Distribution Agreement

In presenting this thesis as a partial fulfillment of the requirements for an advanced degree from Emory University, I hereby grant to Emory University and its agents the non-exclusive license to archive, make accessible, and display my thesis in whole or in part in all forms of media, now or hereafter known, including display on the world wide web. I understand that I may select some access restrictions as part of the online submission of this thesis. I retain all ownership rights to the copyright of the thesis. I also retain the right to use in future works (such as articles or books) all or part of this thesis.

__________________________________________  ________________
Signature of Student                        Date
PUBLIC HEALTH INFORMATION SYSTEMS
ARCHITECTURE AND IMPLEMENTATION

By
Cara A. Rivera
Degree to be awarded: M.P.H.
Executive MPH

Melissa Alperin EdD, MPH, MCHES     Date

Laurie Gaydos, PhD                         Date
PUBLIC HEALTH INFORMATION SYSTEMS
ARCHITECTURE AND IMPLEMENTATION

By
Cara A. Rivera
Degree to be awarded: M.P.H.
Executive MPH
# Table of Contents

Introduction .......................................................................................................................... 2

I. World’s Ear Application and Registry ............................................................................. 2
   Problem Statement .......................................................................................................... 2
   Project Details ................................................................................................................ 2

II. National Chronic Kidney Disease Registry ................................................................. 15
   Problem Statement ....................................................................................................... 15
   Project Details ............................................................................................................... 16
   Registry Development Discussion .................................................................................. 21

III. How to Train Your Dragon- Clinical Informatics Training Development .............. 21
   Problem Statement ...................................................................................................... 21
   Project Details ............................................................................................................... 21
   Clinical Informatics Training Development Discussion .............................................. 24

Conclusion .......................................................................................................................... 24
Introduction

This thesis document demonstrates the skill and knowledge that has been acquired during my Executive Master's of Public Health program. The written document will provide an overview of three key deliverables that summarize my main areas of development:

- Public Health Systems Architecture
- System Development and Implementation
- Business and Program Management in Public Health
- Program evaluation

As a budding informatician, the aforementioned areas of development are invaluable. The public health informatics deliverables detailed in this document provide an example of the variety that can be found in the work of a public health informatician. The ability to incorporate emerging technologies, conduct strategic planning, and appropriately evaluate public health systems and programs will play an important role in leading public health organizations through changes over time.

The projects described in this document allowed me to explore and demonstrate how emerging technologies can be adapted to a public health informatics architecture. Additionally, I have acquired the skills to identify, at a high level, the system interfaces that would be required to utilize the new technologies in a public health setting.

1. World’s Ear Application and Registry

   Problem Statement
   Individuals with Meniere’s disease and other vestibular disorders are often unable to determine the root cause of their ailments. Meniere’s can cause debilitating vertigo and permanent hearing loss in the effected ear.

   Recommendation- The proposed informatics capability is a cloud based application that connects with hearing aids and other medical devices to provide health data to the user’s medical providers. It is also recommended that a registry be established for patients with varying levels of hearing loss, inner ear and balance disorders, and those with unexplained non-epileptic seizures and/or syncope. The registry will provide a full view of the patients’ vitals and overall health which will simplify and improve accuracy of diagnosis.

   Project Details
   BUSINESS NEED

   According to WHO (2017), there are approximately 360 million people living with disabling hearing loss in the world. Many of these cases stem from preventable causes. WHO has the Programme for the Prevention of Deafness and Hearing Loss. The aim of this program is “To establish community-based, sustainable and inclusive strategies for ear and hearing care, integrated within the primary health care systems of WHO's Member States1.”

   A registry is needed to gather data regarding symptoms, chief complaints, treatment/intervention results, and comorbidities on patients suffering from Meniere’s Disease and other hearing and balance related ailments. The accompanying application World’s Ear application works with
patient hearing aids and other health wearables to collect information that is not readily available to physicians during in house visits.

The application is necessary to provide physicians and care providers with health data during a patient’s everyday life in environments that are difficult to recreate in a clinical setting.

PUBLIC HEALTH AND BUSINESS IMPACT

The data gathered may be helpful in identifying attack triggers, stressors, and identify the exact points of change in vital signs related to the disorder. The affected individual may have no symptoms between attacks, though over time the hearing loss tends to get progressively worse. This type of data collection will provide more information to make a sound diagnosis. Accurate diagnosis of the target ailments will improve the accuracy of prevalence and treatment data.

