcement include the business case and preference for accessible technology.
- Provide incentives to vendors.
- This conference is a promising strategy. Ensure that academics and the discipline is connected to customers/consumers at different levels.
- There is a need for working groups focused on these topics.
- Building (not adding) ally at each and every stage; integrating (by choice and compliance) society for AT.
- DoD contract with Cerner could set the standard for interoperability across healthcare; opportunity is to make EHRs accessible. Can we leverage this opportunity to make interoperability interface with accessibility? The new 508 could make this a better accessibility engine = application notes added to technical support materials. Aging, disability, literacy, digital literacy, and health literacy; global public inclusion infrastructure; preferences on how the information has to appear in order to use it for people with disabilities. Two steps: 508 and usable; person centeredness; consumers do not have enough investment in the EHR; accessibility and indecision; 508 and Global Public Inclusive Infrastructure (GPII) to make it easier to determine what each person needs.
- The central content for military EMR is an opportunity to set the standard for EMR accessibility.
- Cooperative strategic advocacy of access and priorities.
- Making hospitals accountable for public disclosure of accessibility.
- A large global communications campaign to drive more ally visibility to health IT manufacturers and push for fully accessible technologies.
- Go to CVS and retailers to make accessible kiosks available as they are being developed.
- Make use of innovative technology forums to focus on getting health IT to talk to one another.
- Take advantage of systems to manage silos. Legislators must talk to each other.
- Because systems are not interoperable and proprietary technology does not communicate with other technologies, there is a need to input health histories repeatedly. Such interoperable systems will need to address security and privacy as well as accessibility.

3. What role do you think your agency or organization is best positioned to play in helping to advance these solutions?
    - Industry leadership; advocacy; research and publication; collaboration.
    - Research – integrate National Living and Medicine – they have funding and support; translate research to help implement; health and wellness – implement tools for customers; EMR vendor-implement tools and users.
    - Any time there is a funding announcement; include business for case/performance for accessible tech.
    - NIH – development of accessible apps and CDC info mapping driver.

- VA; DOJ; GSA – influence OMB drafted IT acquisition directives (IT software, category information, coordinated cross agency "buy" and licensed software tracking) work to ensure accessibility is a component.
- Set standards for accessibility of interface and content (digital literacy, general literacy, and authoritative literacy); provide guidance to DOP for design implementation.
- Access Board – new 508 standards, technical assistance of EHR accessibility.
- Include National Library of Medicine and AHRQ in this discussion.
- End user – as a daily or monthly user, highlight the issues and let people know about problems in accessibility.
    - Provide feedback for remediation (as a user).
- Advocate for technology solutions that are accessible and easy to use.
- Provide access for ally; focus on vendors.
- We can make sure our future efforts take better advantage of what technology is available.
- Kiosks such as My Health Net exist in the VA. Mobile health/connected health needs visibility and data on the barriers and the facilitators.
- Research is vital. Information seeking behavior of individuals and caregivers.
- We can provide individual customized consultation to vendors on how to implement and evaluate solutions.
- Research reporting on findings from states implementing PHR/LTSS in HCBS settings.
- As a vendor, bringing in recommended practices.
- Coalesce industry involvement around chief accessibility officers and more health IT focus on human factors.
- Sharing research results.
- Collaborate, advocate, litigate, research, and publish.
- New 508 standards. Technical assistance for EHR usability. Set standards for accessibility of EHR interface and content to support aging, disability, literacy, digital literacy, and health literacy. Provide DoD/Cerner with guidance for design and implementation. Use 508 and GPII early in the development cycle.

Small Group Huddle Discussion 2: National Policy Perspectives: Incorporating Accessibility and Usability into Health IT and Electronic Long-Term Services and Supports (eLTSS) Systems and Initiatives – Barriers and Levers of Change

The second small group huddle followed a panel on national policy perspectives on barriers and levers of change for incorporating accessibility and usability into health IT and electronic Long-Term Services and Supports (eLTSS) systems and initiatives. Participants spent a few minutes organizing their thoughts on three questions. Next, they discussed their responses and selected the most promising 1-2 ideas to share.

1. What technical, legal, or policy barriers or challenges related to the accessible health IT agenda discussed today do you think are most important to address in the near term (next 2 years) and beyond?

- Enforceable standards.
  - Federal agencies need to work together.
  - Federal agencies need to be the model for accessibility.
  - Lack of an emphasis on holding healthcare providers accountable for accessible information.
  - Hospitals and universities who may be unprepared to make materials and training accessible.
  - Need for technical examples especially electronic medical records with hard-to-create example.
- Unclear ownership of the health care record.
  - If they own it, can they profit?
- Limited ability to aggregation of health data.
  - Sharable electronic records can also build a collective understanding of a condition and impact shareable care.
- Industry and vendors do not understand needs and need to align results with end-users.
- Vendors lock down application program interface (API).
- Lack of awareness.
  - Ignorance of the law and even more important – ignorance of needs.
  - People are not aware of their rights.
  - What are the legal requirements vs. voluntary standards?

2. What opportunities or promising strategies discussed today, or drawn from your own experience, do you believe could best respond to these barriers or challenges?
   - Federal regulations to hold providers more accountable.
     - Align regulations with vendor requirements, do not merely accept self-certification.
   - Help systems with 508 compliance.
     - Need to move past the idea that enforcement is a barrier to putting out guidelines.
     - Promote tools to help large entities (universities/health systems) become more accessible.
     - Shift from a “nuisance” checkbox to needs based awareness.
     - Create personas that represent a variety of disabilities.
     - Leverage existing tools.
   - Make person ownership of data clear with financial penalties. California is an example.
     - Use of independent data ethics panel to remove control of data from those who hold it and put it in independent hands that can control it and preserve it for users but also allow some use for national good.
   - File complaints against major health IT vendors.
     - Create an outreach campaign about rights and find consumers to file complaints.
   - Accessibility needs to be a part of the design phase and not after the fact.

- Rethink the approach to accessibility. As an example, a deaf person getting information in a video in American Sign Language, their primary language, as opposed to the written word which is their second language.
- Share API so open the system and make it open and transparent.
- Make end users more aware of standard and have them test whether a product is meeting the standards.

3. What role do you think your agency or organization is best positioned to play in helping to advance these solutions?
    - Hospital: encourage vendors to be ADA compliant.
    - CMS: form a coalition of public and private entities and promote legislation in 50 states that says patients own their health records.
    - Provide technical options and awareness.
    - Support a data ethics board on the aggregation and ethical government use of data.
    - Identify available resources for accessible health IT.
    - Advocacy groups – research the topic, define outcomes, and educate consumers.
    - Research groups – provide proof of concept that accessible health IT is possible.
    - American Federation for the Blind (AFB): supply testers; continue to research existing standards; raise international awareness; AFB is a publisher and researcher.
    - Provide proven solutions as proof of ability to implement accessible health IT.
    - We are a hospital. We could encourage our vendors or submit a complaint.
    - Make people aware of the issues.
    - Supply the testers including people with spina bifida or healthcare providers.
    - As a vendor, we have responsibility to bring client lists and the processes for the design of products and existing products to fulfill the needs of people with disabilities.
    - Make organizations aware of tools/educational materials available to hospitals and universities that they can purchase.

Small Group Huddle 3: Advancing Research and Development, Identifying Best Practices and Building Collaborative Public-Private Partnerships.

The third huddle followed presentations on public-private partnerships. The groups discussed research and development challenges and potential strategies to address those gaps.

1. What research or development gaps and industry challenges associated with achieving accessible and usable health IT discussed today do you think are most important to address in the near term (next 2 years) and beyond?
    - Learning health system to address outcomes.
    - Change from corporate culture "compliance" toward a drive for visibility/HX/as part of the development of health IT culture.
    - Research from other countries (not USA).
    - Harmonization of international standards.
    - Bring research from academic or high quality settings to “real life” small community with no expertise.

- Personalizing health IT and community-based research.
- Training for basic and advanced developers.
- Accessible health IT for people with intellectual disabilities.
- Increased participation by people with disabilities.
- Involvement by consumers.
- Leveraging the SOS.
- Knowledge translation.
- Compliance-based approach promotes the bare minimum. Instead, the emphasis should be on improving the human experience.

