Office of the National Coordinator for Health Information Technology

Sync for Genes Resources Toolkit

Insights and Resources for Stakeholders

May 2023

Prepared by Carradora Health on behalf of the Office of the National Coordinator for Health Information Technology (ONC) under Contract No. A+ GS35F0565T-140D0420F0486

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Executive Summary

The Sync for Genes project was launched in 2017 by the Office of the National Coordinator for Health Information Technology (ONC), initially in partnership with the National Institutes of Health (NIH). Sync for Genes supports ONC's aim to improve health and care through the access, exchange, and use of data, particularly by advancing the development and use of industry-supported genomic standards to standardize the sharing of genomic information among laboratories, providers, patients, and researchers.

Genomic data continues to play a critical role in advancing personalized medicine, improving patient outcomes, and accelerating medical research. Early work in the Sync for Genes project highlighted the necessity for robust industry-supported data exchange standards, such as the Health Level Seven (HL7®) Fast Healthcare Interoperability Resources (FHIR®) standard, to enable the effective exchange and utilization of genomic data by researchers, clinical care teams, patients, and caregivers. Furthermore, it became apparent that existing standards required greater specificity and granularity.

With input from the genomics community and industry, the Sync for Genes project identified and prioritized a list of challenges impeding the widespread adoption, implementation, integration, and use of genomic data in the clinical and research domains. These challenges were addressed as project phases, involving stakeholder discussions and technical demonstrations by participating organizations. Importantly, it was recognized that these challenges were interconnected, with the outcomes of one challenge providing the necessary input to tackle the next.

The Sync for Genes project has made substantial progress in advancing genomic standards, while acknowledging the ongoing challenges in reconciling existing standards with the evolving complexity of requirements. To promote broader implementation and utilization of these standards, continued progress relies on a collaborative approach, engaging various stakeholders to work together in addressing these challenges.

This toolkit provides a comprehensive summary of the findings and recommendations from each phase of the Sync for Genes project, as well as an informative collection of resources and guidance for implementing genomic data sharing. Designed to support a wide range of stakeholders, the resources toolkit underscores the importance of genomic standards and the wealth of knowledge generated throughout the project. It also highlights areas that would benefit from focused efforts and further collaboration, providing stakeholders with the essential tools to leverage the lessons learned from the Sync for Genes project.

PURPOSE OF THE RESOURCES TOOLKIT

This toolkit is intended to support stakeholders in understanding the progress made in the Sync for Genes project and to highlight resources that facilitate the adoption, implementation, integration, and use of genomic data. The goals of the toolkit include:

- **Promoting awareness** about the Sync for Genes project and showcasing the cumulative progress made across the phases.
- **Sharing genomic resources** that can aid in adoption and implementation decision-making processes.
- **Engaging stakeholders** by providing existing resources to support adoption and implementation.
- **Encouraging broader utilization** of the Sync for Genes project's outcomes to drive advancements in genomic data sharing.

Please note this toolkit is an informational resource informed by technical experts and is not legal advice or guidance from the Office of the National Coordinator for Health Information Technology (ONC). It is also not intended to be comprehensive, but rather is a broad, curated list of resources and considerations.

TARGET AUDIENCE

Recognizing the diverse interests and needs of various groups, the resources toolkit is designed to cater to a wide range of stakeholders who play a crucial role in the genomic data sharing ecosystem. This includes, but is not limited to, the following groups:

Group	Organization Type
Health Information Technology (IT)	• Health IT Developers • Standards Developers • Exchange Facilitators (e.g., health information exchanges [HIEs]) • Registries • State Public Health Departments
Genomics	• Laboratories • Researchers • Healthcare Organizations • Pharmaceutical Organizations • Direct-to-Consumer Testing Companies
Clinical Delivery	• Healthcare Organizations (e.g., Learning Health System [LHS] academic medical centers, independent clinics)
Healthcare Research	• Research Groups • Healthcare Organizations • Academic Institutions • Government Organizations/Programs (e.g., public health departments) • Other Organizations Administering Research Programs/Projects

Group	Organization Type
Payers	• Commercial Insurance Providers • Medicaid and Medicare
Patients	• Patient Organizations • Other Patient-Inclusive Organizations • Educational Organizations (e.g., schools)

NAVIGATING THE RESOURCES TOOLKIT

This toolkit offers background information and highlights common themes that emerged from the ONC's Sync for Genes project. It is organized into topic areas, each representing a unique challenge that has impeded the adoption, implementation, integration, and use of genomic data. These topic areas are designed to provide an introductory understanding of the challenges and potential solutions, providing stakeholders with the knowledge needed to effectively tackle these issues.

