

## HITAC Annual Report for Fiscal Year 2018

### List of HITAC Members' Comments

The Annual Report Workgroup collected comments from HITAC members and convened to propose solutions for each comment, as noted below.

Section	Subsection	HITAC Member	Original Language	HITAC Member's Suggestion	Proposed Solution
<b>Executive Summary</b>					
Health IT Infrastructure Landscape	Patient Access to Information	Denise Webb	Continued information and education, as well as improved accessibility and increased use of application programming interfaces (APIs), are needed to increase patient awareness of the use of data and health IT resources.	Continued information and education for patients on the use of their data and available health IT resources for patients, improvements in accessibility of the data, and increased use of application programming interfaces are needed.	No change was made because revisions would remove intent of increasing patient awareness.
Health IT Infrastructure Landscape	Patient Access to Information	Cynthia Fisher	Access to health IT can have a positive impact on health, health care, and health equity by supporting shared decision-making between patients and providers, providing personalized self-management tools, and delivering accurate, accessible, and actionable health information.	<b>Real-time, machine-readable, free-of-charge, access to health IT, including net price information</b> , can have a positive impact on health, health care, and health equity by supporting shared decision-making between patients and providers, providing personalized self-management tools, and delivering accurate, accessible, and actionable health information.	One change was made by mentioning the concept of free access in the Gap Analysis instead, otherwise, no changes were made. Access to electronic data can be inferred from the context. The Annual Report Workgroup believes that discussion of access to price information and in real-time should be tabled for consideration in FY19 report.
<b>HITAC Progress in FY18</b>					
ISP Task Force Accomplishments		Cynthia Fisher	These additional areas include medication/pharmacy data, evidence-based care for common chronic conditions, closed loop referrals, social determinants of health (SDOH), and cost transparency.	These additional areas include medication/pharmacy data, evidence-based care for common chronic conditions, closed loop referrals, social determinants of health (SDOH), and <b>price</b> transparency.	No change was made because the HITAC ISP Task Force assigned the name of the category as "cost transparency."
<b>Landscape Analysis</b>					
Interoperability	Background	Clem McDonald		To my eyes, the primary problem in general interoperability is and has always been lack of or non-use of universal code to label the discrete	No changes were made. Annual Report Workgroup believes this concern is already covered by the



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				observations. HL7 V2 worked pretty well within hospitals but not across hospitals because of the lack of universal observation labs. We have progress , all big commercial labs can send LOINC codes, and FHIR more or less requires them. But documented by Health insurance companies we get LOINC codes lab results from big commercial labs (who were not covered by HIPAA) but hardly any from hospitals. (who are covered by the various laws). Probably worse for other kinds of reports.	standards discussion and that it may not be the primary problem.
Interoperability	Background	Clem McDonald		Regarding delivery to patients, the problem there is providing a destination. ONC should require that health care visit encounters would ask the patient for destination address (where to send the record). Would be easy to add a new field. Then find way to send existing PHRs, or encrypted email. Think also about stimulating an open source PHR that anyone could down load as their destination.	No changes were made. Annual Report Workgroup believes topic should be tabled for consideration in FY19 report.
Interoperability	Standards and Implementation Specifications to Support Priority Uses of Health IT/ USCDI	Clem McDonald		Imaging reports (and images) are not separately listed here, but they are listed under clinical notes in the larger USCDI on the web ( <a href="https://www.healthit.gov/isa/us-core-data-interoperability-uscdi">https://www.healthit.gov/isa/us-core-data-interoperability-uscdi</a> ). Think you should spell it out the same way in this report as on the web version to avoid confusion. The USCDI section in the report does not mention Imaging reports, though they are prominently presented in the NPRM. Seems like they should be in the USCDI.	Change was made. Annual Report Workgroup believes more specific topic of imaging reports should be tabled for consideration in FY19 report.