2. What opportunities or promising strategies discussed today, or drawn from your own experience, do you believe could best close these gaps and respond to the challenges?
    - Standards and interoperability.
    - Understanding that population metrics are showing advertisement and socialization business opportunities. These lead to innovation.
    - Public-private partnerships and grassroots movements leading to education.
    - Integrating accessible solutions in a timely manner; accessibility (screen readers are very useful); there should be a language selection option for user interface instruction; design of universal icons and signage.
    - Getting ahead of the curve with newer technologies, i.e., wearables.
    - Reliance on more devices. IBM being global. Increased independence.
    - Federally funded research and policy driven motivation for industry.
    - Development of health IT accessibility tools and accessible APIs.
    - If you involve laymen in an SOS, you also need to involve them in language and tech transfer.

3. What role do you think your agency or organization is best positioned to play in helping to promote these solutions?
    - Research demonstrating improved outcomes.
    - Personalizing health IT.
    - It is difficult for community-based projects to get funding that seems to be restricted for large academic institutions.
    - With cloud computing, DOT is getting into the next generation public-private partnerships and working with the ICDR and NIDILRR. More needs to happen such as Seeing-Eye GPS, BlindSquare. We need usability information for veteran transportation. There is a lack of willingness of different agencies to share information.
    - We have a team of people with disabilities and can help test apps and IT.
    - Promotion of existing solutions.
    - Provide a testbed and expertise related to DHH/LV/blind accessible health IT.

Appendix B: Presentations

Please note: not all panelists used a presentation during the conference.

Day One: Exchanging Perspectives, Identifying Barriers and Facilitators

Welcome and Introduction

- Margaret Campbell, PhD, NIDILRR, Administration for Community Living, U.S. Department of Health and Human Services

---

Panel 1: Voices and Perspectives of End User Needs, Barriers, and Opportunities Associated with Using Health IT Systems and Tools

- MaryAnne Sterling, Connected Health Resources
- Jeromie Ballreich, Johns Hopkins University
- Carol Bradley, Sutter Health
- Gail Hunt, National Alliance for Caregiving

Panel 2: Building Blocks for Accessible and Usable Health IT: Overview of Current Landscape - What Standards and Tools Exist and Where are the Gaps?

- Judy Brewer, Web Accessibility Initiative, World Wide Web Consortium
- Muhammed F. Walji, PhD, UTHealth School of Dentistry, National Center for Cognitive Informatics and Decision Making in Health Care
- Janey Barnes, PhD, User-View, Inc.
- Caitlin Blood, MPH, Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services

---

Panel 3: National Policy Perspectives: Incorporating Accessibility and Usability into Health IT and Electronic Long-Term Services and Supports (eLTSS) Systems and Initiatives - Barriers and Levers of Change

- Amanda Maisels, JD, U.S. Department of Justice
- Raja S. Kushalnagar, JD, LLM, PhD, National Technical Institute for the Deaf
- Jodi G. Daniel, JD, MPH, Office of the National Coordinator for Health Information Technology, U.S. Department of Health and Human Services
- Michael R. Smith, MPA, Centers for Medicare and Medicaid Services
- Caroline Ryan, Administration for Community Living, U.S. Department of Health and Human Services

---

Day Two: Advancing Research and Development, Identifying Best Practices, Building Collaborative Public-Private Partnerships

Opening Remarks

- Tiffani Bright, PhD, Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services
- Wendy Nilsen, PhD, Smart and Connected Health Program, National Science Foundation

---

Panel 4: R&D Perspectives: What We Know and Need to Know to Drive Accessible Health IT Policy and Practice - Metrics, Data, and Best Practices

- Madeleine Rothberg, National Center for Accessible Media at WGBH
- Dean Karavite, The Children's Hospital of Philadelphia
- David H. Gustafson, PhD, Center for Health Enhancement Systems Studies, University of Wisconsin-Madison
- James Rimmer, PhD, School of Health Professions, University of Alabama at Birmingham

---

Panel 5: Industry and Advocacy Perspectives - Next Steps in Creating an Accessible Health IT Ecosystem

- Elaine A. Blechman, PhD, Prosocial Applications, Inc., Smart Health Records, Inc., University of Colorado-Boulder

Appendix C: Resources

Guidelines

2015-2020 Strategic Plan explains how the ONC intends to apply the effective use of information and technology to help the nation achieve high-quality care, lower costs, a healthy population, and engaged individuals.

Assistive Technology Act of 1998 provides all 56 states and territories with financial assistance that supports programs designed to maximize the ability of individuals with disabilities to obtain Assistive Technology (AT) devices and services.

Authoring Tool Accessibility Guidelines (ATAG 2.0) has two main parts. Part A is about making the authoring tool itself accessible. Part B is about the authoring tool helping authors produce accessible content. It is organized in the following layers: principles, guidelines, and success criteria.

Federal Health IT Strategic Plan 2015-2020 lays out the vision, goals, and actions that the federal government will pursue immediately and in the coming years.

Federal Information Technology Acquisition Reform Act (FITARA)requires CIOs to thoroughly review their IT investments.

General Usability Design Principles are guidelines based on the ways users (doctors, nurses, patients, etc.) think and work. They include 14 general design principles: consistency, visibility, match, minimalism, memory, feedback, flexibility, error messages, prevent errors, closure, undo, language, control, and help.

Health Literacy Online is an online, research-based set of guidelines that provides six strategies for developers to write and design health websites that are accessible to users with limited literacy skills.

International Organization for Standardization (ISO) scale: ISO 9241: Ergonomics of Human System Interaction. ISO 9241 provides requirements and recommendations for human-centered design principles and activities throughout the life cycle of computer-based interactive systems. It is intended to be used by those managing design processes, and is concerned with ways in which both hardware and software components of interactive systems can enhance human–system interaction.

National Interoperability Roadmap was published by ONC to guide the nation toward meeting the goal of sharing information more broadly across providers, consumers, and others.

Nondiscrimination in Health Programs and Activities is a proposed rule that will assist some of the populations that have been most vulnerable to discrimination and will help provide those populations equal access to health care and health coverage.

Section 1557 of the Affordable Care Act implements new protections for individuals with disabilities and extends to the insurers participating in the health insurance marketplaces.

Title I: Management of Information Technology within Federal Government - (Sec. 101) Requires the heads of the following agencies to ensure that their respective chief information officers (CIOs) have a significant role in information technology (IT) decisions, including annual and multi-year planning, programming, budgeting, execution, reporting, management, governance, and oversight functions.

TURF Framework for EHR Usability is a unified framework for EHR usability that stands for task, user, representation, and function. These are the four components that determine the usability of an EHR system.

Web Content Accessibility Guidelines (WCAG 2.0) is a stable, referenceable technical standard. It has 12 guidelines that are organized under 4 principles: perceivable, operable, understandable, and robust.

User Agent Accessibility Guidelines (UAAG 2.0) guides developers in designing user agents that make the web more accessible to people with disabilities. User agents include browsers, browser extensions, media players, readers and other applications that render web content.

Initiatives and Projects

Accessible Designs for Personal Health Records Project is a collaborative project with the Department of Biomedical and Health Informatics of The Children's Hospital of Philadelphia (CHOP), and Inglis.

Blue Button Initiative encourages healthcare providers, insurance companies, labs and drug stores to make health information actionable for patients.

Bright Futures is a national health promotion and prevention initiative, led by the American Academy of Pediatrics and supported by the Maternal and Child Health Bureau, Health Resources and Services Administration.

e-Connected Family Caregiver: Bringing Caregiving into the 21st Century is a report that describes the results of a study conducted to examine family caregivers' receptivity to technology.

Electronic Long-Term Services and Supports (eLTSS) Initiative is an ONC-CMS partnership that focuses on identifying and harmonizing electronic standards that can enable the creation, exchange and re-use of interoperable service plans by health care and community-based long-term services and supports (CB-LTSS) providers, payers, and individuals.

Health IT Certification Program is a voluntary program that sets the foundational capabilities, standards, and requirements, so that users have what they need from the technology.

Home and Community Based Services (HCBS) Test and Experience of Care Survey is a CMS initiative to develop a core set of health care quality measures for benefits under Medicaid to develop standards for e-LTSS records and demonstrate PHS.

President's Council of Advisors on Science and Technology is an advisory group of the nation's leading scientists and engineers who directly advise the President and the Executive Office of the President. PCAST makes policy recommendations in the many areas where understanding of science, technology, and innovation is key to strengthening our economy and forming policy that works for the American people.

