

Genetic Counseling Using Workflow-based EMRs

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ABSTRACT

Widespread use of genetic tests for medical treatment and clinical genetic counseling—as a cost-effective treatment for an increasing number of hereditary disorders—has led to study of privacy and disclosure issues, and has compelled governments to limit disclosure of test results. To the best of our knowledge, no clinical workflows for genetic counseling apply applicable information disclosure laws have been documented and enforced in Electronic Medical Records (EMRs). To fill this void, herein we model a representative genetic counseling workflow and show how to simultaneously enforce privacy and informed consents in an open-source EMR. Our prototype provides workflow-guided counseling as well as consent management that enforces state and federal law-compliant genetic information sharing.

Categories and Subject Descriptors

J.3 [Life and Medical Sciences]: Medical Information Systems; H.4.1 [Information Systems Applications]: Office Automation—*Workflow management*

General Terms

Workflow, Healthcare Privacy Laws, Genetic Tests, Information Disclosure, Informed Consent

Keywords

Informed medical consent, Genetic counseling, Electronic Medical Records (EMRs), Workflow management systems

1. INTRODUCTION

As genetics research advances, the list of predictable diseases is growing. For example, having been identified genetic mutations which associated with diseases include breast cancer, ovarian cancer, sickle cell anemia, etc. Studies have shown that preventive care costs significantly less than treatment upon diagnosis of a disease [18, 26]. Therefore, genetic

tests, along with family history, are becoming a common practice in identifying risks of many hereditary conditions. clinical genetic services are the complex processes, usually involve genetic tests for finding gene mutations to make eventual disease onset predictable and Genetic counseling for explaining genetic test outcomes and suggest possible courses of action [12] to genetic tests requesters. Genetic test results are not only being used as indication basis for providing preventive and preemptive treatment for hereditary diseases, but also being broadly utilized for research purposes to discover more and more new findings. To compare with other medical researchers, researchers in genetic medicine need to use both genetic test results and their owners’ identifiable information, so more open accesses are required, e.g. using an opt-out consent that is much less rigorous in format for sharing data.

Genetic tests usually involve finding known changes - referred to as *mutations* - in a gene of a person that cause diseases. Researches have identified genetic mutations associated with various diseases such as breast cancer, ovarian cancer, sickle cell disease, β -thalassemia, left ventricular non-compaction cardiomyopathy (LVNC), and Alzheimer disease and many others. As new research on known gene mutations become available, and medically acceptable as indications, more diseases are added to the list for genetic tests that are available.

Several companies such as 23andMe [1], Gene by Gene [4], Color Genomics [3] etc. offer genetic tests and risk assessment services in the direct consumer market. Additionally, larger laboratories such as Myriad Genetics cater directly to health-care providers [8]. Information from these results are analyzed by professionals in genetic science who then provide counseling services to patients. With increased competition and lower costs of genetic tests [7], genetic counseling is going to play an important role in preventive care. This places genetic counselors in a critical path to explain the outcomes of genetic tests, and suggest possible courses of action [19].

Conducting genetic tests involves addressing ethical and privacy issues. Samples of human blood/tissue, and derived genetic information are able to precisely identify an individual and a group of related people that may be susceptible the same diseases as the original sample donor. Consequently, when genetic sequence information is shared without consent, lost, stolen, or used for a purpose other that which consent was obtained, the identity of a person is compromised. This information can be used by a third party to discriminate or worse harm the donor or a group of people. Prince et. al. describe three practical genetic counseling

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cases that illustrates genetic discrimination [20]. Individuals may face discrimination in life, disability, and long-term care insurance. In other cases when genetic information privacy is compromised, an individual may experience stigma of having to carrying a genetic marker for a disorder or disease.

Although, genetic tests have existed for a while, using genetic information for diagnosis and treatment is a part of a larger process, that is being broadly termed as genetic counseling. Consequently, the precise process (workflows) used by medical practitioners for genetic counseling is not very well defined. A good counter example is the workflow for hemo-dialysis where the a standard workflow for treatment is used by medical practitioners [24]. Although there is a raise in the bio-medical masters degrees awarded by medical schools [14], less than 35 universities have degrees specialization in genetic counseling [2]. This results in difference in the process followed during genetic counseling. As a means of articulating different workflows currently emerging in genetic counseling and their larger usage in patient diagnosis and treatment, we have developed a prototype for genetic counseling in a flexible way of specifying and using these workflows. In our prototype, we implement a workflow based on [17]. However, our tool can be easily modified to accommodate the changes in the workflow at a later stage.