STRATEGIC ALIGNMENT

<table>
<thead>
<tr>
<th>Goal</th>
<th>Project Response Rank</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improve the health of 1M/10M</td>
<td>H</td>
<td></td>
</tr>
<tr>
<td>Provider of choice</td>
<td>H</td>
<td></td>
</tr>
<tr>
<td>Innovative discovery</td>
<td>M</td>
<td></td>
</tr>
<tr>
<td>Education destination of choice</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Best place to work</td>
<td>L</td>
<td></td>
</tr>
<tr>
<td>Strategic growth and investment</td>
<td>L</td>
<td></td>
</tr>
</tbody>
</table>

Scale: H – High, M- Medium, L – Low, N/A – Not Applicable

Emory Healthcare Strategic Goals:

SCOPE

OBJECTIVES

Improving health outcomes for patients with Meniere’s Disease, syncope, non-epileptic seizures and other inner ear and balance disorders by gathering data that is typically not captured during the time of need.

The objectives of the World’s Ear are as follows:

- Collect data during patients’ daily lives to capture vital information during ailment flare ups.
- Advance treatment and intervention options for Meniere’s Disease patients
- Advance research on Meniere’s Disease and other vestibular disorders by providing data on triggers, complications, and disease progression
HIGH-LEVEL REQUIREMENTS

The following table presents the requirements that the project’s product, service or result must meet in order for the project objectives to be satisfied.

<table>
<thead>
<tr>
<th>Req . #</th>
<th>Requirement Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>The registry must be capable of collecting data from the target patient group (Meniere’s Disease, syncope, non-epileptic seizures, vestibular disorders)</td>
</tr>
<tr>
<td>2.</td>
<td>The registry and application must be built on a cloud based solution</td>
</tr>
<tr>
<td>3.</td>
<td>The solution must integrate with medical devices to collect and analyze data</td>
</tr>
<tr>
<td>4.</td>
<td>The solution must support HL7 messaging standards.</td>
</tr>
</tbody>
</table>

MAJOR DELIVERABLES

The following table presents the major deliverables that the project’s product, service or result must meet in order for the project objectives to be satisfied.

<table>
<thead>
<tr>
<th>Major Deliverable</th>
<th>Deliverable Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completed registry</td>
<td>The completed registry will contain information for patients with Meniere’s disease, unexplained syncope, non-epileptic seizures, and inner ear balance disorders</td>
</tr>
<tr>
<td>Application for Health Wearable connection</td>
<td>The application will enable health wearables and hearing aids to feed information to a patient portal that can be accessed by the patient’s physician during a visit.</td>
</tr>
</tbody>
</table>

Additionally, the registry and application increases patient choice in providers. Vestibular disorders and the target ailments for this project are unfortunately often diagnoses of exclusion¹. Therefore, patients may be required to see several different types of specialists and providers over a period of time. Limited patient information and health data connections may cause frustration, misdiagnosis, and/or missed opportunities for identifying health data correlations. Increased access to the aforementioned data points will allow varying providers to address patient needs and increase the accuracy of diagnosis.

---

¹ Reference: "Vestibular disorders are often diagnoses of exclusion. This means that patients may be required to see multiple specialists to determine the cause of their symptoms."
EMORY HEALTHCARE ORGANIZATIONAL INFRASTRUCTURE

The Emory Healthcare systems that will be affected by the implementation of the World’s Ear application and registry are:

**Transactional Systems:** The health information collected by the application and placed into the registry will be supplemented by physician entered data from patient EHRs, LabCorp, Quest and other relevant EeMR data.

**Repositories:** World’s Ear technology will require a new repository that will integrate with Emory Healthcare’s existing Clinical Data Warehouse.