Smart and Connect Health Initiative is jointly supported by the National Science Foundation (NSF) and the National Institutes of Health (NIH), to accelerate the development and use of innovative approaches that would support the much needed transformation of health and healthcare from reactive and hospital-centered to preventive, proactive, evidence-based, person-centered and focused on well-being rather than disease.

Standards and interoperability eLTSS Initiative is a community-based initiative designed to identify, evaluate, and harmonize standards needed for the creation, exchange and re-use of key domains and associated data elements of Community-Based Long-Term Services and Supports (CB-LTSS) person-centered planning; and accessible person-centered service plans that are interoperable and used by providers, beneficiaries, accountable entities and payers.

Testing Experience and Functional Tools (TEFT) is a program created in response to the ACA Section 2701 requirement for HHS to identify and publish initial and voluntary core sets of adult quality measures for adults eligible for Medicaid.

Organizations, Centers, Programs

Center for Integrated Programs funds state-level activities in state financing, device reutilization, short-term device and device demonstration, as well as state leadership activities.

Connected Health Resources is an organization helping communities and organizations give ongoing support to family caregivers.

Elder Tree is an AHRQ-funded collaboration between the Active Aging Research Center at the University of Wisconsin-Madison, the state of Wisconsin, the Wisconsin Institute for Health Aging, and local county aging and disability resource centers.

International Association of Accessibility Professionals mission is to define, promote, and improve the accessibility profession globally through networking, education, and certification in order to enable to creation of accessible products, content, and services.

National Center for Cognitive Informatics and Decision Making in Healthcare (NCCD) is funded by ONC under the Strategic Health IT Advanced Research Projects (SHARP) to support improvements in usability, workflow, and cognitive support for EHR.

The National Science Foundation (NSF) is an independent federal agency created by Congress in 1950. NSF is the only federal agency whose mission includes support for all fields of fundamental science and engineering, except for medical sciences.

Pediatrics Research Consortium (PeRC) supports effective research within the Children’s Hospital community by coordinating extensive practice-based research network (PBRN). They cater to the diverse needs of the three main parties that benefit from practice-based research: 1) Researchers, 2) Care Centers and Practices, and 3) Patients and Families.

Federal CIO Council is the principal interagency forum on Federal agency practices for IT management.

RecTech is a NIDILRR-funded Rehabilitation Engineering Research Center focused on expanding new knowledge and research on recreation technology for people with disabilities.

Small Business Innovation Research (SBIR) is a highly competitive program that encourages domestic small businesses to engage in Federal Research/Research and Development (R/R&D) that has the potential for commercialization. Through a competitive awards-based program, SBIR enables small businesses to explore their technological potential and provides the incentive to profit from its commercialization.

Web Accessibility Initiative develops internationally recognized guidelines for web accessibility and usability through an open, transparent, multi-stakeholder process.

Technical Accessibility Resources

Automated Accessibility Tester provides development teams with the ability to add accessibility-compliance checking into their automated deployment processes that leverage Selenium. The service also helps these teams manage issues throughout the lifecycle of the application.

Contrast checker is a tool provided by WebAIM.

Digital Content Checker provides the ability to automatically check EPUB and Hyper Text Markup Language (HTML) content for accessibility-compliance issues.

Safety Enhanced Design Briefs are intended for anyone who develops and implements health IT applications, particularly for electronic health records (EHRs) who want to learn more about human factors and design.

Tips for Getting Started with Web Accessibility These tips introduce some basic considerations for making websites more accessible to people with disabilities, and provide links to additional guidance.

Tips on Developing for Web Accessibility includes basic considerations to help developers get started developing content that is more accessible for people with disabilities.

Web AIM (Web Accessibility in Mind)'s mission is to expand the potential of the web for people with disabilities by providing the knowledge, technical skills, tools, organizational leadership strategies, and vision that empower organizations to make their own content accessible to people with disabilities.

World Wide Web Consortium (W3C) is an international community where Member organizations, a full-time staff, and the public work together to develop Web standards.

Usability Resources

Catalyzing Technology to Support Family Caregiving was published by the National Alliance for Caregiving and provides a good starting point for innovators who want to better understand a caregiver's needs.

General Usability Design Principles 14 general design principles that can be applied to the development of EHRs.

Gerhardt-Powals' cognitive engineering principles is a set of principles for enhancing computer performance. These heuristics, or principles, are similar to Nielsen's heuristics but take a more holistic approach to evaluation.

MeasuringUsability.com is a quantitative research firm focusing on the statistical analysis of human behavior and quantifying the user experience.

Nielsen's Heuristics are 10 general principles for interaction design. They are called "heuristics" because they are broad rules of thumb and not specific usability guidelines.

NISTIR 7804 is a publication entitled "Technical Evaluation, Testing and Validation of the Usability of Electronic Health Records".

Safety Enhanced Design Briefs are design briefs intended for anyone who develops and implements health IT applications, particularly for electronic health records (EHRs) who want to learn more about human factors and design.

SHARPC is focused on providing decision-making support to physicians to ensure patient safety.

Inspired EHRs: Designing for Clinicians a freely available online book is written for anyone who develops and implements health IT applications**,** but particularly for electronic health record (EHR) vendor teams who want to learn more about human factors and design. Designers who want to learn about the needs of EHR users, medical informatics students, and EHR users who want to learn more about design principles might also benefit from reading this book. The contained information is open-source.

What Family Caregivers Need from Health IT and The Healthcare System to be Effective Health Managers a report describing the caregiving information cycle and caregiver information needs at each stage.

Tools

Accessible Workplace Connection application is a single global accommodation process that helps ensure employees who have disabilities equal opportunity to advance and contribute.

Developing a Web Accessibility Business Case for Your Organization social, technical, financial, legal, and policy factors with guidance on developing a customized business case.

IBM Accessibility: Redefining Personalization IBM designs and delivers human-centric solutions that reduce technology barriers and personalize experiences on any device so everyone, regardless of age or ability, has equal access to the information they need for school, work, and life.

IBM Bluemix is a risk management solution to accelerate development, improve testing, and verify the accessibility of content.

iMHere is an app designed for the aging populations and those with chronic conditions and/or disabilities. The goal is to break the common intervention of bringing therapists to consumers' home to teach them about preventative self-care and monitoring.

Inclusion by Design IBM has made accessibility an integral function of its design thinking, helping designers develop a real empathy for users and deeper understanding of how physical, cognitive, and situational disabilities affect the use of a product.

National Quality Website Survey is an evaluations instrument that measures six website criteria and reliability development requirements including: identify, purpose, content, development, privacy, user feedback, and content updating.

Open Notes is a tool that allow patients and caregivers to communicate with their health care providers.

PedsNet is a pediatric learning health system dedicated to discovering and implementing new ways of providing the best care and improving health care outcomes.

Personalized Online Weight and Exercise Response System (POWERS) is a community mapping information and communication technology for promoting physical activity for youths with disabilities.

SMART Health IT is the interface between healthcare data and innovation. The goal of SMART is audacious and can be expressed concisely: an innovative app developer can write an app once, and expect that it will run anywhere in the health care system.

Tealeaf embeds accessibility into intuitive commercial offerings with a mobile accessibility check and accessibility overlays that improve the usability of a website. Tealeaf customer experience management solutions provide critical visibility, insight and answers to help companies meet online conversion and customer retention objectives.

Twinlist: A Multi-Step Interface to Reconcile Medication Lists illustrates the use of spatial layout and multi-step animation, to help medical providers see what is different and what is similar between the lists (e.g. intake and hospital lists), and rapidly select the drugs they want to include in the reconciled list.

Appendix D: Speaker and Leadership Biographies

Interagency Committee on Assistive Technology (ICAT) and Steering Committee Leadership

DAVID BAQUIS
Accessibility Specialist
U.S. Access Board

Mr. David Baquis is an Accessibility Specialist with the U.S. Access Board. He delivers presentations, writes technical assistance materials, and responds to public inquiries on Sections 508 of the Rehabilitation Act and 255 of the Telecommunications Act. He is currently involved with updating the Board's rule on information and communication technology accessibility, which includes requirements for health information technology. His background blends experience in healthcare, consumer education, disability issues, technology and public policy.

