



Office of the National Coordinator
for Health Information Technology

PRE-WORK: Discovery Workshop on eConsent: From Birth to End of Life

AUGUST 16, 2022, 1:20PM – 2:00PM

DISCOVERY WORKSHOP DESCRIPTION AND BREAKOUT SESSION FOCUS

The use of **technology** to enable electronic consent (eConsent) for how and when a person’s electronic health information (EHI) is shared is central to placing patients in control of decisions regarding their data.

The focus of the breakout session is to document **technical** standards, workflows and or solutions to enable the electronic capture and sharing of consent decisions for the exchange of all or a portion of EHI.

When you registrated for the workshop, you selected a breakout troom to join. In this packet you will find five personas for each breakout room, their corresponding moderators , as well as example questions that may be asked during the session.

Please use this packet to prepare for your breakout session.

SCENARIO DISCUSSION QUESTIONS:

Each scenario contains three different use cases. A request for EHI from:

- a healthcare provider (HIPAA covered entity or their business associate)
- a non-healthcare provider (non-HIPAA covered entity)
- an individual

Who has the EHI	Healthcare Provider or their business associate (HIPAA covered entity provider or their business associate)											
Who is the EHI going to	Healthcare provider				Non-Healthcare				Individual/Guardian/Proxy			
Who needs to Consent	Individual		Guardian/Proxy		Individual		Guardian/Proxy		Individual		Guardian/Proxy	
What Portion of EHI	All EHI	Some EHI	All EHI	Some EHI	All EHI	Some EHI	All EHI	Some EHI	All EHI	Some EHI	All EHI	Some EHI

DISCUSSION POINTS FOR THE BREAKOUT SESSION:

Technical Standards

What technical standards are used to electronically:

- 1) Capture consent decisions?
- 2) Share consent decisions?
- 3) Specify which portion of EHI (all or some)?



Workflows

Describe workflows that exist today to support electronic capture and sharing of consent decisions:

- 1) Within the same system?
- 2) Between different systems?
- 3) Facilitated by third party apps
 - a. Is this the patient's app or the providers app?
- 4) Is there an IDEAL scenario to enable electronic capture and sharing of consent decisions?

What solutions are you using to

- 1) Capture consent decisions?
- 2) Share consent decisions?
- 3) Specify which portion of EHI (all or some)?

Additional points for discussion

- 1) Critical use cases, barriers, or enabling factors.
- 2) Are there special circumstances to consider?

BREAKOUT ROOMS

These are not real scenarios. Fictitious names and organizations used for discussion purposes only.

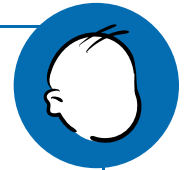
Moderated by:



Sue Kressly MD
FAAP



LaVerne Perlie
MSN BSN RN



BIRTH/+MATERNAL

Caden Jones*, (20 Weeks Old)/ Samantha Jones (40 Years Old)

Healthcare Provider to Healthcare Provider: Caden was born with neonatal abstinence syndrome and receives care from three separate specialists. One of his specialists, Dr. Oliver, has requested a copy of Caden's immunization records from ABC Health System Hospital where he was born.

Healthcare Provider to Court (Non-HIPAA Covered Entity): Judicial proceedings to settle custody are underway between Caden's parents, Mr. and Mrs. Jones. The court has requested drug screening lab results for both Caden and Mrs. Jones from Caden's newborn stay at ABC Health System Hospital.

Healthcare Provider to Individual (Parent): Mrs. Jones, would like to keep her own record of Caden's care. She has requested copies of Caden's medical records from ABC Health System Hospital. She does not want any of her own medical information from his delivery included in this request.

*Fictitious names and organizations used





Moderated by:



Kristine McCoy
MD MPH



Angelina Sulaka
Esq.



CHILDHOOD

Stew Dexter*, (10 Years Old)

Healthcare Provider to Healthcare Provider (HIPAA covered entities/business associate): Stew begins exhibiting behavioral problems at home and at school and starts to see a child psychiatrist, Dr. Fondo. His pediatrician has just requested a copy of Stew's evaluation and plan of care from Dr. Fondo.

Healthcare Provider to School (Non-HIPAA Covered Entity): The psychiatrist at Stew's elementary school, Dr. Moore, requests a copy of Stew's original intake and assessment forms from Dr. Fondo.