**End User Analytics:** The end-user analytics listed above will be utilized to create data visualizations and analysis for patient data. The visualizations and analysis from the registry will provide a comprehensive view of the patient’s symptoms, patterns, and overall health.
## ENTERPRISE ARCHITECTURE

### BUSINESS PROCESSES

<table>
<thead>
<tr>
<th>Process</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Send data</td>
<td>Push data from application to registry</td>
</tr>
<tr>
<td>Data agreement for health wearables</td>
<td>A data use/sharing agreement will be required for health wearables that are not considered medical devices.</td>
</tr>
<tr>
<td>Install application on mobile devices</td>
<td>Patients enrolled in the World’s Ear application and registry will install the application on the device that is connected to their health wearable.</td>
</tr>
<tr>
<td>Link health wearable with application</td>
<td>Following the installation of the application on the appropriate device, the user will need to link their health wearable to the application to ensure the proper data connection.</td>
</tr>
<tr>
<td>Physician query for patient data</td>
<td>Information from the World’s Ear application will be accessible to the patient's provider</td>
</tr>
<tr>
<td>Analyze Data</td>
<td>Application data will be available for viewing by patients and physicians in a variety of views in order to best show potential links.</td>
</tr>
<tr>
<td>Establish Database</td>
<td>A new database must be created to process and store information from the World’s Ear application.</td>
</tr>
<tr>
<td>Secure Data</td>
<td>Data will be secured in accordance with Emory Healthcare encryption standards</td>
</tr>
<tr>
<td>Consent</td>
<td>Consent will be collected from the patient prior to enrollment in the application or registry.</td>
</tr>
<tr>
<td><strong>Link Patient’s Health Wearable with Application</strong></td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td><strong>Description</strong></td>
<td>Patients’ health wearable is synced with the World’s Ear application.</td>
</tr>
<tr>
<td><strong>Trigger Event</strong></td>
<td>Patient consents to health data being transferred from their wearable to a registry with physician access to all predetermined data points.</td>
</tr>
</tbody>
</table>
| **Result** | • Patient gains access to the World’s Ear application  
• The patient’s health wearable transmits relevant data to the application |
| **Business Process Steps** | 1. User received World’s Ear application access credentials  
2. User sets up user name, password, and authentication requirements  
3. Establish a connection between health wearable and application via Bluetooth capability  
4. User agrees to data transmittal |
| **Shared Data** | Data transferred and stored within Emory Healthcare |
| **Predecessor** | Patient and Physician determine the need for World’s Ear |
| **Successor** | User consults physician for follow up and data analysis assistance |
| **Constraints** | Emory Healthcare policies and regulations |
| **Failures** | Patient’s health wearable is unable to |
| **Performance Measures** | Health wearable connection success rate  
# of patients providing consent/# of patients successfully linked to the application |
### Data Agreement for Health Wearables

<table>
<thead>
<tr>
<th>Description</th>
<th>Create and sign agreement with Health wearable partners to share user data with World’s Ear application and registry</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trigger Event</td>
<td>Communication with wearable company regarding data sharing</td>
</tr>
<tr>
<td>Result</td>
<td>Vendor agrees to share data with both application and registry</td>
</tr>
</tbody>
</table>
| Business Process Steps | 1. Send request to establish business agreement.  
2. Conduct collection of agreement materials with other party.  
3. Establish terms of agreement  
4. Establish data exchange requirements.  
5. Establish security protocol.  
6. Establish Privacy requirements.  
7. Sign agreement.  
8. Send notification of agreement to business partner |
| Shared Data | Data stored with Emory Healthcare Dizziness and Balance Center |
| Failures | Company does not agree to data sharing terms |
| Performance Measures | Number of data agreements exceeds the number of rejections |

### INFORMATION ARCHITECTURE (IA)

The following service categories will be affected by the implementation of World’s Ear application and registry.

- **Data interchange** - The systems will have the ability to communicate with one another, therefore a new data connection from the World’s Ear application, Emory Healthcare’s PowerChart, and the World’s Ear registry must be established.

- **Data Management** - A new database will be established to house and secure all application and registry data for this project.

- **Software Engineering** An API is required for the set up of the World’s Ear application

- **Security** - Data encryption and access controls shall be put into place in order to secure patient and users data within the application and registry systems. Security will also be added to protect data in motion as data moves from the registry to Emory Healthcare systems.
• **Graphics & image** – Graphics and images will be developed in order to enhance the user interface of the application and registry.

**TECHNICAL ARCHITECTURE (TA)**

**Service Access and Delivery**

• **Access Channels**- Service delivery may be impacted by this project due to the interoperability requirements of the application and existing Emory Healthcare systems. These links will require communication between systems and also push notifications to providers through patient EHRs.

• **Service Requirements**- Existing Emory Healthcare service requirements for the protection of Emory Healthcare patients and their data must be adhered to for both the application and registry.