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Interoperability	Standards and Implementation Specifications to Support Priority Uses of Health IT/ HL7® Fast Healthcare Interoperability Resources (FHIR)® Standard	Steven Lane	HL7® is also leading the Da Vinci Project to accelerate the adoption of HL7® FHIR® as the standard to support and integrate value-based care data exchange across communities.[i] National interoperability initiatives such as DirectTrust, Sequoia Project, Carequality and CommonWell Health Alliance are all working to advance the use of HL7® FHIR® in their efforts.	HL7® is also leading the Da Vinci Project to accelerate the adoption of HL7® FHIR® as <del>the</del> a standard to support and integrate value-based care data exchange across communities.[i] National interoperability initiatives such as DirectTrust, <del>The</del> Sequoia Project, Carequality and CommonWell Health Alliance are all working to advance the use of HL7® FHIR® in their efforts.	Two changes were made, however, Carequality does not italicize the "e" in their name in text, only in their logo.
Interoperability	Patients' Experience of Health Information Exchange	Raj Ratwani		Health information may also be presented in a way that is not usable or comprehensible to patients.	Change was made.
Interoperability	Patients' Experience of Health Information Exchange	Cynthia Fisher		At end of paragraph, add: "In this transient, mobile world, patients should have real-time, machine-readable, free-of-charge access to their electronic health information."	One change was made by mentioning the concept of free access in the Gap Analysis instead, otherwise, no changes were made.
Privacy and Security	Health Information Sharing for Research Purposes	Steven Lane	Several companies and programs are collecting health information for research using mobile devices and web applications, including Apple's ResearchKit platform, the PatientsLikeMe and 23andMe websites, and the NIH All of Us Research Program.	Several companies and programs are collecting health information for research using mobile devices and web applications, including Apple's ResearchKit platform, the PatientsLikeMe and 23andMe websites, <del>Epic's Cosmos research database</del> , and the NIH All of Us Research Program.	Change was made.
Privacy and Security	Patient Matching and Verification	Clem McDonald		Understand Medicare might introduce their own medical records ID. Think that would be good. Given that many hundreds of millions of SS# are in use, hundreds of thousands of patients will have the same last four. So not much threat to privacy but it would help greatly to avoid collisions in matching with other keys. Last 4 SS#	No changes were made. Annual Report Workgroup believes topic should be tabled for consideration in FY19 report.

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				is used widely in ordinary commericis [commercial interactions?]. So don't understand the reluctance to include it in EMRS as a potential matching key.	
Privacy and Security	Disaster Planning for Health IT	Steven Lane	Building interoperable systems across healthcare will pave the way for communities to better respond to and recover from future disasters. This past summer, the California Emergency Medical Services Authority (CalEMSA) established the Patient Unified Lookup System for Emergencies (PULSE) to provide selected healthcare professionals, while volunteering during a disaster, the ability to search and return personal health information about patients they are treating in the field. PULSE, developed by ONC and supported across HHS, proved through an emergency exercise that it was able to successfully integrate the California Trusted Exchange Network (CTEN), California's Disaster Health Care Volunteers (DHV) system, and four health information exchange organizations. Although PULSE is currently operational in parts of Southern California, the vision is to grow PULSE statewide and eventually nationwide in time for the next emergency.[v] This work may function as a model for other states and communities to build upon as needed, modified to meet local conditions.	Building interoperable systems across healthcare will pave the way for communities to better respond to and recover from future disasters. <del>This past summer</del> Over the past few years, the California Emergency Medical Services Authority (CalEMSA) has established the Patient Unified Lookup System for Emergencies (PULSE) to provide selected healthcare professionals, while volunteering during a disaster, the ability to search and return personal health information about patients they are treating in the field. PULSE, developed by ONC and supported across HHS, proved through an emergency exercise that it was able to successfully integrate the California Trusted Exchange Network (CTEN), California's Disaster Health Care Volunteers (DHV) system, and four health information exchange organizations. Although PULSE is currently operational in parts of Southern California, the vision is to grow PULSE statewide and eventually nationwide in time for the next emergency.[v] This work may function as a model for other states and communities to build upon as needed, modified to meet local conditions.	Changes were made.