Healthcare Provider to Individual (Parent): Mrs. Dexter is concerned that the school and Dr. Fondo do not have the same information and has requested a copy of Stew's records from Dr. Fondo. She will compare them to the records she has from the school.

*Fictitious names and organizations used

Moderated by:



Hannah Galvin
MD FAAP FAMIA



Liz Turi M. Eng
CPHIMS



ADOLESCENCE

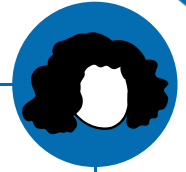
Alyssa Wright*, (17 Years Old)

Healthcare Provider to Healthcare Provider (HIPAA covered entities/business associate): Last fall, Alyssa suffered a sports related injury while playing soccer. While her recovery was going smoothly, she is now experiencing returning symptoms. Her mother has decided on a second opinion with a new orthopedic specialist, Dr. Rothschild. Dr. Rothschild has requested a copy of Alyssa's medical record from her previous specialist.

Healthcare Provider to Summer Camp Employer (Non-HIPAA Covered Entity): Alyssa will be a junior camp counselor at a sleep away camp this summer. Her employer requests a medical physical be completed as a condition of employment. Her employer requests that her pediatrician share her medical physical report with her employer.

Healthcare Provider to Individual: Alyssa downloads a new wellness health app, that is popular with the girls at her school. She wants to populate the medical health section of the app with her medical test results from her last visit to her PCP. She follows the app's links and instructions for the app to send an electronic request to her PCP for the test results.

*Fictitious names and organizations used



Moderated by:



Tricia Lee Rolle
Pharm D, MS,
PhD



Stephan Konya

ADULTHOOD

Pam Levington*, (45 Years Old)

Behavioral Healthcare Provider to Healthcare Provider (HIPAA covered entities/business associate): Pam is receiving care from Dr. Thompson, an addiction specialist, at ABC Health Center. Pam receives a notice that ABC will be closing. If she continues receiving care from Dr. Thompson at a new XYZ facility, XYZ will request that ABC transfer her medical records to XYZ. While Pam would like to continue receiving care from Dr. Thompson, she would like to know if part of her record can be restricted. She is concerned that her sister who is a healthcare provider at XYZ will learn of her treatment.

Healthcare Provider to Online Trial Enrollment (Non-HIPAA Covered Entity/Business Associate): Pam would like to enroll in a clinical trial she’s learned about online. The enrollment process requires review of her medical history. Pam would like her primary care provider to only share necessary information for enrollment, not her full record.

Behavioral Healthcare Provider to Individual: Pam is still concerned about receiving care at the XYZ facility. She would like an electronic copy of her medical record from ABC Health Center to take to a provider of her choosing.

*Fictitious names and organizations used

Moderated by:



David Wang
MD



Carmela Couderc

END OF LIFE

Bill Howard*, (82 Years Old)

Healthcare Provider to Healthcare Provider (HIPAA covered entities/business associate): You First Cancer Center completed a Physician Orders for Life-Sustaining Treatment (POLST) form for Mr. Howard. Mr. Howard is moving into Caring Hands Home, a skilled nursing facility which has requested a copy of the POLST and other/associate medical information from You First Cancer Center for their records. Caring Hands partners with an HIE to maintain this information. Mr. Howard consents for POLST and other medical information to be made available through the HIE to other health care providers.

First Responders to HIE (HIE Business Associate): One afternoon, the staff at Caring Hands Home find Mr. Howard unresponsive. They call emergency services. Enroute, the city's paramedics and first responders check the HIE and request to view Mr. Howard’s POLST.

Healthcare Provider to Individual (Proxy): Mr. Howard is now incapacitated. His nephew and healthcare proxy, Jim, has a copy of the advance care directive from Mr. Howard’s lawyer. He is concerned that Mr. Howard’s POLST form may not reflect his latest wishes. Jim would like to discuss his uncle’s end of life wishes with his providers. He requests a copy of Mr. Howard’s POLST when he arrives at the hospital.

*Fictitious names and organizations used



Discovery Workshop on eConsent: From Birth to End of Life

Breakout Room Moderator Bios

BIRTH/MATERNAL BREAKOUT

Sue Kressly, MD, FAAP
Pediatric Health IT SME, and Founding Partner, Kressly Pediatrics

Dr. Sue Kressly is board certified in general pediatrics and clinical informatics with over 30 years of pediatric experience and 15 years of clinical IT experience. She has held several leadership roles at the American Academy of Pediatrics and has served on numerous pediatric Health IT industry workgroups advancing health technology for children and families.