The two US federal laws that regulate sharing of genetic information are Health Insurance Portability and accountability act of 1996 (HIPAA) [10], and Genetic Information Non-discrimination act of 2008 (GINA) [5]. HIPAA considers genetic information to be confidential medical information and regulates health-care providers. GINA regulates employers and health insurance companies but not health-care providers in using genetic information and protects individuals from discrimination based on genetic conditions. However, GINA does not apply to federal government employees or employers with fewer than 15 employees. These complex laws in addition to the fragmented laws in each state forms the basis of information sharing and consent management workflows of our prototype system. In creating our prototype system, we also noticed significant regulatory gaps that creates additional burdens in providing automated work-flow based guidance in genetic counseling.

Challenges. The following are the challenges to implement a work-based EMR for genetic Counseling:

- Genetic Counseling is a new and an emerging field where the work-flow has not been standardized, although providing a basis to do so would facilitate this emerging area and the mission of training genetic counselors.
- Genetic information collected for tests and their sharing have to conform with HIPAA [10] and GINA [5] regulations.
- State laws to protect Genetic information varies and adds complexity to the system. HIPAA specify that stricter sharing laws mandated by state regulation can override HIPAA policies.
- Although commercial systems may include Genetic Counseling in their packaged EMRs, it is difficult to verify their work-flow as they are closed source.

Contributions. In order to address the above limitations of existing EMR systems, we present, to the best of

our knowledge, a first of it's kind end-to-end managed EMR prototype for genetic counseling that can accommodate the emerging workflows and diversity of state regulations (or lack thereof) in a re-programmable way. Our working prototype has the following features:

- Automatically suggests Genetic Counseling for known disease codes
- Enforces a standardized work-flow for Genetic Counseling
- Automates paperless information sharing and medical treatment consent in accordance with local laws

The rest of the paper is organized as follows: Section 2 describes the closely related work in this area. In section 3 we describe the implementation of our system. Finally, we present our conclusions in Section 4.

2. RELATED WORK

Electronic Medical records for Genetic Counseling

Electronic Medical Records (EMRs) plays a vital role of book keeping in the health-care industry. However, EMRs for genetic counseling present a unique set of challenges [13] as identified by Belmont et al. A major issue identified by the Belmont study the required uniformity in representing collected genetic data. Additionally, this study highlights the privacy, ethical and legal issues of handling genetic data in EMRs. Ours is a flexible freeware based platform to study these issues.

Scheuner et. al. conduct a case study to verify if the current EMR systems meets genetic information needs [21]. This study involved results and conclusions gathered from discussion about 56 patient's electronic medical records with 10 EMR specialists, 16 medical geneticists, and 12 genetic counselors. An overall lack of support for functionality, structure, and tools for clinical decision making was an important finding.

A more recent study of the state of EMRs supporting genomics for personalized medicine again identifies structure of data as a challenge [22]. The authors also identify clinical workflow management as a priority area that needs further research , development and testing. Functionality, structure, and support for genetic information specific data is easily added to an EMR system. However, current EMR systems for genetic counseling still lack support for workflow enforcement and the ability to collect specialized genetic information sharing consents and enforce them on EMRs that contain the data.

Genetic Counseling ontology

The Gene Ontology Consortium has developed an ontology to store structured gene information in databases [16]. The ontology provides structured terms and vocabulary to store information regarding gene, gene products and sequences. The structure and terms developed by this team lacks support to capture the terms used for informed consent requirements laid out by law. In a more closely related work, authors in [26] describe an ontology for treatment consent. The ontology presented by the authors for treatment consent is insufficient to capture the terms and vocabulary used for information disclosure consent. In this work, we develop the ontology containing the structure and terms required for information disclosure consent.

