

WEDI Workgroup (WG) / Sub Work Group (SWG) Template
Genomic Data Exchange

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| WG/SWG Topic(s): | Genomic Data Exchange |
| WG/SWG Lead(s) (Name, Email, Phone): | Katherine Johansen Taber, Adam Scott and Grant Wood |
| Primary List Serve Address | WEDI-Genomics@lists.wedi.org |
| WG/SWG Scope of Work | |
| What is in scope? Provide the topic and definition of the topic. | The newly formed Workgroup emerged from an initial investigation into a wide range of genomic information exchange issues – including genomic data formats, exchange, privacy controls, security, storage, management, governance, care coordination and payer-provider collaboration – from the preliminary taskforce in the first quarter of 2015. This workgroup will focus on creating a common stakeholder vision and roadmap on how to incorporate genomic data into the American healthcare system. The workgroup will also develop recommendations for healthcare stakeholders and potentially government agencies. |
| Identify any assumptions | <ul style="list-style-type: none"> • All business issues submitted to the WG will be addressed. • Issues outside the WG's scope will be forwarded to the most appropriate WEDI group. • WG participants will work collaboratively to address identified issues. |
| What is out of scope? | <ul style="list-style-type: none"> • Development of standards themselves • Providing specific advice, legal or consulting, to individual organizations • Commenting on the regulatory oversight process of lab testing and genomic testing |
| WG/SWG Purpose | |
| What is the primary goal? | <ul style="list-style-type: none"> • Evaluate and outline a common stakeholder vision for genomic data in healthcare • How to build a national infrastructure to support this genomic data • How to create seamless workflows to enhance the delivery and coordination of care |
| What business problem will be minimized or resolved by this workgroup? | With all of the latest advances in genomic sequencing, profiling, testing and phenotyping, the healthcare industry is quickly entering a completely new era of personalized medicine. We are dealing with very large data sets that are unprecedented in healthcare. This progress will require more advanced health information technology, capable of rapidly accessing, exchanging and processing information to fully inform diagnostic, treatment and prevention decisions at the point of care. This workgroup will investigate not only how to build a national infrastructure to support this genomic data, but how to use actionable analysis to create seamless workflows to enhance the delivery and coordination of care. |

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| Stakeholders | Healthcare providers HIT Vendors Payers Specialty Associations/Societies Patient Advocacy Groups Broader Technology Community Regulatory Agencies & Policy Makers Labs |
| Describe the central problem this project will attempt to resolve. What are some of the symptoms of this problem? Are there any corollary problems? | The initial taskforce discussions reviewed the current landscape of clinical genomics and identified some of the key opportunities, challenges, strategies, and risks to integrating genomics into care coordination. Broadly speaking, these issues can be categorized into three domains: <ul style="list-style-type: none"> • Data access and integration - how should standardized genomic data be easily retrieved in discrete formats for actionable decision-making, interpretation, and reinterpretation • Data exchange – how should genomic data be rapidly, safely, and securely transmitted between stakeholders (including laboratories, providers, patients, and health plans) • Data governance – how should genomic data be securely stored to protect the privacy and confidentiality of information with robust privacy and consent models |
| Are there other regulatory or contractual obligations that might affect how this project is implemented? | FDA Regulations ONC – Meaningful Use |
| Objectives / Measures of Success / Deliverables <i>(template allows for 3 projects for a specific WG/SWG)</i> | |
| Project #1 Title: | Issues and Trends in Electronic Genomic Data Exchange |
| What outcomes do you expect to achieve? Will there be a phased in approach? | A white paper will provide an overview of key issues and suggested action items around the electronic exchange of genomic data. |
| What is the ideal outcome? | Develop written educational materials to serve as resources and promote discussion for stakeholders interested in the electronic exchange of genomic data. |
| How would you define success for this workgroup? | The WG provides relevant resources and recommendations for stakeholders related to the electronic exchange of genomic data. |
| What are the potential business impacts if the solution(s) is not implemented? | The health care industry lacks knowledge and understanding of the electronic exchange of genomic data. |
| What are the current deliverables or outcomes that are expected and the completion dates for each deliverable? | The WG expects to publish this white paper in the 3 rd quarter of 2015. |
| How much time or resources need to be committed to complete deliverables? | The WG will meet on a regularly scheduled basis in order to complete the deliverables. Time and resources will be dependent on the number of resources to develop and the topics. |
| Environmental Factors / Support Needs | |
| Are there other individuals/entities/work groups that need to provide input? | Coordinate with the Privacy/Security Workgroup if touching on either of these type of issues when constructing content. |

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| What tools does the workgroup need to acquire to ensure this project is successful? | No special tools will be required at this time, other than standard items such as a listserv. |
| Do you need additional administrative support? | Assistance from the WEDI administrative staff will be helpful. |
| Do you need additional project management support? | Assistance from the WEDI administrative staff will be helpful. |
| Do you need additional communication support? | Assistance from the WEDI administrative staff will be helpful. |
| Additional Comments or Concerns | |
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