Laverne Perlie, MSN, BSN, RN
Nurse Consultant, Office of Policy, Interoperability Division, ONC

LaVerne works with federal and external stakeholders across the following domains: health IT adoption, patient safety, care coordination, health equity, and health information exchange. Currently, she serves as the Project Officer and Health Equity workgroup lead for the Strengthening the Technical Advancement & Readiness of Public Health via the Health Information Exchange Program (The STAR HIE Program). LaVerne established and led the ONC/ANIA (American Nursing Informatics Association) quarterly education webinar series, providing education by ONC nurses to ANIA members and other nurse informaticists. LaVerne is a graduate of Walden University School of Nursing Informatics and has over 25 years of healthcare experience.

CHILDHOOD BREAKOUT

Kristine McCoy, MD, MPH
Primary Care and Public Health Consultant and Senior Visiting Scholar, Robert Graham Center

Dr. McCoy is a family physician and consultant currently serving as Senior Visiting Scholar at the American Academy of Family Physicians' Robert Graham Center for Policy Studies. Her scholarship there looks at the intersection of medical care with other early childhood systems.

Dr. McCoy previously served as the co-PI for New Jersey's Integrated Care for Kids cooperative agreement with CMMI, which aims to ensure that high risk Medicaid enrolled children receive a coordinated suite of "Core Child Services" in order to thrive and avoid out of home placement. As technology lead, she created the blueprint for a modular software suite to enable distributed community care coordination. She concurrently served as Clinical Director for the Greater Newark Regional Health Hub tasked with creating a population health strategy for the Newark, NJ region based on a regional HIE and access to Medicaid claims.

Dr. McCoy obtained her undergraduate and medical degrees at Stanford University and her MPH at UCLA.

Angelina Sulaka, Esq.

Senior Advisor, Risk & Compliance, ONC Enterprise Risk Management Division, ONC

Angelina Sulaka is the Senior Advisor in the Enterprise Risk Management Division (ERMD) for ONC. Angelina shapes ERMD strategy and processes as well as advises on all ERMD functions, including ERM, internal controls, GAO/OIG audit, FOIA, and ethics compliance. Most recently, Angelina served as the Policy Advisor for Legal Compliance and Risk for the U.S. Agency for Global Media (USAGM). Angelina was instrumental in advancing USAGM's ERM program by developing and implementing risk management policies and processes to strengthen the Agency's compliance and risk culture. Angelina holds leadership roles across the Federal ERM space in both the Cyber-ERM Community of Interest and the Small Agency Community of Practice with the Association for Federal Enterprise Risk Management (AFERM). She started at USAGM in 2016 as a Presidential Management Fellow (PMF) working in the Offices of the General Counsel and the Chief Information Officer, specializing in procurement and cybersecurity. Previously, she worked in legal and government affairs for international manufacturing companies and DC-based trade organizations. Angelina began her career practicing criminal law in Detroit.

Angelina hails from Michigan and is the mother of four little ones, ages 1-6 years old! Sidenote: she has used health apps for fertility, pregnancy, and post-pregnancy and won't go to a doctor who doesn't use a "patient portal!"

She earned her Bachelor of Arts degree in political science and romance languages and Literature from the University of Michigan – Ann Arbor, and her Juris Doctor (Law Degree) from the University of Detroit-Mercy. She is a licensed attorney, community organizer, and serves on several local non-profit boards.

ADOLESCENCE BREAKOUT

Hannah Galvin, MD, FAAP, FAMIA

CMIO, Cambridge Health Alliance; Board Co-Chair, Shift

Dr. Hannah Galvin is a clinical informatics thought leader and nationally recognized expert in the segmentation of data and consent management to promote patient-driven privacy and sharing preferences and to advance equitable interoperability. Dr. Galvin has guided major professional societies and health IT vendors regarding complex issues of patient agency and privacy to support the evolving technology-enabled continuum of care. She advised the ONC Advisory Committee Health IT for the Care Continuum Task Force in relation to the recent 21st Century Cures Act on interoperability, information blocking, and the ONC Health IT Certification Program. She previously served as a member of the ONC Patient Choice for Research Consent Technical Working Group. She co-founded and serves as board co-chair for Shift, the independent healthcare task force for equitable interoperability, governed by the American Medical Association (AMA), American Academy of Pediatrics (AAP), Electronic Health Records Association (EHRA), Integrating the Healthcare Enterprise USA (IHE USA), Drummond Group, and ONC.