Genetic Counseling informed consent

Obtaining informed consent for diagnosis (including testing) and treatments is a very well studied area and a mandatory requirement on care providers. In particular, care providers are required to obtain informed consent for genetic counseling like any other treatment. A preliminary study convened jointly by the National Institute of Health (NIH) and the Center for Disease Control (CDC) [15] present the risks and ethical issues involved in collecting and storing tissue samples for genetic tests in a research setting. Ethical and legal issues are similarly present in a clinical genetic counseling process.

Authors in [25] present an automated and paper less informed consent management system for medical treatments. This work provides a generic framework to enforce informed consent for minors. The work presented in [25] only enforces general treatment consent. This work does not specifically address the additional issues related to genetic counseling and sharing of genetic information. Genetic counseling requires enforcement of information disclosure, research and sample and genetic information retention consents in addition to treatment consent. The objective of this work is to create a workflow that enforces all types of mandated informed consent requirements in the genetic counseling process to comply with local, state and federal regulations.

3. SYSTEM

This section presents details of our prototype genetic counseling EMR system within a sample enforced workflow. We first describe genetic counseling workflow and the challenges involved in modeling the process. Then we present a model of this workflow using a work-flow engine. Next, we describe the different types of informed consent for genetic counseling. We then collate the federal and state laws that regulate disclosure of genetic information. Then we describe how we enforce the disclosure consent for genetic counseling to comply with various state and federal laws. Lastly, we describe how we integrate the workflow enforcement with an open-source Medical Record System (OpenMRS).

3.1 Genetic Counseling Work-flow

The Genetic Counseling Definition Task Force defines *Genetic counseling* as *The process of helping people understand and adapt to medical, psychological, and familial implications of genetic contributions to disease*. A team of health care workers involving, but not limited to, Medical Practitioners, Bio-curators, Genetic Counselors, Molecular Pathologists, Medical Geneticists play an important role in Genetic Counseling. Similar to other medical procedures, genetic Counseling follows a well defined protocol. This protocol involves several tasks performed by the caregivers in a particular sequence called the workflow.

Although genetic counseling has been around for a while, we were unable to find a documented and modeled workflow for this process. Therefore, we present a detailed documentation for clinical genetic counseling. We model our workflow based on a presentation about clinical genetic counseling from Stanford's Clinical Genomics program [17]. In addition to the previous presentation, we refer to another presentation by O'Daniel et. al on Genomic Medicine [18] for additional details. Here we provide a detailed documentation and overview of the Genetic Counseling workflow. Figure 1 shows the workflow for genetic counseling mod-

eled using a workflow editor, created using an open-source workflow system YAWL [23].

Our modeling of the workflow is tailored to genetic counseling for Hereditary Cancer Syndromes. However, this can be modified to accommodate any other genetic disorder. The following list walks through the details of the individual tasks involved in the process of providing genetic counseling to a patient. The following list focuses on describing individual tasks involved in the genetic counseling process. We present the details of consent management later in section 3.2.

1. Collection of Medical Records, Family History, and Social History:

- *Require Genetic Counseling:* A genetic counseling case originates with a physician's referral for a genetic counseling. Alternatively, in other cases a patient self requests genetic counseling after learning of a manifestation of a genetic disorder in a family member.
- *Patient Walk-in:* In the case where a patient self requests genetic counseling, upon arriving at the genetic counselors office, the patient is asked to provide social and family history. Additionally, if copies of medical records are provided, they are recorded in the system. In our workflow model, the patient is presented with a detailed family and social history questionnaire to assess the risk of a suspected Hereditary Cancer Syndrome. We model this questionnaire based on forms developed by the Virginia Women's Center [11].
- *Physician's Referral:* When a physician refers a patient for genetic counseling, the patient is asked to sign release forms for medical records from the referring physician (if not already provided). Else, if the patient brings in copies of medical records, they are recorded in the system.
- *Requirements Review:* Information collected from the patient is reviewed for completeness. If any, missing information is collected from the patient, patient's primary care physician or public sources of ancestry information. This is shown in the 'Collect More Information' process in the modeled workflow (Fig. 1). Once all of the information (to the best of patients knowledge) is collected, one or more of following people review the collected information: Genetic Counselor, Molecular Pathologist, Medical Geneticist. Next, they verify if a genetic test is available to answer the questions posed by the patient or the treating physician.