As you navigate through the toolkit, you will find:

- Background Information: An overview of ONC's Sync for Genes project, its objectives, and the progress made in each phase.
- Foundational Themes: Common themes that have emerged throughout the Sync for Genes project. These themes encompass the critical aspects of genomic data sharing and usage that require improvement, as well as the potential barriers to achieving successful implementation.
- Additional Resources: Supplementary materials to provide further information and support for the adoption, implementation, integration, and use of genomic data.

OUT OF SCOPE

While the resources toolkit serves as a valuable resource to help stakeholders, it is important to clarify what it does not include:

- Actual "tools": The "toolkit" refers to a collection of information, findings, recommendations, and resources to assist stakeholders in addressing genomic data integration challenges.
- Downloadable software: The toolkit does not provide ready-to-use software solutions for creating interfaces between clinical, research, and lab systems for exchanging and using genomics data.
- Customized implementation plans: While the toolkit provides general recommendations and strategies, it does not offer tailored plans specific to individual organizations or projects.

CORE RESOURCES

Over the course of Sync for Genes, a collection of essential resources has emerged, playing a significant role in the successful execution of the project. These core resources underpin the adoption, implementation, integration, and use of genomic data, serving as the foundation for progress in the field of genomic data sharing.

HL7 FHIR Standard

HL7 Genomics Reporting Implementation Guide

HL7 FHIR Genomics Implementer Guidance

HL7 Clinical Genomics Work Group

Global Alliance for Genomics and Health (GA4GH)

Sync for Genes

Launched in 2017 by the Office of the National Coordinator for Health Information Technology (ONC) in partnership with the National Institutes of Health (NIH), Sync for Genes aims to facilitate the standardized sharing of genomic information among laboratories, providers, patients, and researchers. By advancing the development and application of industry-supported standards, such as the Health Level Seven (HL7®) Fast Healthcare Interoperability Resources (FHIR®) standard, Sync for Genes helps to enable consistent sharing and use of genomic data in research and clinical care.

Sync for Genes builds on the insights gained from Sync for Science, a public-private partnership involving ONC, the Harvard Medical School Department of Biomedical Informatics, and NIH's *All of Us* Research Program. This collaboration aimed to develop a streamlined, scalable, and secure method for individuals to access and share their electronic health record (EHR) data with researchers. Sync for Science utilizes and collaborates with open FHIR application programming interfaces (API) standards, enabling researchers to securely obtain EHR data from third-party applications as directed by patients.

From the onset, the Sync for Genes project recognized the complexities inherent in precision medicine and genomic data, requiring interdependent solutions to address numerous challenges. As a result, the project adopted a systematic, phased approach to address these interconnected challenges, categorizing them based on their role in adoption, implementation, integration, and use. Each phase tackled a specific challenge, providing a solution for subsequent phases to build upon. The project's design aimed to demonstrate incremental progress across a series of phases, with each phase expanding on the accomplishments of its predecessors. Sync for Genes identified the most pressing challenges, their position within the adoption, implementation, integration, and use paradigm, along with their interdependencies, resulting in five distinct phases:

Phase 1: Standardizing Genomics Data

- Establishing an understanding and agreement on the data to be shared.

Phase 2: Integrating Genomic Data

- Testing data exchange and integrating it into existing systems after reaching consensus on necessary data.

Phase 3: Engaging Laboratories

- Ensuring standardized genomic lab test result data, allowing for its integration and use.