**Service Platform and Infrastructure**

• **Software Engineering**- An API will be created for the application data that will flow between the registry, application, and Emory Healthcare systems.

• **Database/Storage**- Additional databases must be constructed in order to house data for the application and registry.

**Component Framework**

• **Security**- Security will be impacted due to the need to protect patient data. User access will be restricted to patients and physicians enrolled. Authentication procedures will be put in place in order to appropriately grant user access.

• **User Presentation/Interface**- With the addition of the World’s Ear application, user interface will be tailored to provide a user friendly experience. The registry presentation will be simple in order to streamline physician efforts.

• **Data Management**- Data management will be affected due to the need for connectivity to other systems involved. Additionally, data management will come into play as the visualization capabilities are utilized by providers and patients.

• **Data Interchange**- Data will be shared among the registry, application, and Emory Healthcare systems.

**Service Interface and Integration**

• **Interoperability**- The project will require interoperability of Emory HealthCare Powerchart, World’s Ear application, World’s Ear registry, and patient EHR.
SKILLS/ROLES NEEDED FOR PROJECT IMPLEMENTATION

<table>
<thead>
<tr>
<th>RESOURCE REQUIREMENTS</th>
<th>Number of Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Roles for Project Time &amp; Maintenance</td>
<td></td>
</tr>
<tr>
<td>Project Lead</td>
<td>1</td>
</tr>
<tr>
<td>Project Manager</td>
<td>1</td>
</tr>
<tr>
<td>Data and System Governance Advisor</td>
<td>2</td>
</tr>
<tr>
<td>Business Analyst</td>
<td>1</td>
</tr>
<tr>
<td>Middleware</td>
<td>1</td>
</tr>
<tr>
<td>Developer/Testing</td>
<td>3</td>
</tr>
<tr>
<td>Network Infrastructure</td>
<td>2</td>
</tr>
<tr>
<td>System Administration</td>
<td>1</td>
</tr>
<tr>
<td>Data Architecture</td>
<td>2</td>
</tr>
<tr>
<td>Service Management Office</td>
<td>1</td>
</tr>
<tr>
<td>Functional SME/Internal Stakeholders</td>
<td>2</td>
</tr>
</tbody>
</table>

The project consists of two implementations of new systems for Emory Healthcare’s Dizziness and Balance Center. Therefore, a total of 17 individuals will participating in the development and implementation. The number of person resources allows the project to remain under two years at 16 months.

RISK MANAGEMENT

Identified Risk:

- **Data Sharing**: Existing health wearable companies may be hesitant or unwilling to share data.

  Data sharing and usage agreements will be established prior to the launch of the application. Additionally, the majority of health wearables connecting to the application and registry will be medical device health wearables which will decrease the potential for data sharing conflicts.

- **Lack of physician participation**: Physicians may be reluctant to utilize yet another system for patient care management.

  In order to increase physician/care provider participation, training will be provided. Physicians will be able to use their current documentation systems and with a push of a button transfer information to the World’s Ear registry.
• Probability – Medium
• Potential– Medium

• Resource: Availability of the project resources due to other inflight projects. Mitigation will involve setting clear timeline expectations and communicating impact updates frequently with business unit. Including the coordination of available state resources.
  • Probability: Low
  • Potential: Medium

• Scope: Evolving scope of enhancements. Mitigation will involve careful requirements gathering and iterative review and testing of implemented features with business product owner and users. Change request process will be applied as necessary.
  • Probability: Low
  • Potential: Medium

• Interoperability: The ability to facilitate interoperability across EHR and application data due to the existence of legacy systems and current cloud system technical specifications.
  • Probability: Medium
  • Potential: Medium

Work with system development team and pilot IT system groups to ensure the necessary HL7 implementation protocols are in place.

Update project stakeholders and organizational leadership of interoperability component status and resolution.

• Data Standards: The ability to establish singular data standards across all systems, while maintaining the ability to adhere to Emory Healthcare regulations and policies.
  • Probability: Low
  • Potential: Medium

Work with system data stewards and IT data groups to ensure systems data standards and protocols follow defined data classifications for the Emory Healthcare.

Update project stakeholders and organizational leadership of data standards component status and resolution.