MARGARET CAMPBELL, PHD
Senior Scientist for Planning and Policy Support
National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)
Administration for Community Living (ACL)
U.S. Department of Health and Human Services

As a senior scientist with the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR), within the Administration for Community Living (ACL), U.S. Department of Health and Human Services, Dr. Campbell's primary responsibilities involve: providing scientific direction for strategic planning and priority development in the areas of aging with disability, technologies for successful aging, health promotion and health disparities, and accessible health IT; serving as a project officer for NIDILRR's grants in these areas; and coordinating NIDILRR's research capacity-building efforts for the Advanced Rehabilitation Research Training (ARRT) program. In addition, Campbell represents NIDILRR to: the Institute of Medicine Forum on Aging, Disability and Independence, the Healthy People 2020 Federal Interagency Workgroup; and the Aging and Disability Federal Collaboration Working Group, focused on accelerating research to practice across aging and disability lines. Dr. Campbell previously served as the Research Director for the NIDRR-funded Rehabilitation Research and Training Center on Aging with Disability at Rancho Los Amigos National Rehabilitation Center, Downey, CA. Advanced degrees are in Human Development and Family Studies, Cornell University (1986), and Social Relations from Lehigh University (1978).

KATHY MCCOY, PHD
National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)
Administration for Community Living (ACL)
U.S. Department of Health and Human Services

Dr. Kathleen F. McCoy is a technology and cloud consultant for the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR), formerly known as NIDRR, which is now part of the Administration for Community Living (ACL) within the U.S. Department of Health and Human

Services. Her emphasis there has been on assistive technology, accessibility, and the cloud. As part of her work with NIDILRR, she serves as the co-chair of the Interagency Committee on Disability Research (ICDR) Interagency Committee on Assistive Technology (ICAT). In addition to consulting for NIDILRR, McCoy is Professor and Chair of Computer and Information Sciences at the University of Delaware with primary interests in accessibility for people with disabilities and natural language processing. She is the co-Editor-in-Chief of Association for Computing Machinery (ACM) Transactions on Accessible Computing (TACCESS), and has held many leadership roles with respect the ACM's Special Interest Group's Annual Conference on Computers and Accessibility (including program chair and general chair).

SAMANTHA MEKLIR
Director, Division of Strategic Policy
Office of the National Coordinator for Health IT
Office of Policy
U.S. Department of Health and Human Services

Ms. Samantha Meklir directs the Division of Strategic Policy in the Office of the National Coordinator for Health IT, Office of Policy within the U.S. Department of Health and Human Services (HHS). In this role, she oversees emerging policy issues and practices for leveraging health information technology across the broader health care continuum. She joined ONC in 2015 and has been with HHS for over fifteen years; she began her federal career as a Presidential Management Intern (PMI) and worked at both HRSA and CMS in various positions focusing on Medicaid legislation and programs, health information technology and quality, and the safety net. Ms. Meklir has a bachelor's degree in American Studies from Tufts University and a master's degree from the Lyndon B. Johnson School of Public Affairs (UT Austin).

Speakers

MATTHEW ATER
Vice President, Services
Freedom Scientific

Mr. Matt Ater is the Vice President of Services for Freedom Scientific (FSI), the worldwide leader in Assistive Technology solutions for persons who are blind or who have low vision. He joined FSI to deliver new solutions to both existing and new customers. As the VP of Services, Matt works with industry and government to develop new solutions to support the blind and visually impaired community.

Mr. Ater brings over 20 years of experience in working with people with disabilities. He began his career training disabled government employees on Assistive Technology. In 1996 he joined the Columbia Lighthouse for the Blind as the Director of Assistive Technology and in 2001 he joined HumanWare as the Federal Account Manager. From 2002 through 2013 Matt worked for subsidiaries of VSE Corporation as a certified Project Manager for SSA, Treasury and other federal agencies delivering support and technology to disabled employees.

FRANK BAITMAN
Chief Information Officer
U.S. Department of Health and Human Services

Frank Baitman has held leadership positions in the private and public sectors, focusing on innovation, technology and business strategy. He is currently the Chief Information Officer with the U.S. Department of Health and Human Services (HHS) where his emphasis is on delivering improved business outcomes from the agency's IT investments. He is also co-chair of the Federal CIO Council's Privacy Committee.

Prior to joining HHS, he served as a White House Entrepreneur-In-Residence on assignment at the Food and Drug Administration, where he helped to build the Innovation Pathway 2.0. He also served as Chief Information Officer for the U.S. Social Security Administration and co-chaired the Federal CIO Council's Accessibility Committee's efforts to improve services to Americans with disabilities.

He received his Master's Degree in Public Management at the University of Maryland at College Park and his Bachelor of Arts Degree from the State University of New York at Albany.

JEROMIE BALLREICH
Doctoral Student
Johns Hopkins University

Ten years ago, Jeromie Ballreich's life dramatically changed. During his junior year of college, he suffered a spinal cord injury leaving him a C5 quadriplegic. After 6 months in the hospital, he returned to his hometown in central Pennsylvania, where he had tremendous family and community support. With their support, he focused his efforts on adapting to his disability and completing his education, while dealing with a gauntlet of medical setbacks. Since his accident, he completed his Bachelors from Lafayette College, a Masters in Health Economics from Johns Hopkins University and is currently a fourth year doctoral student in Health Economics at Johns Hopkins University. He is an active researcher working on multiple projects including economic evaluations alongside clinical trials, a project on interventions aimed at high-cost high-needs people, and his dissertation cancer drug prices. He currently resides in Baltimore, Maryland with his girlfriend Katie, and his cat Walter.

JANEY BARNES, PHD
Human Factors and Usability Specialist
User-view, Inc.

Dr. Barnes is a Human Factors and usability specialist and is principle of User-View, Inc. She has 20 years as Human Factors consultant serving diverse domains including healthcare, medical device, transportation, telecommunications, and financial. She has extensive experience with human-centered design and evaluation activities for improved health and wellness for many user groups including individuals with disabilities, older adults, and caregivers. She is a current member of HIMSS, Human Factors and Ergonomics Society, and the User Experience Professionals Association. Currently serves as a member on the HIMSS Usability Community. Dr. Barnes previously served as the Chair of the HIMSS Usability Community and served on the ONC's Health IT Implementation, Usability and Safety Workgroup.

ELAINE ANN BLECHMAN, PHD
Founder & President, Prosocial Applications, Inc.
CEO, Smart Health Records, Inc.
Professor Emerita, U. Colorado-Boulder

Dr. Blechman received her PhD from UCLA, serving as Professor of Psychology, University of Colorado-Boulder from 1990-2011, then Professor Emerita. Her work on resilience-promoting behavioral medicine has been supported by the National Institute of Mental Health and the National Institute of Drug Abuse and has resulted in 7 books and several hundred journal articles and chapters.

Dr. Blechman's focus on health IT for people coping with chronic conditions led to her service as first co-chair of the consumer empowerment technical committee, ANSI/HIMSS Health Information Technology Standards Panel, board member of the Public Health Data Standards Consortium, and representative of patient-mediated health information exchange in the Trillium Bridge, US-EU Health Information Exchange initiative.

As Founder and President of Prosocial Applications, a Colorado R&D company, Dr. Blechman directs a user-centered evaluation of how people coping with chronic conditions can use health IT to satisfy needs including self-determination, safety, spending, and symptom surveillance.

JUDY BREWER
Director, Web Accessibility Initiative
World Wide Web Consortium

Judy Brewer directs the Web Accessibility Initiative (WAI) at the World Wide Web Consortium (W3C). Her work includes coordinating development of accessibility guidelines for Web content, browsers, mobile, and authoring tools; improvement of resources for evaluation of Web sites; development of education and outreach resources; exploration of research which may impact future Web accessibility; and promoting harmonization of web accessibility standards internationally. WAI standards and guidelines are used by many governments and organizations around the world to help ensure equal access to the Information Society for people with disabilities. She is a principle research scientist at MIT's Computer Science and Artificial Intelligence Laboratory. Prior to joining W3C, she worked on initiatives to increase access to assistive technology and mainstream information and communications technology. Recent awards include the Newell Perry Award from the National Federation of the Blind in 2014, and the Migel Medal from the American Foundation for the Blind in 2015.