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Patient Access to Information	Background	Cynthia Fisher	Patients' electronic access and use of their health information will be critical for enabling individuals to better monitor their health as well as manage and coordinate their care.	Patients' <b>real-time</b> electronic access and use of their health information, <b>including both clinical and net price information</b> , is critical for enabling individuals to better monitor their health as well as manage and coordinate their care.	No changes were made. Discussion of access to price information and in real-time should be tabled for consideration in FY19 report.
Patient Access to Information	Patient-Controlled Data Collection, Access, and Sharing	Cynthia Fisher	The use of APIs can improve individual electronic access to their health information and better support the growing market of patient-facing applications that are designed to allow individuals to access, aggregate, and act on their health information.	The use of APIs can improve individual electronic access to their <b>real-time</b> health information, <b>can help patients understand the price of their care in advance</b> , and better support the growing market of patient-facing applications that are designed to allow individuals to access, aggregate, and act on their health information.	No changes were made. Discussion of access to price information and in real-time should be tabled for consideration in FY19 report.
Patient Access to Information	Use and Sharing of Social Determinants of Health Data	Denise Webb	...2) patient access to community resources and ongoing care plan engagement with the care team for, and 3) ...	...2) patient access to community resources and ongoing care plan engagement with the care team <del>for</del> , and 3) ...	Change was made.
Patient Access to Information	Emerging Platforms for Data Sharing by Patients and Caregivers	Denise Webb		Suggest spelling out meaning behind name "CARIN" and adding a description to the glossary.	No changes were made. The organization uses their name as a proper noun rather than as an acronym. The glossary only contains general terms and the mission of the organization is already explained in the text. However, text was updated to mention bipartisan, collaborative nature of the group as described on their web site.
Patient Access to Information	Emerging Platforms for Data Sharing by Patients and Caregivers	Clem McDonald		"We have to be careful about the use of "unstructured" because there has to be some structure, e.g., patient ID, date. Think they really mean payload in narrative but not that the content is unstructured."	No changes were made. The word "unstructured" is only mentioned once in the report and is used consistently with the definition in ONC's proposed rule.



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<b>Gap Analysis</b>					
Interoperability	Need to Increase Level of Interoperability	Raj Ratwani	Increased automation, supported by improved interoperability, is an important step to help reduce provider burden related to the use of health IT systems.	Increased automation, supported by improved interoperability and <b>improved usability of exchanged information</b> , is an important step to help reduce provider burden related to the use of health IT systems.	Change was made, and usability broadened to apply to more than exchanged information.
Interoperability	Ongoing Efforts Regarding Open APIs, Information Blocking, Trusted Exchange Framework, and Standards and Implementation Specifications	Denise Webb	...that Implementation of the framework...	In this sentence, "implementation" should be lower case.	Change was made.
Interoperability	Lack of Knowledge about User Experience of Health Information Exchange	Denise Webb	Work remains to implement this framework and develop consensus process and outcome measures...	Work remains to implement this framework and develop a consensus process and outcome measures...	Change was made.
Interoperability	Need to Improve Data Quality, Provenance, and Usefulness	Steven Lane		I would suggest including a few sentences mentioning the tremendous data quality initiative being carried out by the VA, where they are carefully examining the content of the C-CDA documents they receive from healthcare organizations and provide feedback to the organizations and their EHR vendors regarding how data quality could be improved.	No changes were made. Annual Report Workgroup believes topic should be tabled for consideration in FY19 report.
Interoperability	Need to Improve Data Quality, Provenance, and Usefulness	Steven Lane		I would also suggest changing the word "Usefulness" to "Utility."	No change was made. Usefulness and utility are synonyms, according to the Random House Unabridged Dictionary which defines utility as "the state or quality of being useful; usefulness."
Interoperability	Need to Improve Data Quality,	Steven Lane		I would suggest adding a brief discussion of the challenges that	No changes were made. Annual Report Workgroup believes topic