• Security: The ability to implement a standard security framework across all system based on the individual policies currently implemented by Emory Healthcare. Security standards must adhere to Hi-Tech and HIPAA regulations.
  • Probability: Medium
  • Potential: Medium
Analysis of Alternatives

The World’s Ear project consists of two major parts, the application and the registry. The intent of this project is to utilize emerging technologies to bridge medical data gaps that can help patients suffering from several sudden hearing loss diseases and balance disorders.

Implementation of the World’s Ear application and registry will allow Emory Healthcare to improve upon the following strategic goals set forth by the agency:

- Improve the health of 1M/10M
- Innovative discovery
- Provider of choice

Several alternatives have been considered for the World’s Ear project. A major consideration was the development of an application only rather than an application and registry. The development of an application without a registry will allow for the collection of important data for the target patient groups. This option may be favorable for patients with data sharing concerns. However, limitations exist for this option. Without the inclusion of a registry with this application, there will be limited ability to analyze unknown correlations, comorbidities, and risk factors.

The alternatives analyzed below considered for this project deal with the cloud provider utilized for both the application and registry portions. The strategic goals and infrastructure of Emory Healthcare were translated into criteria that would be used to evaluate the different types of cloud providers used in the World’s Ear solution. Each technology was rated on a scale from 1 (lowest)-5 (highest). The scores were totaled to indicate which solution best aligns with the strategic initiatives of Emory Healthcare’s Dizziness and Balance Center and Emory Healthcare as an agency.
Evaluation Matrix

The criteria below were evaluated on a scale of 1-5. 1 indicates least favorable and 5 indicates most favorable.

<table>
<thead>
<tr>
<th>Criteria</th>
<th>AWS</th>
<th>Microsoft Azure</th>
<th>Oracle</th>
</tr>
</thead>
<tbody>
<tr>
<td>Integration</td>
<td>3</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Security</td>
<td>4</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>User-friendliness</td>
<td>3</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Increase efficiency</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Low cost</td>
<td>3</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Data Volume</td>
<td>4</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>IA Strategic Alignment</td>
<td>4</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>TA Strategic Alignment</td>
<td>4</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td><strong>Score</strong></td>
<td><strong>30</strong></td>
<td><strong>29</strong></td>
<td><strong>25</strong></td>
</tr>
</tbody>
</table>

AWS has a focus on compute, storage, and IaaS. AWS will allow for the required information to be stored in the cloud. AWS will also allow for enough flexibility to integrate with other third parties for running applications should the agency choose to do so.

The data volume criteria references the capacity for big data and memory allowance. This will be important for World’s Ear as it expands beyond the chosen agency to others throughout the country.

Mission Statement

Emory Healthcare’s (EHC) current mission is to serve humanity by Improving Health through integration of education, discovery and health care delivery².

Vision

Emory Healthcare’s vision is to be recognized as a leading academic and community health enterprise, differentiated by discovery, innovation, education, and quality, compassionate, and patient- and family-centered care.

Emory Healthcare focuses on the quality of care and patient interaction in order to improve the overall health of patients. More specifically, Emory Healthcare’s Dizziness and Balance Center
consists of a multi-specialty group of physicians and physical therapists with specialists from Neurology, Physical Therapy, Ophthalmology and Otolaryngology. The center works with patients suffering from a variety of vestibular and balance disorders. EHC values innovation and collaboration in order to provide patients with the best and most effective care. The innovations set forth by this project are in line with the mission and vision of Emory Healthcare and work towards improving diagnostic and treatment accuracy.

**Project Assumptions**

Although the application and registry will be primarily utilized by the Dizziness and Balance Center, Emory Healthcare as an organization supports the implementation. Therefore, all other focus areas and physician groups will have access and data sharing capabilities as well. This will allow physicians to ensure continuity of care and accurate diagnosis by connecting patients with any of these target disorders.