TIFFANI J. BRIGHT, PHD
Senior Service Fellow
Center for Evidence and Practice Improvement
Agency for Healthcare Research and Quality (AHRQ)
U.S. Department of Health and Human Services

Tiffani J. Bright is a Senior Service Fellow at the Agency for Healthcare Research and Quality (AHRQ) in the Center for Evidence and Practice Improvement. As a member of the Division of Health IT, her work focuses on clinical decision support (CDS), mobile health (mHealth), and dissemination of patient-centered outcomes research (PCOR) findings. Dr. Bright leads the mHealth grant portfolio, which is supporting the development and evaluation of novel approaches using mHealth tools to disseminate PCOR findings into clinical practice. She is also co-leading a CDS initiative to disseminate and implement PCOR findings through CDS. Prior to joining AHRQ, Dr. Bright served as the Director of Medical Informatics, Surveillance, and Epidemiology at the Bureau of Correctional Health Services for the New York City Department of Health and Mental Hygiene. Dr. Bright received her doctorate in biomedical informatics from Columbia University.

JODI G. DANIEL, JD, MPH

Director, Office of Policy
Office of the National Coordinator for Health Information Technology (ONC)
U.S. Department of Health and Human Services

Ms. Jodi G. Daniel serves as Director of the Office of Policy, in the Office of the National Coordinator for Health Information Technology (ONC), at the Department of Health and Human Services (HHS). She leads ONC's regulatory activities to develop standards and certification criteria for electronic health records. Ms. Daniel developed HHS's foundational legal strategies for health IT, as the first Senior Counsel for Health Information Technology in the Office of the General Counsel of HHS. Ms. Daniel played a central role in developing health information privacy policies and drafting the HIPAA Privacy Rule and Enforcement Rule, as an Attorney in the Civil Rights Division of the Office of General Counsel. Ms. Daniel earned a law degree from Georgetown University and a Master's in Public Health from Johns Hopkins University.

CAITLIN (CAITIE) BLOOD, MPH
Fellow
HealthyPeople.gov and Healthy People 2020 outreach

Caitie Blood is the Healthy People Communication Fellow with the Office of Disease Prevention and Health Promotion. She works on HealthyPeople.gov and Healthy People 2020 outreach and promotion efforts. She recently received her MPH in Behavioral Science and Health Education from the Rollins School of Public Health at Emory University and is a Certified Health Education Specialist. Her interests include health communication, health information technology, chronic disease prevention, and social marketing.

CAROL J. BRADLEY, JD
Disability Access/504 Officer
Sutter Health

Ms. Bradley has 20+ years of experience in disability, disability access, and leadership. She developed a disability compliance program for Sutter Health, a California comprehensive not-for profit healthcare system. Key elements included:

- Training thirty care-level ADA Coordinators on all aspects of disability access,
- Accessible medical equipment surveys, standards, and purchasing,
- Collaborating with the web team on the disability access responsibilities and implementation into on-going operations
- Consulting with the facilities, construction, and plant operations professionals on disability access requirements in the physical environment

Ms. Bradley served as a member of the Access Board's Medical Diagnostic Equipment Advisory Committee responsible for recommendations on national standards for medical equipment accessibility. She served as the ADA Coordinator for the City of Sacramento, and ran several non-profit organizations providing services to people with disabilities. She has trained on a variety of topics over her career including all aspects of disability access--Titles I-III.

DAVID (DAVE) H. GUSTAFSON, PHD

Professor
University of Wisconsin-Madison
Center for Health Enhancement Systems Studies

Dr. Gustafson directs the University of Wisconsin−Madison's Center for Health Enhancement Systems Studies, which includes the national program office for the Network for Improvement of Addiction Treatment, and Center of Excellence on Active Aging Research (Agency for Healthcare Research and Quality). His research interests focus on developing systems engineering tools to support sustainable individual and organizational improvement. HIs individual change research develops and tests computer systems to help people deal with significant issues affecting quality of life including addiction, cancer and aging. He published over 270 reviewed publications including seven books. He is a member of the National Academy of Engineering, and Fellow of the Association for Health Services Research, the American Medical Informatics Association, the WK Kellogg Foundation and the Institute for Healthcare Improvement, which he co-founded and was board vice-chair. He co-chaired the federal Science Panel on Interactive Communications in Health and serves on NIH's Dissemination and Implementation in Health Study Section.

GAIL GIBSON HUNT
President and Chief Executive Officer
National Alliance for Caregiving

Gail Gibson Hunt is the founder, President and CEO of the National Alliance for Caregiving and a member of the Patient Centered Outcomes Research Institute (PCORI) Board of Commissioners. Established in 1996, the National Alliance for Caregiving is a nonprofit coalition of national organizations focused on advancing family caregiving through research, innovation and advocacy. To learn more, please visit www.caregiving.org.

DEAN KARAVITE
Lead Human Computer Interaction (HCI) Specialist
The Children's Hospital of Philadelphia (CHOP)

Dean Karavite is the Lead Human Computer Interaction (HCI) Specialist at The Children's Hospital of Philadelphia (CHOP), Department of Biomedical and Health Informatics (DBHi).

He has fifteen years' experience at three major academic medical centers applying information technology to clinical research with a focus on improving outcomes while simultaneously applying HCI methods in improving the usability of these systems for clinicians, patients and families. His work has been applied to a number of clinical areas including cardiology, surgery, and pediatrics. Dean has participated in dozens of funded studies and is a contributing author on over 20 peer-reviewed articles. He has also worked outside of healthcare including IBM, User Centered Design Services, and as a consultant in developing assistive technology solutions for people with severe disabilities. Dean has a Masters in Information Science with a concentration in HCI from the University of Michigan, School of Information.

RAJA KUSHALNAGAR, JD, LLM, PHD
Assistant Professor
National Technical Institute for the Deaf, Rochester Institute of Technology

Dr. Kushalnagar is an Assistant Professor in the Information and Computing Studies Department at the National Technical Institute for the Deaf at the Rochester Institute of Technology in Rochester, NY. He teaches information and computing studies courses.

His research interests focus on the intersection of disability law, accessible technology, and human-computer interaction. He is focused on enhancing accessibility to multimedia content for deaf and hard of hearing consumers.

He worked in industry for over five years before returning to academia and disability law policy. Towards that end, he completed a J.D. and LL.M. in disability law, and an M.S. and Ph.D. in Computer Science. He served on the Federal Communications Commission's Consumer Advocacy Commission. He has published several peer-reviewed publications in accessible technology, and at the intersection of disability and intellectual property law. He has received several grants related to accessible computing. He can be reached at raja.kushalnagar@gmail.com.

LARRY L. LEWIS, JR.
Management Analyst, Section 508 Office
U.S. Department of Veterans Affairs

Congenitally blind, Mr. Larry Lewis was mainstreamed into the public school system where the instructions he received made him a fluent Braille reader and writer and a strong advocate for Braille literacy for students who cannot affectively access large print. A Master of Arts in English has imparted to him the necessity for both written and verbal skill-sets. A Master of Science in Special Education (Blind Rehabilitation) has broadened his once myopic perspective of persons who are blind and visually impaired as well as persons who have secondary disabilities.

Mr. Lewis has been employed in both International product and sales management capacities for leading manufacturers in the adaptive technology industry. He is the Founder of Flying Blind LLC, which provide consulting, website remediation, training, and reselling services. In July, 2013 Mr. Lewis joined the VA's Section 508 Office where he oversees its Section 508 testing of Mobile Content Developed for its employees and Veterans.

DAVID A. LINDEMAN, PHD
Director of Health
Center for Information Technology Research in the Interest of Society (CITRIS)
Director
UC Berkeley, Center for Technology and Aging (CTA)

Dr. Lindeman is Director Health, Center for Information Technology Research in the Interest of Society (CITRIS), UC Berkeley and Director, Center for Technology and Aging (CTA). He has worked in the field of aging, disabilities and long-term care for over 30 years as a health services researcher and gerontologist, focusing on health care technology, chronic disease/dementia, disability, community-based/residential services, workforce, caregiving, and public policy. His current research focuses on the incubation, development, and scaling of mHealth, sensor, telehealth, data analytic, and precision medicine initiatives that address critical health care challenges covering the continuum of aging and disability issues, ranging from prevention to complex chronic conditions. Dr. Lindeman previously served as the founding Director Mather LifeWays Institute on Aging; Associate Professor of Health Policy, Rush University; and Co-Director, UC Davis Alzheimer's Disease Center. He serves as an advisor to government agencies, foundations, businesses, and venture firms.