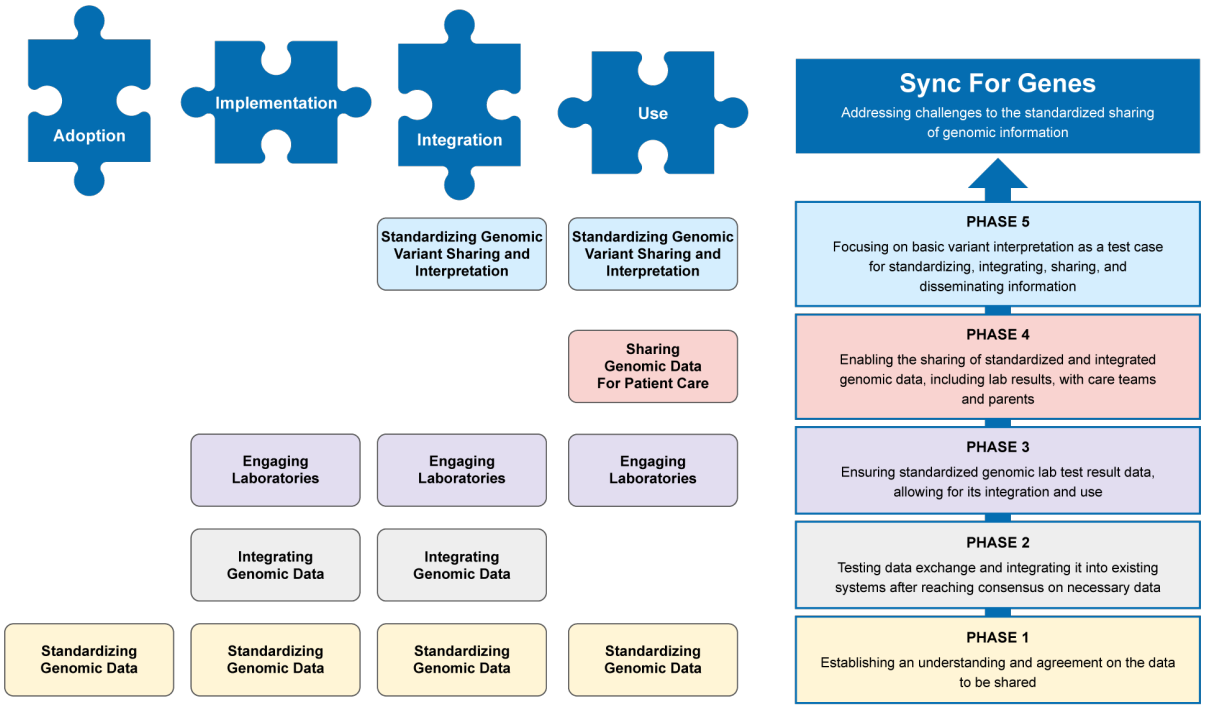
Phase 4: Sharing Genomic Data for Patient Care

- Enabling the sharing of standardized and integrated genomic data, including lab results, with care teams and patients.

Phase 5: Standardizing Genomic Variant Sharing and Interpretation for Clinical Knowledge

- Focusing on basic variant interpretation as a test case for standardizing, integrating, sharing, and disseminating information, providing the "real world" feedback necessary to enhance the use of genomic data.

The outcomes of each Sync for Genes phase serve as the essential building blocks for achieving the data sharing, access, and use goals crucial for advancing genomic research and clinical care. By successfully addressing the challenges and interdependencies within each phase, the project helps to streamline the adoption, implementation, integration, and use of standardized genomic information.



Addressing Challenges

Each phase of the Sync for Genes project engaged technical experts and conducted demonstrations to examine specific challenges and provide solutions.