2. **Pre-test counseling:** Once an insurance or payment authorization is obtained, the patient meets with a genetic counselor for pre-test counseling. The genetic counselor performs the following sub-tasks for pre-test counseling:

- An informed consent is obtained for counseling, i.e., Genetic Counseling Treatment Consent. As a part of this informed treatment consent, the counselor provides the patient with information about the risks and benefits of this process.

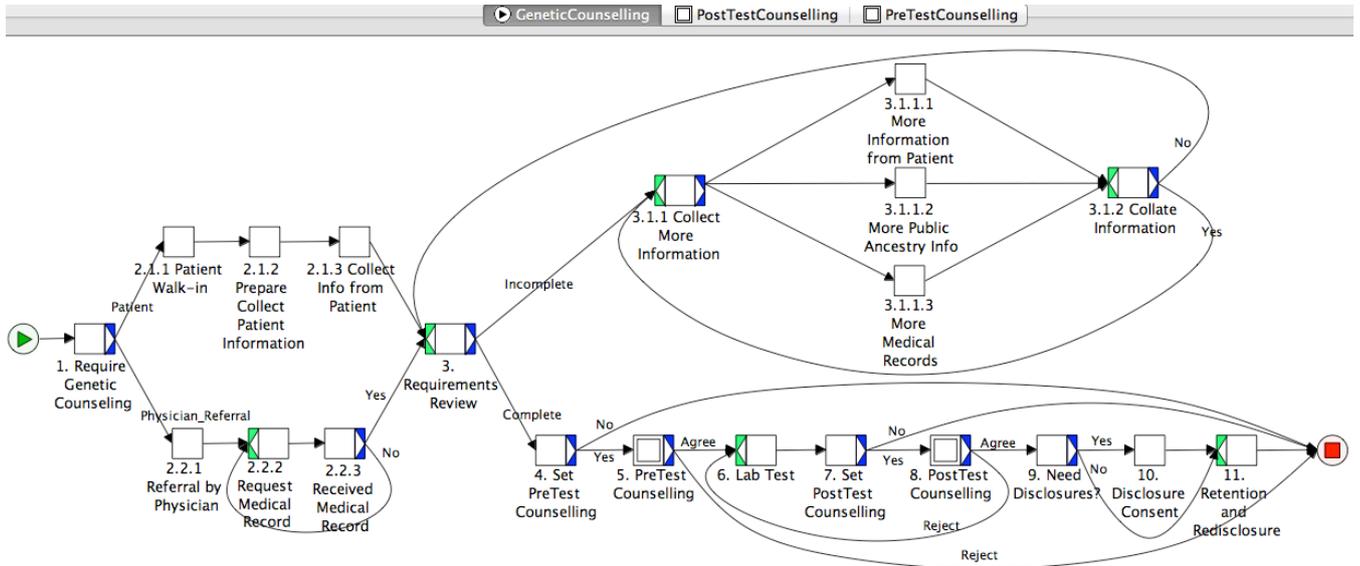


Figure 1: Genetic Counseling Workflow

- The family, social, and medical history provided by the patient is reviewed.
 - The counselor discusses the expected range of results and their impact on the patient and their relatives. Additionally, the counselor discusses other potential incidental findings that may be in the report. Incidental findings are those findings in the test results that are not associated with the primary reason for conducting the test, but indicative of other genetic disorders. The counselor also discusses ethical issues that could arise from conducting or disclosing these test results. Before ordering the tests, any questions or clarifications from the patient are answered.
 - If applicable, consent for sharing information for research purposes is collected.
- 3. Lab work:** Blood or tissue samples are collected from the patient for genome sequencing. Generally, 1 tube of blood is collected for sequencing. An additional tube may be collected for confirmatory studies. Another tube of blood may be collected from the patient with appropriate consent for research purposes. The blood and tissue samples are then sent to a laboratory for sequencing and the sequenced genetic information is returned to the genetic counseling team. We do not model the workflow for genome sequencing in the laboratory in this paper.
 - 4. Post-test counseling:** Once the sequencing results are reported back to the genetic counseling team, a draft report is prepared. This draft report is reviewed by a review team consisting of Genetic Counselors and/or Medical Geneticists, Physicians, and/or content experts. Once reviewed, the final report is uploaded into the EMR and is ready for the patient. When the patient meets the counselor to discuss the test results, the following sub-tasks are performed:
 - The test results are reviewed by the counselor with the patient. Once the review is complete, the counselor assess the comprehension and coping skills of the patient.
 - If the additional evaluation or referral for treatment (e.g. prophylactic mastectomy) is warranted, referrals or orders are issued by the genetic counselors. Alternatively, the patient may decline to accept the recommendations of the genetic counselor. If the recommendations are declined, it is recorded in the EMR.
 - The counselor finally discusses implications of the findings on related family members. At this point, the genetic counselor may recommend the patient to personally inform related family members about the test results and treatment options by providing templates. Alternatively, they may obtain consent to disclose test results to affected family members.