SHARON LEWIS
Principal Deputy Administrator
Administration for Community Living (ACL)
U.S. Department of Health and Human Services

Sharon Lewis serves in the dual roles of Principal Deputy Administrator of the Administration for Community Living, as well as HHS Secretary Burwell's Senior Advisor on Disability.

From March 2010 to November 2013, Ms. Lewis served as the Commissioner of the Administration on Intellectual and Developmental Disabilities. Prior to her appointment as Commissioner, she served as the Senior Disability Policy Advisor to U.S. House Committee on Education & Labor, advising members of the Committee on legislative strategy and disability-related policy issues in education, employment and healthcare, and as a Kennedy Public Policy Fellow for U.S. Senate Subcommittee on Children & Families. Sharon is the recipient of numerous awards, including the 2010 Distinguished Leadership in National Disability Policy Award and the Consortium for Citizens with Disabilities Chairman's Award.

In Oregon, Sharon worked on public policy for the Oregon Developmental Disabilities Coalition and for the Arc. She served as the co-chair of the Oregon Family Action Coalition Team, founded DisabilityCompass.org and managed the Oregon Partners in Policymaking Program, working with individuals with disabilities and family members to participate in policy decisions at all levels. Sharon is a parent to three daughters, including one with disability. She is a native of Michigan and a graduate of Washington University in St. Louis.

AMANDA MAISELS, JD
Deputy Chief
U.S. Department of Justice – Disability Rights

Amanda Maisels is a Deputy Chief in the Disability Rights Section of the U.S. Department of Justice and has worked in the disability rights arena for 16 years. The Disability Rights Section enforces Titles I, II, and III of the Americans with Disabilities Act (ADA). Ms. Maisels has handled a variety of cases enforcing the ADA and oversees enforcement work addressing accessible technology, employment discrimination, and other areas. Some of the more notable matters she has worked on include a lawsuit against the state of New York involving institutionalization of adults with mental illness, and a settlement agreement with edX, Inc., a provider of Massive Open Online Courses, regarding the accessibility of its website, platform and mobile applications for individuals with visual and other disabilities.

Ms. Maisels graduated from Harvard Law School and clerked for Judge Henry H. Kennedy, Jr. on the U.S. District Court for the District of Columbia.

MARY LOU MENDEZ
Management Analyst, Section 508 Office
U.S. Department of Veterans Affairs

As a member of the VA Section 508 team, M. Mary Lou Mendez supports project teams in developing accessible products. She currently coordinates the development of e-learning courses and other web-based resources to teach VA employees and contractors about various aspects of Section 508. She edits the "508 Xpress" newsletter produced by the VA Section 508 Office.

Prior to joining the Section 508 team, she served as a Visual Impairment Services Team (VIST) Coordinator at a VA Medical Center, where she used assistive technology to access computerized patient records as part of her job, providing counseling, assessment and training to legally blind veterans

Ms. Mendez received a Master's Degree in Rehabilitation Counseling from Syracuse University and a Bachelor of Arts Degree from the State University of New York at Potsdam.

WENDY NILSEN, PHD
Program Director
Smart and Connected Health Program
National Science Foundation

Dr. Nilsen is Program Director for the Smart and Connected Health program at the National Science Foundation. Her work focuses on the intersection of computing, technology and health. This includes a wide range of methods for data collection, data analytics, data visualization and turning data to knowledge through effective and efficient human-computer interfaces. More specifically, her efforts in this area of research include: serving as the lead for the NSF/NIH Smart and Connected Health announcement, serving as co-chair of the National Information and Technology Research and Development's Health Information Technology Community of Practice, convening meetings to address methodology in mobile technology research; serving on numerous federal technology initiatives; and, leading training institutes.

BAMBANG PARMANTO, PHD
Professor
Health Information Management and Biomedical Informatics
University of Pittsburgh

Dr. Parmanto is Professor of Health Information Management and Biomedical Informatics at the University of Pittsburgh. He is the Director of the Rehabilitation Engineering Research Center (RERC) on Information & Communication Technology (ICT) Access, a center funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). He is Director of the Health and Rehabilitation Informatics Lab, an interdisciplinary lab that focuses on developing accessible telehealth & mobile health technologies for supporting self-management and improving health of individuals with chronic and complex conditions such as persons with disabilities. He has been working in the area of Web accessibility and telehealth in the past 15 years.

WILLIAM PETERSON
Executive Director, Office of Accessible Systems & Technology
U.S. Department of Homeland Security

Mr. William Peterson is Executive Director of the Office of Accessible Systems & Technology at the U.S. Department of Homeland Security (DHS) that is responsible for improving the usability and accessibility of the Department's electronic and information technologies. Mr. Peterson came to DHS after spending more than 8 years at the National Institute on Disability and Rehabilitation Research (NIDRR) where he served as one of NIDRR's principal scientific program managers for national and international programs in the areas of biomedical and rehabilitation engineering. While at NIDRR, he managed the agency's $20 million Rehabilitation Engineering Research Center (RERC) program and served as program officer for numerous projects pertaining to universal design, accessible technology and engineering. Mr. Peterson is the founding Co-Chair of the Interagency Committee on Disability Research, Subcommittee on Technology where he served from 1996 to 2005. Mr. Peterson came to NIDRR from the National Rehabilitation Hospital where he directed the Rehabilitation Engineering Department. Mr. Peterson holds both a bachelor's degree and a master's degree in Biomedical Engineering from Arizona State University.

JOHN G. PARÉ, JR.
Executive Director for Advocacy and Policy
National Federation for the Blind

Mr. Paré is the Executive Director for Advocacy and Policy at the National Federation of the Blind. In this position he oversees the continuing growth of NFB-NEWSLINE®, the largest electronic newspaper service in the world, and the Federation's national Governmental Affairs and Public Relations offices. He has testified before the House of Representatives Committee on Appropriations Legislative Branch Subcommittee regarding library services for blind Americans. He has also appeared on CNN, Fox, BBC, and various radio programs to discuss issues affecting blind Americans. He has testified before the United Nations World Forum for Vehicle Harmonization regarding the dangers posed by silent vehicles.

MARK D. RICHERT, ESQ.
Director of Public Policy & Senior Advisor
American Foundation for the Blind (AFB)

Mark Richert serves as the Director of Public Policy and Senior Advisor for Strategic Initiatives for the American Foundation for the Blind (AFB). He is AFB's primary representative before the U.S. Congress and Executive Branch agencies, and is responsible for the development and implementation of AFB's public policy, policy research and strategic partnerships. Prior to joining AFB, he was the Executive Director of the Association for Education and Rehabilitation of the Blind and Visually Impaired.

Over the course of his career, he has been a strong advocate for people with vision loss. He has crafted provisions of copyright law establishing the right to reproduce copyrighted works in specialized formats and authored critical legislation, the Alice Cogswell and Anne Sullivan Macy Act, which would bring sweeping reforms to America's special education system for students with sensory disabilities. Mr. Richert is a graduate of the George Washington University National Law Center and lives in Arlington, Virginia.

JAMES RIMMER, PHD
Professor, School of Health Professions
Lakeshore Foundation Endowed Chair in Health Promotion and Rehabilitation Sciences
University of Alabama at Birmingham

Dr. James Rimmer is a Professor in the School of Health Professions and the first Lakeshore Foundation Endowed Chair in Health Promotion and Rehabilitation Sciences at the University of Alabama at

Birmingham. His research interests explore the use of new and emergent technologies in developing biobehavioral and environmental strategies to promote beneficial physical activity and healthful weight management in people with disabilities. He and his technology team have developed a web-based health risk appraisal (HRA) and wellness coaching platform that includes rich-tailored messaging support (telephone, Internet, text message, video) to provide a flexible, cost-effective health promotion delivery system nationwide for weight management and improvement in various health outcomes. Dr. Rimmer directs two federally funded centers, the National Center on Health, Physical Activity and Disability and the Rehabilitation Engineering Research Center on Interactive Exercise Technologies and Exercise Physiology for People with Disabilities. He was recently appointed Chair of the Science Board of the President's Council on Fitness, Sports and Nutrition.