**Goals and Objective Timelines**

<table>
<thead>
<tr>
<th>Priority: Preventative Care and Disease Management</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Strategy:</strong> Increase focus on preventative care and disease management for vestibular disorders and balance disorders to include Meniere’s Disease, non-epileptic seizures, benign paroxysmal positional vertigo (BPPV) and others.</td>
</tr>
<tr>
<td><strong>Goal:</strong> Develop and implement strategy for increased knowledge regarding vestibular disorders</td>
</tr>
</tbody>
</table>

**Outcome Objective:** Within year 1 of project implementation conduct analysis of Emory Healthcare Dizziness and Balance Center patient communication

<table>
<thead>
<tr>
<th>Activities/Interventions</th>
<th>Responsible Party</th>
<th>Process Indicator</th>
<th>Outcome Indicator</th>
</tr>
</thead>
</table>
| Strengthen communication with patients to increase treatment efficiency | EHC Communications lead | • Conduct patient interviews  
• Determine patient knowledge gap regarding health, treatments, and progress | Achieve an 80% satisfactory rating on patient knowledge surveys. |
| Expand resources to support transitions of care that enable patients to utilize app and registry to document comorbidities as well | EHC Communications lead  
Executive Dizziness and Balance Center lead | • Document comorbidities of interest | Achieve a 25% increase in the number of patients registered for application and registry use annually. |
Increase physician check ins based upon application results

<table>
<thead>
<tr>
<th>Physicians</th>
<th>Patients</th>
<th>Application data management</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Develop check in goals for patients and physicians</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Establish baselines for patients and require communication when wearable indicates a significant change in vitals</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Physician & patient communication compliance at least 75%. Results showing that patients have received communication s from their physician related to their health wearable in accordance with their established communication agreement.

References

3. https://www.emoryhealthcare.org/about/mission-vision-values.html

II. National Chronic Kidney Disease Registry

Problem Statement
Currently, the United States does not have a national chronic kidney disease registry that encompasses information on patients with varying stages of chronic kidney disease and transplant status. According to Centers for Disease Control and Prevention (CDC), approximately 30 million adults have chronic kidney disease (CKD), varying among stages 1-5. CDC identified the need for a national kidney disease registry for improved monitoring of CKD. Many existing registries take into consideration only the information available for those on dialysis. A comprehensive registry that includes data on laboratory results, medical history, blood type, and intervention status is needed. The creation of a National Chronic Kidney Disease Registry will
track intervention effectiveness, track kidney donor and recipient matches, assist with clinical trial matching for CKD patients, and increase the accuracy of CKD burden reporting for the United States.

Project Details

Project Scope

Design and build a cloud-based national chronic kidney disease registry that assists in long-term tracking of CKD in the United States. The registry must be in compliance with all HIPAA regulations for the protection of patient data.

Project Goal(s)(ROI)

The National Chronic Kidney Disease Registry will create a repository of information on chronic kidney disease burden within the United States. The implementation of a national system may increase the likelihood of kidney transplant matches and reduce long transplant lists. Tracking chronic kidney disease in the United States via national registry will provide a reliable data source for information on chronic kidney disease of all stages. The registry will assist in identifying patients for inclusion into clinical trials, as well as improve population-level reporting, surveillance, analytics, and the comprehensiveness of longitudinal studies on chronic kidney disease and comorbidities of interest.

Key Stakeholders

<table>
<thead>
<tr>
<th>Centers for Disease Control and Prevention</th>
<th>Health Care Electronic Medical Records</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Kidney Registry</td>
<td>State Health Departments</td>
</tr>
<tr>
<td>Veterans Health Administration</td>
<td>Existing Kidney Disease Surveillance Systems</td>
</tr>
<tr>
<td>Centers for Medicare and Medicaid Services</td>
<td>Dialysis and CKD Patients</td>
</tr>
<tr>
<td>Dialysis Centers</td>
<td>Insurance Companies</td>
</tr>
<tr>
<td></td>
<td>State Legislators</td>
</tr>
</tbody>
</table>

The aforementioned stakeholders touch the lives of those affected by CKD. Each of the entities listed above will be able to provide essential data points that, when combined, will create a big picture view of potential intervention opportunities. The information that is currently siloed creates a barrier to identifying effective preventive care and faster transplantation. Bringing together the listed stakeholders and the essential data points closes a gap in chronic kidney disease research and treatment for our nation.

Business Requirements

- The solution must be deployed in a commercial cloud environment.
- The solution must be able to take advantage of and translate between multiple transport mechanisms.
- The solution must support current messaging standards that relate to kidney disease.
• The solution must take into consideration standards that are likely to become widely used in 3-5 years.
• Technological limitations of reporters must be considered to support standard message formats.
• The solution must be capable of maintaining personal health information and protecting the security of that data in compliance with federal regulations.
• The system must utilize Puppet to manage all cloud-based components.