 - Lastly, if required, the counselor may schedule follow up appointments .
 - 5. Disclosure and other Consent:** At the end of the genetic counseling process, the care provider may be required to obtain consent to retain samples and/or genetic information (sequencing results) and genetic test reports based on state and federal regulation. Additionally, the care provider may require additional disclosure consents to share information with other individuals or entities as required by law. If consent to retain genetic samples and test information is denied, they must be destroyed and/or purged from the EMR records. Once these housekeeping tasks are complete, the genetic counseling workflow comes to an end.

3.2 Informed Consent in Genetic Counseling

As discussed earlier, if a proper workflow is not enforced for genetic counseling in the EMRs, it may leave health-care

Figure 2 shows the workflow specification for the different types of consent modeled in YAWL. The consent workflow runs as a separate service in the workflow engine. When a consent a task requires consent in the genetic counseling workflow, the consent workflow is invoked to manage the consent requirements. In the case of information disclosure consent, the workflow checks the purpose for the information request. HIPAA classifies these purposes into different disclosure categories described later in this section. If the disclosure type requires a consent, the consent workflow enforces this requirement. For simplicity, our modeled workflow enforces retention and research consent for all states as it is a best practice. For a detailed working of the treatment consent tasks, we refer you to [25].

In order for the workflow to enforce all of the above consents for genetic counseling, we use a rule base to codify laws. We do so by first modeling the term structure we use to specify rules and then use OWL Description Logic (DL) to specify these rules using the terms created in our ontology. We use the open source ontology editor Protégé and Pallet reasoner to create the rules and specify the rules respectively. During the counseling process, the workflow engine YAWL invokes the rule bases's run-time to determine the required consents and generates the required consent forms that are displayed to the patient. Once the patient signs the forms, the workflow proceeds to the next step, thereby enforcing federal and applicable state laws during the counseling process.

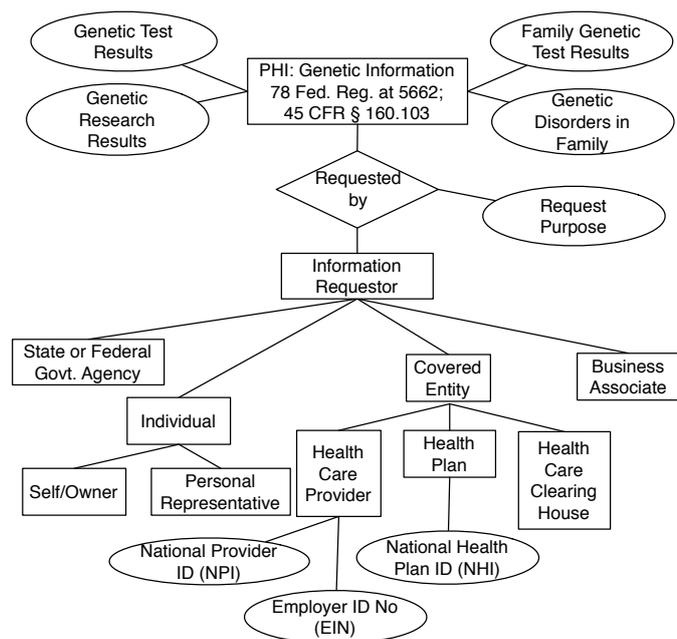


Figure 3: Entity-Relationship Diagram for Genetic Information

In order to model the terms structure for genetic information disclosure, we start by identifying the relationship between the information requester and Protected Health Information (PHI) as defined by HIPAA. Figure shows the ER diagram for information disclosure consent in genetic counseling 3. The figure shows the *requests* relationship between an *information requester* and *Genetic Information*. Genetic