MADELEINE ROTHBERG
Project Director
WGBH National Center for Accessible Media

Madeleine Rothberg works to ensure that technology is accessible to all users, including people with disabilities. She focuses on providing access to multimedia and information technology both through directly accessible solutions such as captions, talking software, and audio description, and through improvements to infrastructure such as interoperability standards. Madeleine leads the Accessible Designs for Personal Health Records Project. She co-chairs the IMS Global Accessibility Working Group and contributes to the accessibility metadata effort for Schema.org. Personal health records, digital libraries, assessment questions, STEM textbooks -- we can improve them all with accessibility and usability.

CAROLINE RYAN
Social Science Analyst
Office of Integrated Care Innovations
Administration for Community Living (ACL)

Caroline Ryan is a Social Science Analyst in the Office of Integrated Care Innovations at the Administration for Community Living (ACL). At ACL, Caroline analyzes policy trends and advances innovative program strategies related to care transitions, health care, health information technology, aging, and disability. She also has experience designing, implementing and evaluating community-based care transitions programs, and as a 2009 Practice Change Fellow, she created a transition program for Medicare beneficiaries in observation status.

KEL SMITH
Principal
Anikoto, LLC

Kel Smith is Principal of Anikto, LLC. and a longtime author, speaker and practitioner in digital accessibility and e-health. His articles have appeared in numerous publications, with over presentation credits spanning 100 cities in seven countries. Kel has appeared on CBC Radio's "The Current," Yahoo News, the Globe & Mail Canada, WBAL Radio and the BBC, among others. He is the author of the book Digital Outcasts: Moving Technology Forward Without Leaving People Behind, published by Morgan Kaufmann in 2013. He lives and works in Philadelphia and New York City.

MICHAEL R. SMITH, MPA
Director
Division of Community Systems Transformation
Disabled and Elderly Health Programs Group
Center for Medicare and Medicaid Services

As the Director of the Division of Community Systems Transformation in the Disabled and Elderly Health Programs Group at the Centers for Medicare & Medicaid Services, Mike is responsible for directing the division's grant programs and the efforts to diffuse learning from the demonstrations into Medicaid programs. Prior to employment with CMS, he served in leadership capacities within county, state and non-profit organizations as a deputy administrator, chief of staff and executive director respectively. Integrating community based Medicaid funded programs and service into the fabric of everyday life for people with disabilities is the focus of his career. He has an undergraduate degree in psychology with a minor in industrial organizational psychology from California University of Pennsylvania and a graduate degree in public administration from Kutztown University of Pennsylvania.

MARYANNE STERLING, CEA
Co-founder
Connected Resources

MaryAnne Sterling is the Co-founder of Connected Health Resources, focused on healthcare transformation through the eyes of patients and their families. She serves as Ambassador for the Patient Centered Outcomes Research Institute (PCORI), serves on the ONC Health IT Policy Committee's Consumer Workgroup, and is a former Executive in Residence for the HIMSS Foundation, Institute for e-Health Policy.

Ms. Sterling has been a caregiver and advocate for her aging parents for 18+ years. She is a renowned speaker and educator on family caregivers and their health information technology needs and often shares her experience with multiple parents struggling with dementia. Her personal story has been featured in Kiplinger, New York Times, USA Today, and the Wall Street Journal.

She received her Bachelor's Degree in Biology and Biotechnology from the University of Nebraska at Omaha.

JOHN TSCHIDA
Director
National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)
Formerly National Institute on Disability and Rehabilitation Research (NIDRR)

John Tschida has spent the last 15 years using data and research to drive policy change. He comes to NIDILRR from Allina Health in Minnesota, where he served as director of public policy and innovation. In this role, he was developing integrated health delivery systems and financing models for people with disabilities. Allina Health recently merged Courage Center, Minnesota¹s leading nonprofit rehabilitation service provider, where for 14 years Mr. Tschida led a public policy and research team that focused on defining and achieving better outcomes for complex populations. His team received one of the first Health Care Innovation Awards distributed by CMMI at CMS. Prior to joining Courage Center, Mr. Tschida served as a research fellow at the National Rehabilitation Hospital Center for Health and

Disability Research. Earlier in his career, he served as assistant director of the Minnesota House of Representatives Public Information Office. A graduate of Macalester College, Mr. Tschida holds a Master¹s degree in Public Policy and Health Services Research certificate from Georgetown University.

MUHAMMAD F. WALJI, PHD
Associate Dean/Professor
UTHealth School of Dentistry
Associate Director
National Center for Cognitive Informatics and Decision Making in Healthcare (NCCD)

Dr. Walji is the Associate Dean for Technology Services and Informatics and Professor of Diagnostic and Biomedical Sciences at the UTHealth School of Dentistry. He also serves as the Associate Director at the National Center for Cognitive Informatics and Decision Making in Healthcare (NCCD), which is located at the UTHealth School of Biomedical Informatics. The center was funded through the ONC SHARP project to help conduct short and long term research to address urgent issues that relate to designing usable electronic health records.

Dr. Walji's research interests are focused on using informatics approaches to improve the safety of healthcare, with a particular focus on electronic health records. As part of the SHARPC project he was a co-project leader that developed the TURF EHR usability framework and the Turf EHR Usability Software tool. He also leads multi-institutional teams that are developing a patient safety system for dentistry and the BigMouth Dental Data Repository.

FRANCES W. WEST
Chief Accessibility Officer
IBM

Frances West is the IBM Chief Accessibility Officer. In this role, she works to establish IT accessibility standards, shape government policies, and develop human-centric technology and industry solutions that not only create an inclusive workplace environment but are designed to personalize the user experience so that all people reach their highest potential in work and life.

Ms. West is a globally-recognized expert in enabling human ability through accessible information and communications technology (ICT). She regularly speaks at policy forums, has testified on behalf of the IT industry to the U.S. Senate Committee on Foreign Relations, and currently sits on the Board of Directors of the World Institute on Disability and is the board advisor to the National Business & Disability Council.

Appendix E: Co-Chairs and Steering Committee

ICAT and Steering Committee Leadership

DAVID BAQUIS
ICAT Co-Chair
U.S. Access Board

MARGARET CAMPBELL
Steering Committee Co-Chair
National Institute on Disability, Independent Living,
and Rehabilitation Research (NIDILRR)

KATHY MCCOY
ICAT Co-Chair, Steering Committee Co-Chair
National Institute on Disability, Independent Living,
and Rehabilitation Research (NIDILRR)

SAMANTHA MEKLIR
Steering Committee Co-Chair
Office of the National Coordinator for Health Information Technology (ONC)

Members

KARL D. COOPER
American Association on Health and Disability (AAHD)
National Disability Navigator Resource Collaborative (NDNRC)

SCOTT CORY
Administration for Community Living

ALOK DOSHI
Centers for Medicare & Medicaid Services (CMS)
The Center for Consumer Information & Insurance Oversight (CCIIO)
Currently on detail at Federal Communications Commission (FCC)

LINDA HARTMAN
University of Pittsburgh

DENNIS HEAPHY
Disability Policy Consortium

ROBERT JARRIN
Qualcomm

DEBORAH KAPLAN
Office of the Chief Information Officer (OCIO)
Department of Health and Human Services (HHS)

MATT QUINN
Intel Corporation

MARY RODGERS
National Institute of Biomedical Imaging and Bioengineering (NIBIB)
National Institutes of Health (NIH)

MIKE SMITH
Center for Medicaid and CHIP Services (CMCS)
Disabled and Elderly Health Programs Group (DEHPG)

TERESA ZAYAS CÁBAN
Agency for Healthcare Research and Quality (AHRQ)