PHASE 1	PHASE 2	PHASE 3	PHASE 4	PHASE 5
Challenge: Standardizing Genomics Data	Challenge: Integrating Genomic Data	Challenge: Engaging Laboratories	Challenge: Sharing Genomic Data for Patient Care	Challenge: Standardizing Genomic Variant Sharing and Interpretation
FINDINGS/NEED • Pilot testing that includes protected health information • Development of FHIR Genomics • Support for testing and integration • EHR integration of genomic information from laboratories • Testing of apps using FHIR • Incentives for adopting FHIR Genomics	**FINDINGS/NEED** • Alignment of legislation and policies supporting privacy • Security • Data provenance • Data storage and management • Educational support for providers and patients • Adaptation of health information system for genomic use cases • Implementation of FHIR • Cost and business drivers	**FINDINGS/NEED** • Semantic representation • Improved genomic report readability • Better FHIR representation for unsupported data • Greater customization for genomics within FHIR • Benefits of using translator tools to support implementation and use	**FINDINGS/NEED** • Standards to support integration and use of genomic data • Technical, domain, and standards knowledge for implementing genomic standards. • Development of infrastructure to support genomics • Utilization of genomic data • Educational support for patients and providers handling genomic data • Policy considerations	**FINDINGS/NEED** • Development, enhancement, and harmonization of genomic standards • Creation of a sandbox environment for testing • Support for implementation and adoption (use) of genomics • Enabling of Clinical Decision Support (CDS) standards and capabilities

FOUNDATIONAL THEMES

Throughout the Sync for Genes phases, several common themes have emerged. As these findings were consistent, it is likely that the challenges explored will, to some extent, persist in this space for the foreseeable future. These themes not only reflect the core challenges faced by the project, but also highlight the areas where concerted efforts and collaborations are essential to drive progress in the field of genomic data sharing:

- Strategic development and adoption of genomic standards (e.g., FHIR, GA4GH)
- Support and coordination for implementing and integrating these standards
- Targeted education and training on the use of standards and solutions
- Addressing industry challenges impacting adoption, implementation, integration, and use

Continued advancement hinges on a collaborative approach, with various stakeholders working together to address these themes. By focusing on these key areas, the Sync for Genes project has been able to pave the way for more efficient and effective genomic data sharing, ultimately improving patient care and accelerating medical research.

Standardizing Genomic Data
Phase 1

Focus: Adoption, Implementation, Integration, Use

To unlock the full potential of genomic data in patient care, it is necessary to standardize the data to ensure consistency and usability. The standardizing of genomic data is foundational to the adoption, implementation, integration, and use.

Phase 1 focused on standardizing genomic data, involving five organizations from various sectors. They pilot tested use cases from the HL7® Clinical Genomics Work Group's Domain Analysis Model, providing a reference for implementers using FHIR® for genomics.

OUTCOMES

Insights from this phase contributed to the successful publication of the Genomics Reporting Implementation Guide as part of the Health Level Seven (HL7®) Fast Healthcare Interoperability Resources® (FHIR®) Release 3.0.

FHIR Genomics has made significant progress since its initial development. Each HL7 balloting cycle leads to modifications and requested changes to further enhance FHIR Genomics. In addition, the demonstrations selected across all phases for the Sync for Genes project have provided valuable feedback and updates to the FHIR specification, ensuring it reflects the findings of the demonstrations and the larger genomics community.

DEPENDENCIES

- Continuous development and harmonization of standards for genomics to improve interoperability among systems exchanging genomic data and knowledge
- Engagement of a diverse range of users to ensure that the standard addresses the unique needs of each user community
- Recognition of the far-reaching impact of this challenge on all aspects of adopting, implementing, integrating, and using genomic data

RESOURCES

Resource	Owner	Summary
Sync for Genes: Phase 1 Final Report	ONC	This report outlines the inaugural phase of the Sync for Genes project, including the foundational issues around collecting and sharing genomic data with health systems.
HL7 Domain Analysis Model: Clinical Sequencing Release 1	HL7	The Data Access Model (DAM) is the basis for the development of FHIR Genomics. The DAM outlines multiple scenarios centered on sequencing in clinical and translational settings to which FHIR Genomics can be applied.
HL7 FHIR Standard	HL7	Created by HL7, FHIR is a next generation standards framework. FHIR solutions are built from a set of modular components called "Resources". These resources can easily be assembled into working systems to solve real-world clinical and administrative challenges.
HL7 Clinical Genomics Work Group	HL7	This group fosters semantic and syntactic interoperability, focusing on individual genomic data, environmental factors, and family health history. It aims to better understand genetic factors in disease and health, while linking to relevant clinical data and knowledge, and supports many products and activities to this end.
HL7 FHIR Genomics Implementer Guidance	HL7	A FHIR Implementation Guide (IG) landing page showcasing the Clinical Genomics Workgroup's development of standards for reporting structured genomic data using FHIR.
All of Us Research Program	NIH	Aiming to expedite health research discoveries and enable individualized healthcare, this program is building one of the world's largest, diverse health research databases. With six strategic goals to meet by 2026, its Collection and Curation goal emphasizes genome sequencing.