Data Requirements
• Kidney disease inclusion criteria
• Laboratory results: Time and date of test, blood chemistry, hematology, serology
• Treatment plans: Renal replacement report, hemodialysis, peritoneal dialysis, treatment of uremic complications, kidney transplant
• Patient demographics
• Transplant status and results
• Population data
• Death certificate data

Critical Components and Data Sources

| Critical Component                              | Data source/Application            | Usage                                                                 |
|------------------------------------------------|-----------------------------------|                                                                     |
| Amazon Web Services                            | Amazon S3 database                | Cybersecurity Monitoring                                          |
| Puppet                                         | SSL Certificates                  | Configuration management                                          |
| ICD-9 &10 Codes                                | Electronic health records         | Tracking of CKD related health issues                            |
| Renal data                                     | US Renal Data System              | Collection and analysis of end stage renal disease for CKD patients |
| CKD treatment and diagnosis of population      | Veteran Health Administration Health System | Data on subset of general population treated by the Veteran’s Health Administration |
| CKD data                                       | Centers for Medicare and Medicaid Services | Collection of data for underserved population and elderly          |
| Health and nutritional data                    | National Health and Nutrition Examination Survey (NHANES) | Data highlighting CKD comorbidities                              |
Critical component discussion

Each critical component in the table above provides vital information to the National CKD registry. Amazon Web Services (AWS) will allow the registry to be hosted in a commercial cloud environment. Puppet is easily integrated with AWS and will provide the configuration management required to manage all instances of the registry throughout the country. The remaining critical components provide data that, in conjunction, will provide comprehensive views of CKD in the United States.

National CKD Data visualizations

The end users of the National CKD registry will include state and local epidemiologist and CDC’s National Center for Chronic Disease Prevention and Health Promotion, Division of Diabetes Translation group. The visualizations produced by Tableau, SAS, and Microsoft Excel for the National CKD Registry will provide the following information

- GIS mapping of high risk areas
- GIS mapping of highly affected areas
- Identification of CKD resources throughout the U.S.
- CKD Data counts - Exported into excel
- Chronic Kidney Disease & Renal failure mortality by state and region
- Transplant donor mapping

<table>
<thead>
<tr>
<th>Transplant community data</th>
<th>Scientific Registry of Transplant Recipients (SRTR)</th>
<th>standard analysis files, program-specific reports, OPO-specific reports (OSRs), the Annual Data Reports</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population data</td>
<td>U.S. Census Bureau</td>
<td>Document geolocation of CKD burden</td>
</tr>
<tr>
<td>Birth and death data</td>
<td>Vital statistic agencies</td>
<td>Death records showing CKD related illness as cause of death</td>
</tr>
<tr>
<td>Data visualization</td>
<td>Tableau</td>
<td>Data analysis visualizations by region, year, risk factors</td>
</tr>
</tbody>
</table>
National Chronic Kidney Disease Registry Information Flow

Figure 3 CKD Registry Information Flow

Figure 4 CKD Information flow
Puppet Implementation

Due to changes in agency requirements, the National Kidney Registry will utilize Puppet to manage the system’s configuration and updates. Puppet will allow for consistency within the registry and across all CKD registry modules throughout the nation. The Puppet dashboard will track components and changes while having the flexibility to function on several different operating systems. Since Puppet does not require in-depth knowledge of systems architecture or programming, it will remain sustainable for registry use. The IT automation software integrates with Amazon Web Services, which is in line with the original registry design. Administrators will automatically control the ongoing configuration of any number of virtual machines from a single file.

Puppet will be used in the National Chronic Kidney Disease Registry to do the following:

- Ensure compliance with specified desired state and mandates
- Track changes
- Integrate with 3rd-party tools
- Patch management
- Release management
- Monitoring & analytics

National CKD registry Measures of Success

The National Chronic Kidney Disease Registry success will be measured in the following ways:

**Participation**- A minimum of 60% participation for large physician practices, state, and local public health organizations and hospitals.

**Project timeline**- Adherence to the approved project timeline will serve as a metric for success. The project will be completed with limited fund and resources. Additional time added to the development or implementation of the National CKD Registry will negatively impact the project.

**Care improvement** – The CKD registry must provide actionable information for providers and/or participants to be able to modify their behaviors, processes, or systems of care.

