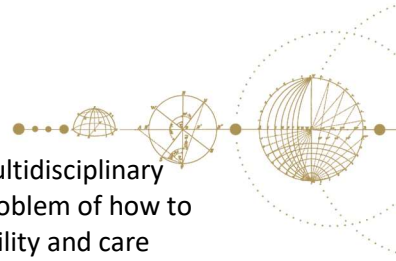


Protecting Privacy to Promote Interoperability Workgroup
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Protecting Privacy to Promote Interoperability Workgroup: White Paper



The Protecting Privacy to Promote Interoperability (PP2PI) Workgroup is a national multidisciplinary interest group of expert stakeholders across the industry assembled to address the problem of how to granularly segment sensitive data to protect patient privacy and promote interoperability and care equity. Stakeholders include more than 160 representatives from health care organizations, professional societies, standards development organizations, health IT vendors, Health Information Exchanges (HIEs) and Interoperability Frameworks, payers, government, government and non-government contractors, privacy law and ethics experts, and patient advocates, among others.¹ PP2PI is supported by HIMSS, IHE USA and Drummond Group, but remains an independent group of volunteer stakeholders and does not receive financial backing from any organization.

The PP2PI group has been founded under the following principles, and recognizes that support for such principles requires addressing the policy drivers and shortfalls in current technology enablers:

- Sharing of patient information between clinical providers in many instances can meaningfully improve patient care. Sharing of patient information at the population level can meaningfully inform government officials, health care organizations, and non-profits and improve the health of communities, reduce costs, and enable research that promotes a learning health system. Finally, patients should have the option to provide proxy access to their electronic health data to non-clinical caregivers who help manage their health and care.
- Empowering patients and including them as a partner in care decisions - including providing the ability to control their own personal health data and how it is shared - has been shown to improve the provider-patient relationship, which in turn has been shown to improve outcomes.
- In certain instances, patients have the right to withhold specific sensitive data, due to state and/or federal law. In other instances, a patient's living situation, culture or values, relationships, or other expressed need may warrant a clinician withholding health information from others, such as personal representatives.

Lacking adequate technical standards for granular segmentation of sensitive data, many organizations resort to blunt algorithms or manual processes to withhold sharing for broad populations in order to comply with state and federal law. This may result in care inequities and potential information blocking, as patients with conditions that are associated with a stigma, when given the option, may be less likely to consent to having their data shared across care systems than others. As some sensitive conditions are more prevalent in disenfranchised populations, this contributes to disparities in care.

Current standards for granularly segmented data are evolving but insufficient. For some time, there have been normative standards for granular segmentation of health information using HL7[®] version 2 and CDA, and the FHIR[®] Data Segmentation for Privacy (DS4P) Implementation Guide (IG) is moving toward normative status. Although the HL7, CDA, DS4P IG standard and the related Consent2Share (C2S) tool (which is not a recognized standard and no longer supported by SAMHSA) have been successfully piloted by a handful of sites, widespread implementation has lagged for a number of reasons including the lack of a regulatory impetus for adoption and failure of the current standards to meet a number of

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high-priority use cases. There has also been a lack of implementation guidance, particularly around controversial issues, such as how to balance patient safety with privacy considerations.

A key deliverable of the PP2PI workgroup, formalized in May 2020, involves developing a set of nationally-acceptable use cases, which will be leveraged to support standards revision and development.

As of June 2021, the following clinical use cases have been developed:

1. Maternal substance use data shared in infant record.
2. Adolescent reproductive health data shared among clinicians, with portal proxy, and payer.
3. Geriatric patient behavioral health data shared among clinicians, with health information exchange, accountable care organization, payer, and portal proxy.
4. Adult patient with social determinants of health data re: intimate partner violence (IPV) shared between clinicians, community-based organizations, and third-party mobile application (in process and in conjunction with The Gravity Project).

Standards development is focused on DS4P, Privacy Consent, and security labels using HL7 2, CDA and FHIR resources. This process includes defining a nationally-available, steward-maintained terminology value set for sensitive conditions and addressing a means to define privacy policies and identify patient consent preferences through a consent management engine and security labeling service.

The PP2PI workgroup will develop an Implementation Guide with consensus-driven guidance around areas identified as specific barriers to implementation, including (but not limited to):

- Recommendations for role-based vs. attribute-based access control provisioning.
- Policies and procedures for break-the-glass access to data.
- Visualization of redacted data and utilization in decision support algorithms.