Dr. Galvin currently serves as Chief Medical Information Officer for Cambridge Health Alliance, an innovative academic public health system dedicated to providing care for all in need throughout the Boston metro north region and is an Assistant Professor of Medicine at Tufts University School of Medicine. An experienced primary care pediatrician and hospitalist with specialization in child abuse medicine, her clinical work focuses on vulnerable populations including at-risk adolescents. Dr. Galvin is dual-board certified in clinical informatics and pediatrics. She trained at Boston Children's Hospital and graduated from Harvard Medical School and Wellesley College.

Liz Turi, M.Eng, CPHIMS

Health IT Program Analyst, ONC

Liz Turi is an Health IT Program Analyst in the Office of Technology, Standards Division, Infrastructure Branch. She has an IT career of nearly 25 years, roughly half of that dedicated to Healthcare IT, with roles from software engineering to implementation to consulting. She has special interests in health equity, SDOH, public health, and interoperability. She is a CPHIMS, and holds a BS in Anthropology from Ball State University, and a MEng in Healthcare Systems Engineering from Lehigh University.

ADULTHOOD BREAKOUT

Tricia Lee Rolle, PharmD, MS, PhD Senior Advisor, ONC

Dr. Rolle is a pharmacist dedicated to improving our healthcare system through the safe use of health information technology. She has been instrumental in improving U.S. healthcare medication management through leadership at the federal level. Her expertise encompasses pharmacy practice, health IT leadership, quality improvement experience, and research expertise.

For the last decade, Dr. Rolle has served as a liaison with top officials of both public and private sectors, including industry executives, professional associations, IT vendors, and state governments to support use of health IT for comprehensive medication management and to increase community engagement in safe use and adoption of health IT.

Dr. Rolle began her career as an inpatient pharmacist and graduate research assistant for West Virginia University Hospital. She holds a Doctor of Pharmacy (Pharm.D.) degree from SUNY at Buffalo and a PhD and Master's degree in Pharmaceutical Systems & Policy from West Virginia University.

Stephan Konya Senior Advisor to the Deputy National Coordinator for Health IT and Innovation Portfolio Lead, ONC

Stephen joined the U.S. Department of Health and Human Services (HHS) in the fall of 2015, as the Senior Innovation Strategist for ONC. In addition to developing the Agency's external and internal innovation strategy, he also serves as a key liaison for innovation related projects and challenges, specifically targeting engagement opportunities with the healthcare startup and investor communities. In this role, Mr. Konya has led several key ONC projects, including the national Health IT Playbook, the ONC Patient Engagement Playbook for Providers, the SMART App Gallery, the FHIR at Scale Taskforce (FAST) Initiative, and is a founding CoChair of the Together.Health Collaborative.

Prior to his position with the Federal Government, he served concurrently as Chief of Staff, Chief Operating Officer, and Chief Results Officer for the Illinois Department of Public Health. Where, in addition to many other responsibilities, he was tasked with leading the agency's Innovation and Open Data strategy, and was appointed Chair of the Open Data sub-committee under the IL Alliance for Health, a CMMI State Innovation Model (SIM) planning grant. Other assignments included being appointed to the IL Commission on the Elimination of Poverty, and Co-Chair of the Illinois Workforce Investment Board's (IWIB) Healthcare Taskforce.

Previously, Mr. Konya served as the Chief of Staff for the IL Department of Commerce and Economic Opportunity, and CFO of the IL Human Rights Commission. He holds a BBA in finance and international

business from Loyola University of Chicago, and was both a Fellow and Mentor of the Mid-America Regional Public Health Leadership Institute (MARPHLI) program, at the University of Illinois-Chicago (UIC), School of Public Health.

END OF LIFE BREAKOUT

David Wang, MD

System Director of Palliative Medicine, Scripps Health

David Wang is System Director of Palliative Medicine at Scripps Health where he leads a service line of thirty providers across a community health system spanning twelve sites of care. Dr. Wang is a national thought leader advancing the integration of palliative care and emergency medicine. He has created nationwide guidelines around clinical practice, operational models, and medical education.

Carmela Couderc

Branch Chief Terminology and Content Delivery, ONC

Health IT professional with a background in integrating standard terminology into clinical EHR applications, co-chair of the HL7 Vocabulary work group.