Integrating Genomic Data
Phase 2

Focus: Implementation, Integration

Genomic data has the potential to revolutionize healthcare and scientific discoveries. To realize this potential, standardized collection and exchange of genomic data are needed, ensuring its usability for researchers, care teams, and patients.

Phase 2 advanced standardized genomic data sharing using the FHIR standard and demonstrating the exchange and integration of genomic test results at the point-of-care. Four organizations participated, each with different focus areas, and their feedback contributed to refining the FHIR Clinical Genomics specification within the HL7 Clinical Genomics Work Group.

OUTCOMES

The representation of genomic data must be consistent to ensure health systems can incorporate the data in a standard and persistent way. Key insights from this phase included:

- Expanding community representation in the HL7 FHIR standard
- Bridging knowledge of genomics and FHIR
- Improving data storage, management, security, and provenance
- Providing better educational support for providers and patients
- Increasing health systems' ability to accommodate genomic use cases and data
- Supporting FHIR implementation, including health IT developer support
- Addressing cost and business drivers
- Tackling scaling and scope challenges, such as limited policies supporting genomic exchange and privacy

DEPENDENCIES

- Necessary standards to support the integration of the data
- Knowledge of genomics, FHIR, and the healthcare environment
- Genomic lab test data that is harmonized to the standard at a granular level to facilitate integration

RESOURCES

Resource	Owner	Summary
Sync for Genes: Phase 2 Final Report	ONC	This report outlines Phase 2 activities, exploring approaches to make clinical genomics available at the point of care.
ClinGen – Clinical Genomic Resource	ClinGen	An NIH-funded resource, ClinGen builds a central resource defining the clinical relevance of genes and variants for precision medicine and research. It relies on ClinVar as a source of variant data from diverse sources.
ClinVar	National Center for Biotechnology Information (NCBI)	A free public archive, ClinVar reports on relationships between human variations and phenotypes, providing evidence to support FHIR and other exchange standards (e.g., GA4GH) for implementing, integrating, and using data in patient care and research.
HL7 FHIR Standard	HL7	Created by HL7, FHIR is a next generation standards framework. FHIR solutions are built from a set of modular components called "Resources". These resources can easily be assembled into working systems to solve real-world clinical and administrative challenges.
HL7 Clinical Genomics Work Group	HL7	This group fosters semantic and syntactic interoperability, focusing on individual genomic data, environmental factors, and family health history. It aims to better understand genetic factors in disease and health, while linking to relevant clinical data and knowledge, and supports many products and activities to this end.

Engaging Laboratories
Phase 3

Focus: Implementation, Integration, Use

As the primary producers of genomic test data, laboratories play a crucial role in exchanging clinical genomic results.

Phase 3 demonstrated the ability to share standardized genomic data generated by laboratories while expanding the adoption of the FHIR Clinical Genomics specification. This phase presented a valuable opportunity to test the specification in genomic laboratory settings, identify gaps, and generate insights for HL7 to refine the FHIR standard.

OUTCOMES

Testing the HL7 FHIR Genomics Reporting Implementation Guide (IG) Standard for Trial Use (STU) 1 resulted in several key findings from this phase:

- Importance of semantic representation for understanding detailed information in exchanges
- Need for greater granularity in FHIR standard for complex genomic report exchanges
- Addressing insufficient support for various data types
- Balancing generalization and customization
- Need for development and utilization of translator tools
- Improving the readability of genomics reports, including interpretation in clinical care

DEPENDENCIES

- Ensuring the standard and its supporting semantics are granular enough to enable interoperability

RESOURCES

Resource	Owner	Summary
Sync for Genes: Phase 3 Final Report	ONC	This report outlines Phase 3 activities, summarizing approaches to exchanging genomic data generated by laboratories.
HL7 Genomics Reporting Implementation Guide	HL7	A balloted HL7 Implementation Guide addressing the representation of various types of variants, their relevance, and different DNA sequencing approaches.