Appendix F: List of Attendees

LAST NAME	FIRST NAME	AFFILIATION	EMAIL
Ater	Matthew	Freedom Scientific	mater@freedomscientific.com
Baitman	Frank	U.S. Department of Health and Human Services	frank.baitman@hhs.gov
Ballreich	Jeromie	Johns Hopkins University	jballre2@jhu.edu
Baquis	David	U.S. Access Board	baquis@access-board.gov
Barnes	Janey	User-View, Inc.	jbarnes@user-view.com
Bishop	Jason	West Virginia University	jcbishop@mail.wvu.edu
Blechman	Elaine	Prosocial Applications, Inc.	eblechman@thesmartphr.com
Blood	Caitie	ODPHP, HHS	csblood489@gmail.com
Bradley	Carol	Sutter Health	bradlec1@sutterhealth.org
Brewer	Judy	World Wide Web Consortium (W3C)	jbrewer@w3.org
Bright	Tiffani	Agency for Healthcare Research and Quality	tiffani.bright@ahrq.hhs.gov
Campbell	Margaret	NIDILRR	margaret.campbell@acl.hhs.gov
Chauvin	George	Allscripts	george.chauvin@allscripts.com
Cooper	Karl	American Association on Health & Disability	kcooper@aahd.us
Daniel	Jodi	HHS/ONC	jodi.daniel@hhs.gov
Doshi	Alok	Office of Strategic Planning & Policy Analysis, FCC	alok.doshi@fcc.gov
Fuller	Sherrilynne	University of Washington	sfuller@u.washington.edu
Gill	Roy	NextGen Healthcare	rgill@nextgen.com
Gustafson	David	University of Wisconsin	dhgustaf@wisc.edu
Hunt	Gail	National Alliance for Caregiving	gailhunt@caregiving.org
Hunter	Julie	IBM	hunterj@us.ibm.com
Jarrin	Robert	Qualcomm Incorporated	rjarrin@qualcomm.com
Kaplan	Deborah	Office of the CIO, HHS	Deborah.Kaplan@hhs.gov
Karavite	Dean	The Children's Hospital of Philadelphia	karavite@email.chop.edu
Kushalnagar	Raja	Rochester Institute of Technology	rskics@rit.edu
Lewis	Larry	Department of Veterans Affairs	larry.lewis3@va.gov
Lewis	Sharon	NIDILRR/ ACL	sharon.lewis@acl.hhs.gov
Lindeman	David	University of California, Berkeley	dlindeman@berkeley.edu
Maisels	Amanda	Department of Justice	amanda.maisels@usdoj.gov
Makar	Ellen	AHRQ/CEPI	Ellen.Makar@ahrq.hhs.gov
Marlowe	Dana	Accessibility Partners	DMarlowe@AccessibilityPartners.com
McCoy	Kathy	NIDILRR	kathy.mccoy@ed.gov

LAST NAME	FIRST NAME	AFFILIATION	EMAIL
Meklir	Samantha	ONC	samantha.meklir@hhs.gov
Mendez	Mary Lou	Department of Veterans Affairs	marylou.mendez2@va.gov
Morin	Gary	HHS NIH OCIO	moring@mail.nih.gov
Nilsen	Wendy	National Science Foundation	wnilsen@nsf.gov
Palena Hall	Liz	ONC	elizabeth.palenahall@hhs.gov
Paré	John	National Federation of the Blind	jpare@nfb.org
Parmanto	Bambang	University of Pittsburgh	parmanto@pitt.edu
Peterson	William	DHS	Bill.peterson@dhs.gov
Phipps	Joshua	CityMouse	phipps@citymouse.com
Quinn	Matthew	Intel	matthew.quinn@intel.com
Reed	Becky	Healthwise	breed@healthwise.org
Richert	Mark	American Foundation for the Blind	4justice@4justice.cnc.net
Rimmer	James	University of Alabama at Birmingham/Lakeshore Foundation	jrimmer@uab.edu
Roberts	Darryl	Battelle Memorial Institute	robertsdw@battelle.org
Rosenblatt	Sharon	Accessibility Partners	srosenblatt@accessibilitypartners.com
Rothberg	Madeleine	National Center for Accessible Media at WGBH	madeleine_rothberg@wgbh.org
Ryan	Caroline	Administration for Community Living	caroline.ryan@acl.hhs.gov
Sheffield	Rebecca	American Foundation for the Blind	rsheffield@afb.net
Smith	Michael	CMS	michael.smith1@cms.hhs.gov
Smith	Kel	Anikto LLC	Kel.Smith@anikto.com
Spohn	George	Ai Squared	gspohn@aisquared.com
Sterling	MaryAnne	Connected Health Resources	msterling@connectedhealthresources.com
Thirumalai	Mohanraj	University of Alabama at Birmingham	mohanraj@uab.edu
Ulrich	Linda	HHS	linda.ulrich@fda.hhs.gov
Vanderheiden	Gregg	Trace R&D Center	gregg@raisingthefloor.org
Walji	Muhammad	UTHealth School of Dentistry at Houston	muhammad.f.walji@uth.tmc.edu
West	Frances	IBM	fwest@us.ibm.com
Williamson	Michelle	CDC	mwilliamson@cdc.gov

Appendix G: About the ICDR

Mission

The Interagency Committee on Disability Research (ICDR) promotes coordination and cooperation among federal departments and agencies conducting disability, independent living, and rehabilitation research programs. The ICDR was established by the 1973 Rehabilitation Act, as amended by the Workforce Innovation and Opportunity Act in 2014. The specific duties of the ICDR are to:

- Identify, assess, and seek to coordinate all federal programs, activities, and projects, and plans for such programs, activities, and projects with respect to the conduct of research related to disability and rehabilitation research, including independent living, assistive technology, and universal design research;
- Obtain input from policymakers, representatives from federal agencies, individuals with disabilities, organizations representing individuals with disabilities, researchers and providers;
- Share information about research being carried out by members of the Committee and other federal departments and organizations;
- Identify and make efforts to address areas of research that are not being adequately addressed;
- Identify and establish clear research priorities;
- Promote interagency collaboration and joint research activities and reduce unnecessary duplication of effort;
- Optimize the productivity of Committee members through resource sharing and other cost-saving activities; and
- Develop a comprehensive government wide strategic plan for disability, independent living, and rehabilitation research.

Organizational Structure

To achieve its mission, the ICDR is organized into an Executive Committee and five standing committees.

Executive Committee

The ICDR is chaired by the Secretary of the U.S. Department of Health and Human Services or her designee. The authorizing statute identifies the leadership from 16 other departments, agencies and offices, as well as others the President may designate, as statutory members who provide leadership and oversight for the committee. Statutory members include:

- Secretary of Health and Human Services,
- Director of National Institute on Disability, Independent Living, and Rehabilitation Research,
- Commissioner of Rehabilitation Services Administration,
- Assistant Secretary of Special Education and Rehabilitative Services,
- Assistant Secretary of Labor for Disability Employment Policy,
- Secretary of Defense,
- Administrator of Administration for Community Living,
- Secretary of Education,
- Secretary of Veterans Affairs,
- Director of National Institutes of Health,

- Director of National Institute of Mental Health,
- Administrator of National Aeronautics and Space Administration,
- Secretary of Transportation,
- Assistant Secretary of the Interior for Indian Affairs,
- Director of Indian Health Service,
- Director of National Science Foundation, and
- Administrator of Small Business Administration.

Other federal departments, agencies and offices can designate representatives to the ICDR as non-statutory members. ICDR standing committee co-chairs also participate. The Executive Committee meets quarterly.

Standing Committees

Standing committees carry out many of the ICDR duties, in their specific area of interest. Each standing committee is led by volunteer co-chairs representing different agencies. Membership is open to federal employees and external stakeholders. Standing committees meet regularly.

Standing committees can be created or discontinued in response to ICDR priorities. The current Standing committees are focused on five topical areas:

- Assistive Technology,
- Disability Statistics,
- Employment,
- Medical Rehabilitation, and
- Health and Health Disparities.

About the ICAT

Leadership:

- Kathy McCoy, PhD, National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)
- David Baquis, U.S. Access Board

The goal of the Interagency Committee on Disability Research (ICDR) is to create and maintain a sustainable interagency coordination network on disability, rehabilitation, and independent living research. The ICDR currently maintains five standing committees, including the Interagency Committee on Assistive Technology (ICAT).

The ICAT identifies, assesses, and seeks to coordinate all federal programs and activities regarding the range of federal assistive technology (AT) research, as well as research that incorporates the principles of universal design. Additionally, the ICAT:

- identifies and makes efforts to address research gaps;
- identifies and establishes clear research priorities related to assistive technology research and research that incorporates the principles of universal design;
- promotes interagency collaboration and joint research activities;

- works to reduce unnecessary duplication of effort regarding these types of research within the federal government; and
- optimizes the productivity of subcommittee members through resource sharing and other cost-saving activities.

For More Information

The ICDR welcomes the participation of federal representatives, researchers, individuals with disabilities and their representatives and others with an interest in disability, independent living, and rehabilitation research. More information about the ICDR can be found at ICDR.acl.gov or by sending an email to ICDRinfo@neweditions.net.