Information is considered as Protected Health Information (PHI) according to HIPAA. Definitions pertaining to Genetic information are included in detail in this legislation. An individual's Genetic information is defined to include the following:

- Genetic test results of the patient
- Genetic Research results of the patient
- Genetic test results of a related family member
- Information about manifestation of a genetic disorder in a family member

HIPAA permits or denies information disclosure of PHI and states the informed consent requirements based on the type of information requester and the purpose for which the information is being requested. HIPAA further classifies an information requester as State/Federal Agencies, Individuals, Covered Entities, and Business Associates. These sub types are shown in the Figure 3. Based on type of the requester requesting access to genetic information, HIPAA classifies request purpose into the following categories:

- **Required Disclosures:** Required disclosures do not require any consent from the patient and are required to be disclosed. E.g. HHS Compliance Review
- **Permitted Disclosures:** These disclosures are permitted by law without consent. However, an organization may choose to implement policies and procedures requiring additional consent requirements. Examples of permitted disclosures include Treatment, Health care Operations, Public Interest and Beneficial Activities etc.
- **Authorized Disclosures:** Authorized disclosures require informed consent from the patient, such as for General Research, Marketing, Psychotherapy Notes etc.

The complete set of Privacy Rules were obtained from HIPAA located at 45 C.F.R. Part 160. These rules are then written into the Pallet reasoner for enforcing information disclosure consent requirements. In addition to the federal information disclosure requirements described in HIPAA. State laws regulate genetic information disclosure. They may have additional or fewer requirements when compared to HIPAA. For example, Delaware has a comprehensive code on regulating disclosure of genetic information and test results. On the other hand, states such as Alabama have no specific legislation.

In 2008, only 27 of the 50 states had specific laws requiring consent to disclose genetic information [6]. As of 2014, this number had risen to 35 [9]. Other states are acting swiftly to protect address the issue of genetic information privacy of it's citizens. We gather all pertinent state laws governing genetic information passed until 2014 from [9]. Table 1 shows genetic information disclosure laws for a sample of selected states. These laws were then transformed into a simple algorithm to permit or deny disclosures of genetic information. Finally, these algorithms were translated into rules in the reasoner as described above. Figure [REF] shows a rule written to enforce a state laws in the Pallet reasoner.

Need from Bo

Flowchart 4 shows how genetic information disclosures are allowed or denied in a based on organizational policies,

State	Informed Disclosure Consent Law	Required/Permitted Disclosures
Alabama	N/A	N/A
...		
Delaware	<ul style="list-style-type: none"> - Unlimited access by subject to their own genetic information - Disclosures are to be authorized by obtaining informed consent of the tested individual describing the information to be disclosed and to whom 	<ul style="list-style-type: none"> - Disclosure is necessary for the purposes of a criminal or death investigation or a criminal or juvenile proceeding or to protect the interests of an issuer in the detection or prevention of fraud, material misrepresentation or material nondisclosure - Disclosure is necessary to determine paternity - Disclosure is authorized by order of a court of competent jurisdiction - Disclosure is made pursuant to the DNA analysis and data bank requirements of §4713 of Title 29 - Disclosure is for the purpose of furnishing genetic information relating to a decedent for medical diagnosis of blood relatives of the decedent - Disclosure is for the purpose of identifying bodies - Disclosure is pursuant to newborn screening requirements established by state or federal law - Disclosure is authorized by federal law for the identification of persons - Disclosure is by an insurer to an insurance regulatory authority - Disclosure is authorized in accordance with §1201(4)d. of this title - Disclosure is otherwise permitted by law
...		
Florida	Informed consent is required to disclose genetic test results	Public entities are exempt from disclosure restrictions. Pursuant to Florida Statutes §119.07(1) and Statutes 42(a), Article 1 of the Florida Constitution
...		
Wyoming	N/A	N/A