Resource	Owner	Summary
Electronic Medical Records and Genomics (eMERGE) Network	National Human Genome Research Institute (NHGRI)	A consortium of U.S. research institutions, eMERGE Network unites researchers to conduct genomics research using electronic medical records for both discovery and clinical implementation.
HLA Reporting Implementation Guide 0.0.1 - Draft	National Marrow Donor Program (NMDP) / Be The Match	Based on NMDP demonstration site findings, this local build details reporting Human Leukocyte Antigens (HLA) genotyping results using HL7 FHIR.
HL7 FHIR Standard	HL7	Created by HL7, FHIR is a next generation standards framework. FHIR solutions are built from a set of modular components called "Resources". These resources can easily be assembled into working systems to solve real-world clinical and administrative challenges.
HL7 Clinical Genomics Work Group	HL7	This group fosters semantic and syntactic interoperability, focusing on individual genomic data, environmental factors, and family health history. It aims to better understand genetic factors in disease and health, while linking to relevant clinical data and knowledge, and supports many products and activities to this end.

Sharing Genomic Data for Patient Care
Phase 4

Focus: Use

Utilizing application programming interfaces (APIs) to share standardized, interoperable genomic data can enhance patient care by facilitating the exchange of genomic information and knowledge among individuals in clinical and research settings.

Phase 4 aimed to develop and test health IT infrastructure for interoperable sharing of genomic data with individuals. Building upon previous phases, it focused on advancing genomic information sharing and knowledge support using standardized FHIR® APIs. Demonstrations showcased electronic genomic data exchange between organizations and data receivers, such as patients or caregivers.

OUTCOMES

A more comprehensive exploration of genomic data sharing incorporated findings from two demonstration sites and detailed discussions on current challenges in genomic data exchange, integration, and use. Key insights from these activities included:

- Developing interoperable genomic standards
- Creating a sandbox environment for genomic standards
- Supporting the implementation and adoption of genomic standards
- Identifying opportunities to improve educational content
- Exploring ways to address policy gaps
- Resolving applicable policy issues

DEPENDENCIES

- Agreement on the data to be exchanged and the necessary level of detail to support its use after the exchange
- Receiving systems capable of accepting the data and ingesting its semantics in a standardized manner, enabling data sharing

RESOURCES

Resource	Owner	Summary
Sync for Genes: Phase 4 Final Report	ONC	This report outlines Phase 4 activities, comprehensively examining challenges to the widespread implementation and adoption of interoperable genomic standards.
HL7 FHIR Genomics Implementer Guidance	HL7	A FHIR Implementation Guide (IG) landing page showcasing the Clinical Genomics Workgroup's development of standards for reporting structured genomic data using FHIR.
HL7 Genomics Reporting Implementation Guide	HL7	A balloted HL7 Implementation Guide addressing the representation of various types of variants, their relevance, and different DNA sequencing approaches.
HL7 FHIR Standard	HL7	Created by HL7, FHIR is a next generation standards framework. FHIR solutions are built from a set of modular components called "Resources". These resources can easily be assembled into working systems to solve real-world clinical and administrative challenges.
HL7 Clinical Genomics Work Group	HL7	This group fosters semantic and syntactic interoperability, focusing on individual genomic data, environmental factors, and family health history. It aims to better understand genetic factors in disease and health, while linking to relevant clinical data and knowledge, and supports many products and activities to this end.

Standardizing Genomic Variant Sharing and Interpretation for Clinical Knowledge

Phase 5

Focus: Integration, Use

Standardizing genomic variant sharing and interpretation for clinical knowledge requires standardization in both genomic variant sharing and data interpretation for more informed clinical decision-making.

Phase 5 aimed to improve access to variant annotation data, facilitating the clinical interpretation of genomic variants. A panel of experts was convened to prioritize future efforts in this area, while a demonstration site showcased real-time sharing of annotated genomic information using GA4GH-encoded knowledge and delivered through HL7® FHIR® Genomics Operations.