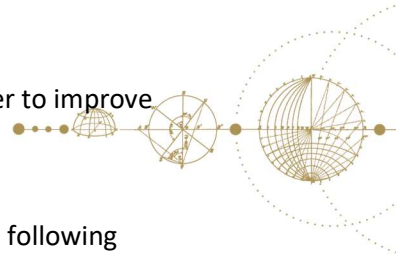
There has been significant concern by clinicians around the patient safety implications of withholding data. Simultaneously, there exist patient safety implications related to the inability to appropriately withhold sensitive data, which has the potential to lead to both immediate and long-lasting harms, including a loss of trust in the health care providers and the system's ability to safeguard private data, as well as potential risk to the patient of harms outside of the health care setting (e.g., IPV resulting from inappropriate information sharing). As such, a primary goal of the PP2PI group is to develop an Implementation Guide with recommendations backed by clinical professional societies, ethicists, and authorities in user experience and patient safety to provide authoritative guidance in this regard.

In these ways, the PP2PI workgroup aims to facilitate the appropriate standards revision and implementation guidance necessary to drive the widespread adoption needed to empower patients to share their data with appropriate protections and decrease disparities in care. Future work will include advocacy for and sponsorship of governmental policy to promote such applications nationwide in order to promote equitable interoperability across the healthcare ecosystem. PP2PI stands ready to collaborate with U.S. Health and Human Services (HHS) to promote goals of sharing sensitive



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information with protection to increase appropriate access and patient control in order to improve health and well-being across all communities in this country.

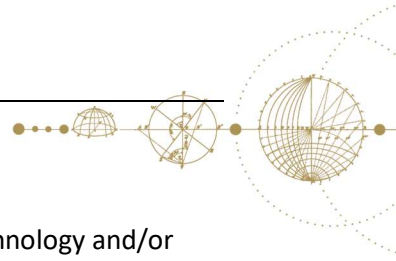


The PP2PI Workgroup includes more than 160 stakeholder members representing the following governmental and non-governmental organizations, electronic health record (EHR) vendors, health information exchanges, and third-party applications, as well as nationally recognized domain experts. The views expressed by PP2PI may not be shared by all stakeholder-affiliated organizations.

American Academy of Neurology (AAN)
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American Academy of Pediatrics (AAP)
American College of Obstetrics and Gynecology (ACOG)
American College of Physicians (ACP)
American College of Preventive Medicine (ACPM)
American Association of Family Practitioners (AAFP)
American Association of Neurological Surgeons (AANS)
AEGIS.net, Inc.
American Health Information Management Association (AHIMA)
American Medical Association (AMA)
American Medical Director of Informatics Society (AMDIS)
American Medical Informatics Association (AMIA)
American Psychiatric Association (APA)
Allscripts
Athenahealth
Beth Israel Lahey Health
Boston Children's Hospital
Cambridge Health Alliance
CarEquality
Carin Alliance
Centers for Medicare & Medicaid Services (CMS)
Central Square Solutions
Cerner
CommonWell Health Alliance
CPSI
DaVinci Project
DC Healthcare Information Exchange
Department of Health and Human Services (HHS)
Drummond Group
eClinicalWorks
Electronic Health Record Association (EHRA)
Gravity Project
Greenway
Harvard Medical School
Health Level 7 International (HL7)



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Healthcare Information and Management Systems Society (HIMSS)

Healthy Arizona & Healthy Communities Collaborative Network

IBM

Individual(s) with expertise in clinical informatics, health informatics/ information technology and/or interoperability

Individual(s) with expertise in infectious disease

Individual(s) with expertise in internal medicine and/or geriatric medicine

Individual(s) with expertise in patient advocacy

Individual(s) with expertise in pediatric medicine

Individual(s) with expertise in privacy, law, and/or ethics

Integrating the Healthcare Enterprise (IHE)

InterSystems Corporation

Leap Orbit

MEDHOST

Meditech

Medstar

Microsoft

MITRE Corporation

Moxe Health

National Partnership for Women and Families

New York eHealth Collaborative

New York-Presbyterian/Columbia University Medical Center

National Institute of Child Health & Human Development (NICHD)

Office of the National Coordinator for Health Information Technology (ONC)

Office Practicum

Omada Health

OpenNotes

Pew Charitable Trusts

Pharmacy Health IT Collaborative

Physician's Computer Company (PCC)

Rhode Island Dept of Behavioral Healthcare, Developmental Disabilities and Hospitals

Santa Clara County

Sequoia Project

Society for Adolescent Health and Medicine (SAHM)

Stanford Medicine

Sutter Health

Tufts University School of Medicine

University of Buffalo

University of Pittsburgh Medical Center

University of Texas Southwestern School of Medicine

Vanderbilt University School of Medicine

Vermont Rural Health Alliance

Veterans Health Administration - Veterans Affairs

Washington State Health Care Authority

Weill Cornell Medicine