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	Provenance, and Usefulness			clinicians, individuals and other stakeholders face when trying to make use of the data that they receive from various sources. Specifically I am referring to the need to ingest discrete, codified data that can be combined with data from other sources and integrated directly into clinical and operational workflows. As you know, this sort of semantic and functional interoperability is a current challenge that we are attempting to address through manual mapping of data elements and other approaches. For interoperable data to be truly useful for stakeholders we need to focus on this level of integration.	should be tabled for consideration in FY19 report.
Privacy and Security	Lack of User Awareness and Education about Privacy and Security Protections	Ken Kawamoto		Formal guidance should also be provided on compliance with relevant privacy and security regulations such as HIPAA of current uses of FHIR APIs, such as in SMART on FHIR applications or CDS Hooks services (e.g., sending of full patient demographic details in all cases, the use of broadly-scoped data access tokens).	No changes were made. Annual Report Workgroup believes topic should be tabled for consideration in FY19 report.
Privacy and Security	Variability in Adoption of Cybersecurity Framework(s)	Denise Webb	According to many of the senior leaders at health care organizations HIPAA compliance alone is not enough...	In the introductory clause of the first sentence, add a comma after "organizations."	Change was made.
Privacy and Security	Variability in Adoption of Cybersecurity Framework(s)	Denise Webb	Paid networks include the Health Information Trust Alliance (HITRUST) Common Security Framework (CSF). Publicly available networks include the International Organization for Standardization (ISO) standards, Center for Internet Security (CIS)	Paid <del>frameworks networks</del> include the Health Information Trust Alliance (HITRUST) Common Security Framework (CSF). Publicly available <del>frameworks networks</del> include the International Organization for Standardization (ISO) standards, Center for Internet Security (CIS)	Changes were made.



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			Critical Security Controls or Effective Cyber Defense, and National Institute of Standards and Technology (NIST) Cybersecurity Framework.	Critical Security Controls or Effective Cyber Defense, and National Institute of Standards and Technology (NIST) Cybersecurity Framework.	
Patient Access to Information	Lack of User Control to Share and Disclose Information	Denise Webb	The DS4P standard allows a provider to tag a C-CDA document with privacy metadata that expresses the data classification and disclosure restrictions placed on the data by applicable law.	The DS4P standard allows <del>a provider to tag</del> tagging of a C-CDA document with privacy metadata that expresses the data classification and disclosure restrictions placed on the data by applicable law.	Change was made.
Patient Access to Information	Accessibility and Usability of Patient Portals and Other Patient-Facing Technology Continue to Need Improvement	Cynthia Fisher		The cost of providing electronic patient access is negligible. Since covered entities can only charge reasonable, cost-based fees for access, access should be provided free of charge.	Change was made.
<b>Recommended HITAC Activities</b>					
Interoperability	Recommended HITAC Activity	Clem McDonald	Address "reality gap" between the perception of what has been certified for a system and what is truly interoperable in the field	One example is the topping out of compliance with standardization of lab testing for which CMS took it off the list. One the 2 largest lab companies (LabCorp) sent a letter documenting that that was far from the truth. Further, the major problem was/is the absence of standard codes (see D'Amore et al 2014). <a href="https://www.ncbi.nlm.nih.gov/pubmed/24970839">https://www.ncbi.nlm.nih.gov/pubmed/24970839</a>	No changes were made. Annual Report Workgroup believes topic should be tabled for consideration in FY19 report.
Interoperability	Recommended HITAC Activity	Sheryl Turney	Further measure whether systems are truly interoperable at both content and transport levels after implementation, especially among smaller practices and by patients	I don't think measure is the right term. Will we have sufficient data to measure? Possibly use assess? Are we really talking about measuring systems interoperability here or assessing interoperability based on function?	Change was made, substituting "evaluate...to establish. measures in the future" for "measure."