OUTCOMES

As variant annotations are frequently used in genomic testing, integrating their findings within a clinical setting is an important step for combining genomics with clinical information. Key findings from this phase included:

- Extending and harmonizing existing standards to support new data types and use cases
- Improving interoperability by harmonizing genomic annotation across domains
- Developing or encouraging the use of an environment for implementers to evaluate standards before installation, document best practices, and share lessons learned
- Identifying and supporting platforms providing guidance for institutions developing infrastructure (hardware and software) to handle genomic data
- Lowering barriers for care teams and patients with thoughtful clinical decision support (CDS)
- Fostering robust training, education, and support to enable standardized genomic data representation, exchange, and use

DEPENDENCIES

- Presenting data to healthcare teams at the point of care requires well-mapped semantic mappings from variant tests to EHRs
- FHIR resources need to be granular enough to support variant mappings
- EHR systems must ingest information in a way that can be displayed during treatment and presented in a manner that makes sense to the care team

RESOURCES

Resource	Owner	Summary
Sync for Genes: Phase 5 Final Report	ONC	This report outlines Phase 5 activities, detailing the findings and recommendations for improving access to genomic variants for clinical interpretation.
GA4GH Variant Annotation Specification (VA-Spec)	Global Alliance for Genomics and Health (GA4GH)	Draft specification intended to define a set of distinct schema to represent different kinds of 'Statements' (central piece of knowledge) made about genetic variantions - each built on a common core information model.
HL7 FHIR Genomics Implementer Guidance	HL7	A FHIR Implementation Guide (IG) landing page showcasing the Clinical Genomics Workgroup's development of standards for reporting structured genomic data using FHIR.
HL7 Genomics Reporting Implementation Guide	HL7	A balloted HL7 Implementation Guide addressing the representation of various types of variants, their relevance, and different DNA sequencing approaches.
HL7 FHIR Genomics Operations	HL7	FHIR Genomics operations provide a uniform interface for applications accessing genomic data repositories, regardless of internal data structures.
HL7 FHIR Standard	HL7	Created by HL7, FHIR is a next generation standards framework. FHIR solutions are built from a set of modular components called "Resources". These resources can easily be assembled into working systems to solve real-world clinical and administrative challenges.
HL7 Clinical Genomics Work Group	HL7	This group fosters semantic and syntactic interoperability, focusing on individual genomic data, environmental factors, and family health history. It aims to better understand genetic factors in disease and health, while linking to relevant clinical data and knowledge, and supports many products and activities to this end.

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ClinVar	National Center for Biotechnology Information (NCBI)	A free public archive, ClinVar reports on relationships between human variations and phenotypes, providing evidence to support FHIR and other exchange standards (e.g., GA4GH) for implementing, integrating, and using data in patient care and research.
Clinical Interpretation of Variants in Cancer (CIViC)	CIViC	CIViC is a free, expert-curated database for clinical interpretation of genomic variations in cancer.
Pharmacogenomics Knowledge Base (PharmGKB)	PharmGKB	PharmGKB is an NIH-funded resource detailing how human genetic variation affects medication response, covering clinically actionable gene-drug associations and genotype-phenotype relationships.
HL7 FHIR Genomics Operations Reference Implementation	Elimu Informatics	This open-source GitHub repository contains a public reference implementation for HL7 FHIR Genomics Operations, using synthetic or anonymized patient data.

Conclusion

The Sync for Genes project has significantly addressed high-priority challenges in the adoption, integration, implementation, and use of genomic data. This work emphasizes the need for ongoing development and refinement of standards for data collection, exchange, interpretation, and use. Standards development organizations like HL7 and GA4GH work diligently to standardize data representation and exchange, but feedback and practical applications of these standards remain crucial. Ensuring sustained coordination between current practices and evolving requirements, as well as expanding the implementation and use of standards, is essential.

The advancement of genomic data sharing relies on individuals and organizations refining and developing standards that accurately represent the work being done in the genomics community. Sharing this information effectively with researchers and care teams is vital. The Sync for Genes project and its stakeholders have made considerable contributions to support the use of genomic data for robust research and improved patient care.