Table 1: State Laws limiting Genetic Information Disclosure

State, and Federal laws 4. When genetic information/test results is requested, information about the requester, Request purpose, and genetic information are collected in the EMR system. This is then passed to the modeled workflow. The workflow then uses the reasoner then informs the modeled workflow if a consent is required. The workflow then triggers the EMR system to display appropriate consent forms. When both state and federal laws exist, HIPAA resolves this contention by providing precedence to the law that does not require a consent for information disclosure. This precedence rule is implemented in the reasoner. The flowchart 4 allows for individual organizational policies in the information disclosure process. However, our implementation does not model any organizational information disclosure policies.

3.2.2 Workflow enforced EMR

Finally, we modify the source code of OpenMRS, an open source Electronic Medical Record System to provide specialized interface for genetic counseling. Additionally, we add JSP scripts to OpenMRS to generate treatment, information disclosure, and research consent. The EMR communicates with the YAWL run-time which in-turn communicates with the reasoner to complete our prototype system. Our system is able to enforce the genetic counseling workflow and all of the consent requirements in accordance with state and federal laws. Figure 4 shows a screen-shot of a patients ge-

netic counseling record displaying an information disclosure consent form. **Need from Bo**

4. CONCLUSIONS

In order to model the genetic counseling workflow, we present and document the details of the sequence of tasks performed by the care providers during Genetic counseling process. We, also study and extract rules from federal and state laws that limit the disclosure of genetic information. We use these rules to implement a workflow enforced Electronic Medical Record System tailored to work for Genetic Counseling.

To the best of our knowledge, our work presents a first working open-source prototype EMR for genetic counseling. Our genetic counseling EMR supports automatic paperless enforcement of treatment consent, information disclosure consent, research consent, and retention consent. This workflow enforced genetic counseling EMR would enable genetic counseling services provided by care providers and health care organizations to comply with state and federal laws concerning genetic information privacy. As a result, our EMR saves care providers and health care organizations from unnecessary litigation that would arise when proper procedure is not followed. Additionally, the electronic audit trail left by our EMR would help care providers and health care organizations in times of litigation.

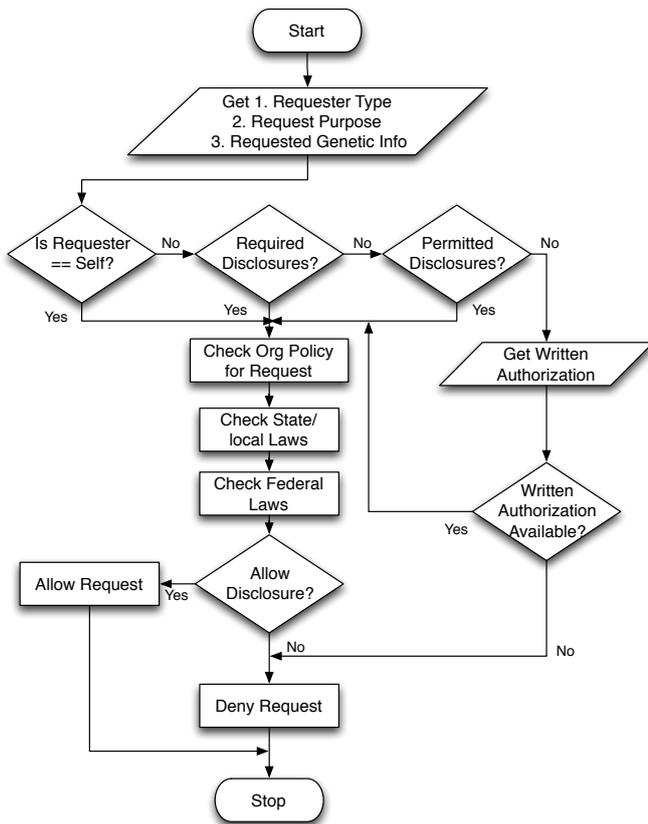


Figure 4: Flowchart for allowing or denying Genetic Information Disclosures

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