**Patient Outcome measures**- Increase in the kidney transplant rate for CKD patients in the United States

**Data Quality** – The registry will have less than 10% entry errors. Since some of the data entry will be done manually by physicians and other key agencies, the system components will conduct automated checks for errors in the data.
References


Registry Development Discussion
The public health applications for registries are endless. Registry implementation provides a broad range of information for public health issues. The use of registries has the potential to remove existing public health and healthcare silos and brings together valuable information.

Next steps and considerations for the development of public health registries is to address information and population need gaps. Registries demonstrate value added when information that is not generally available can be utilized for the advancement of knowledge as well as the treatment of the target population.

III. How to Train Your Dragon- Clinical Informatics Training Development

Problem Statement
Emory Healthcare is Georgia’s largest health system with more than 6,000 providers. Dragon Dictation is a tool that allows these providers to dictate directly into a patient’s chart, rather than type, and without employing costly dictation services. Through Dragon Dictation, providers receive a tool that is aimed at decreasing the time in the electronic medical record per patient, giving more time to care and improving workplace satisfaction. This practicum, one focused on establishing an easy-to-complete training program for Dragon, fulfilled a need for Emory Healthcare as they strive to enhance completeness and overall improvement for the quality of electronic health records. Additionally, an increase in utilization rates for Dragon Dictation among providers has the potential to increase joy in practice and contribute to a decrease in burnout.

Project Details
Objectives

• Assess Emory Healthcare’s current Dragon Dictation training program
• Develop an online, comprehensive curriculum for Dragon Dictation
• Develop training modules to provide additional resources to providers using Dragon Dictation
• Enhance project management skills in an informatics setting

Project Details
To create a revamped curriculum for Dragon Dictation, a thorough review of Emory Healthcare’s current Dragon practices was required. Development of the Dragon Dictation curriculum included the below steps.

• Reviewed Dragon Dictation training
• Conducted interviews with current Dragon Dictation trainers and program leadership
• Trained in Captivate and Canvas, learning tools, to create training modules and videos
• Created video trainings for Dragon modules
• Developed how-to guides for each module
• Prepared training agenda
• Learned PowerChart, the platform for the majority of clinical care at Emory Healthcare, to ensure how-to guide accuracy
• Developed appropriate project management tools to maintain timeline and to ensure all project components were addressed

Outcomes
The following outcomes were achieved to facilitate Dragon Dictation training for providers:

• Curriculum completed for Dragon Dictation users
• Standard operating procedures for Dragon Dictation training
• Agenda for all face-to-face training sessions
• Full training modules
• Video trainings for each Dragon module
• Communications drafted for all training phases
Figure 5 New Provider Process Mapping

Figure 6 Dragon Curriculum Provider Quizzes

Figure 7 Canvas Dragon Training Module
Clinical Informatics Training Development Discussion
The development of training curriculum has implications for public health as it addresses the needs of physicians. This particular curriculum development resulted in physicians being better equipped to do their jobs on a daily basis. Not only does this affect the burnout rate for physicians, but it also provides the agency with the ability to maintain quality care.

The use of Dragon Dictation in a clinical setting has several public health ties. As physicians increase utilization of the tool, they increase the efficiency of physician/patient visits. Through the use of Dragon Dictation, physicians are able to decrease the amount of time spent in an office visit on documentation, and can place more focus on the quality of care delivered. The project will fulfill a need for the agency as they continue to utilize Dragon Dictation to enhance the completeness and overall quality of electronic health records. Additionally, an increase in the utilization rates for Dragon Dictation among physician has the potential to increase work satisfaction and contribute to a decrease in burnout.

Conclusion

Throughout the course of the EMPH program I have developed the skills necessary to design, implement, and evaluate public health systems and projects. The need for individuals who understand how data and technology can be integrated is growing on a daily basis. In public health, information is needed to effectively analyze chronic and infectious disease, to establish public health surveillance systems, to monitor the health and wellness of the public, and much more. In order to conduct this work, an informatician must have the ability to interpret and translate the needs of the stakeholders into actionable and sustainable solutions.

The completion of the work products discussed in this document have had a major impact on my professional path. Over the past year, using the knowledge acquired in the EMPH program, I have led the development of 3 systems in my agency’s center. The success of those projects allowed me to meaningfully contribute to the mission of my agency. I look forward to continued development in public health informatics along my career path.