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Interoperability	Other Opportunities for Further Consideration	Sheryl Turney	Establish usability metrics for health information exchange	Do we mean best practices or actual metrics?	No change was made. Annual Report Workgroup believes that "metrics" is the right term to encourage behavior change.
Interoperability	Other Opportunities for Further Consideration	Carolyn Petersen, Aaron Miri	Identify incentives for exchange across stakeholder groups to improve the level of interoperability and data quality	Identify incentives <del>for exchange</del> across stakeholder groups to improve the level of interoperability and data quality.	Change was made to increase clarity.
Privacy and Security	Recommended HITAC Activity	Sheryl Turney	Identify areas of IoT use that would benefit from guidance and examples of success in the health care industry	Add "including patients' rights & protections related to third party use of data collected via IoT." I think this is a key area we need to focus on. Payers are hearing from vendors that collect data from IoT devices and are selling data which includes personally identifiable data to health care systems for use in developing risk scores, etc. Most patients are not aware that their IoT devices are selling this data for this type of use. Further, this data is being used to develop risk scores that may impact their ability to receive services or prescriptions in the future. I think this needs to cover recommendations and potentially limitations on the use of the data collected by third parties in addition to required patient permissions.	Change was made by inserting a descriptive sentence above recommended HITAC activity using language from gap analysis.
Privacy and Security	Recommended HITAC Activity	Sheryl Turney	Identify educational approaches, technological mitigators, and potential regulatory solutions that offer improved privacy and security protections	Add: "and include limits on secondary or tertiary uses of personally identifiable data including data available through the IoT"	Change was made by mentioning concern in Lack of User Awareness and Education about Privacy and Security Protections section of the gap analysis instead.
Privacy and Security	Recommended HITAC Activity	Sheryl Turney	Consider federal role in setting guidelines for the exchange of data across states	Use a word or activity other than "consider" because activity seems too broad as written. Also, I believe this should include any data the state collects within All Payer Claims Databases that currently are being	Change was made, substituting "review and make recommendations" for "consider." The Annual Report Workgroup believes further discussion of use



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				sold by states to third parties to maintain sustainability but goes beyond research or public health.	of data by states should be tabled for consideration in FY19 report.
Privacy and Security	Recommended HITAC Activity	Denise Webb	Consider the impact of nationwide adoption of cybersecurity framework(s) and delineate cybersecurity accountability for data by role	Use a word or activity other than "consider" because activity seems too broad as written	Change was made, substituting "review and make recommendations" for "consider."
Privacy and Security	Recommended HITAC Activity	Carolyn Petersen, Aaron Miri	Consider the impact of nationwide adoption of cybersecurity framework(s) and delineate cybersecurity accountability for data by role	Consider the impact of nationwide adoption of cybersecurity framework(s) and delineate cybersecurity accountability for data by role <b>within the health IT infrastructure</b>	Change was made to increase clarity.
Patient Access to Information	Recommended HITAC Activity	Sheryl Turney	Measure impact of monetization of data exchange	I don't think measure is the right term. Will we have sufficient data to measure? Possibly use assess?	Change was made, substituting "evaluate...to establish measures in the future" for "measure."
Patient Access to Information	Recommended HITAC Activity	Sheryl Turney	Measure amount/length of time a portal has been online working properly, patient engagement, and/or patient understanding and use of data	I don't think measure is the right term. Will we have sufficient data to measure? Possibly use assess?	Change was made, substituting "evaluate...to establish measures in the future" for "measure."
Patient Access to Information	Recommended HITAC Activity	Denise Webb	Measure amount and length of time a portal has been online working properly, patient engagement, and/or patient understanding and use of data	Measure <b>patient portal operational effectiveness amount and length of time a portal has been online working properly</b> , patient engagement, and/or patient understanding and use of data.	Change was made.
Patient Access to Information	Recommended HITAC Activity	Raj Ratwani	Measure amount/length of time a portal has been online working properly, patient engagement, and/or patient understanding and use of data	To improve usability encouraging user centered and providing design guidelines could be effective. We could add something like: Determine whether patient portal usability guidelines and testing is needed.	Change was made by mentioning concern in Patient's Experience of Health Information Exchange section of the landscape analysis instead.
Patient Access to Information	Other Opportunities for Further Consideration	Denise Webb	For example, measure the impact of clinical grade data collected by patients on testing costs.	For example, measure the impact of clinical grade data collected by patients on <b>clinical</b> testing costs.	Change was made.