



Role of Informatics Coordinator in Catalyzing Adoption of a Self-Service Integrated Data Repository Model

Tamara M. McMahon, Daniel W. Connolly, Bhargav Adagarla, Lemuel R. Waitman
Division of Medical Informatics, Department of Internal Medicine, University of Kansas Medical Center, Kansas City, KS

Introduction

HERON adoption increased in both users and usage with the addition of the Clinical Informatics Coordinator (CIC) whose duties include honest broker, educator, tester, oversight, and general HERON contact.

HERON

Healthcare Enterprise Repository for Ontological Narration (HERON)

- i2b2-based query and analysis tool for electronic medical data
- Implemented in 2010
- De-identified data from multiple hospital and clinical data systems
- Self-service model: No IRB needed by faculty or sponsored participants to access and search HERON

HERON's original purpose was to facilitate translational research:

- Retrospective studies
 - Chart review combined with HERON
- Prospective trials
 - Recruitment (Frontiers Research Participants)
 - REDCap registry integration

The self-service model of HERON has allowed for researchers to explore other uses:

- Quality improvement
- Educational aid

HERON's target audience expanded past researchers to include:

- Study coordinators
- Research assistants
- Students
- Administrators



Figure 2: Example of user backgrounds and number of searches

Figure 3 illustrates the various data types and sources in HERON. Although researchers are familiar with the systems that produce the data in HERON, few are data experts within these systems. As a result, searching HERON can pose challenges. The CIC trains researchers in the various data types within HERON as well as the limitations in this data.

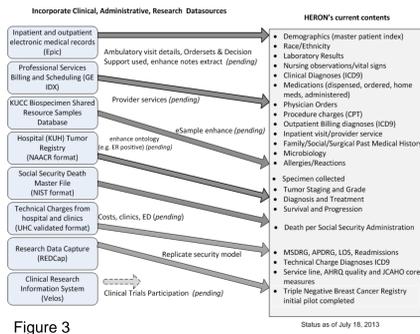


Figure 3

While data can be confusing to search, the analysis can also be perplexing. The CIC trains researchers on what to expect upon data request fulfillment. Originally researchers received a "long and skinny" cvs file with patient data. While easy to import and use with a statistical software package, it proved difficult to understand and use for those doing a smaller scale analysis. As a result, the CIC worked with the HERON software engineers to develop a process for delivering data in a REDCap project, which allows researchers to employ graphical analysis tools within REDCap. Through the REDCap project, the CIC can implement additional security measures by limiting export functionality, assigning user rights, and storing data files on a secure server.

Informatics Coordinator

The Clinical Informatics Coordinator (CIC) joined the HERON team in January 2012. The CIC performs multiple roles, including:

- Creating training materials
 - Instructional web pages
 - Online video tutorials
- Leading a bi-monthly walk-in clinic for researchers with questions regarding REDCap or HERON
- Individual trainings
- Initial project consultations
- Coordinating a two day in-depth training workshop in August 2013
 - Noticeable query increase in months following workshop
 - Attended by 34 attendees in person from a variety of backgrounds (Physicians, Biostatisticians, Students, Research Assistants)
 - 5 attendees from out of state
 - 25 online attendees including some from University of Wisconsin, University of Washington, Cornell University, University of Cincinnati, Johns Hopkins and more
- Honest broker
 - Liaison between the researcher and oversight committee (DROC)
 - Fulfill data requests
- Audit searching history
- Pioneers and Frontiers Participant Registries
 - Technical implementation and maintenance
 - Marketing/promotion
 - Honest Broker

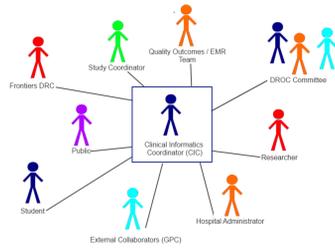


Figure 4: Roles interacting with the CIC

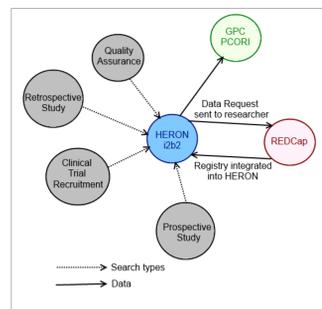


Figure 5

Figure 5 illustrates various reasons for searching HERON in addition to researcher initiated data import and export methods. The CIC assists in each of these areas.

Governance and Review
Data Review Oversight Committee (DROC), which includes members of medical school, hospital and physicians group, granted Limited Data Set (line item access – view only) permissions for all users with system access; opening the door for statistical integration within HERON. The CIC monitors the following DROC related processes:

- REDCap based approval process for sponsorship and data usage requests
- Usage statistics analyses that define the total searches performed in addition to search number by person
- Audits on searches resulting in small patient sets



Figure 6: HERON search audit reports

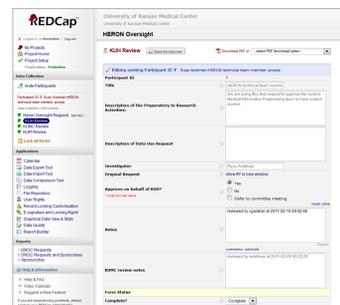


Figure 7: REDCap based DROC review

Use Cases

Saddam Kanaan, PhD

Early adopter for HERON whose dissertation is based upon HERON data. He combined physical therapy nursing data with medical record data on length of stay and discharge placement for Lumbar Spine Surgery patients.

- Produced one accepted paper and one in review
- Cohort size twice as large as those in his literature review
- His work led to additional research by fellow graduate students and Physical Therapy faculty

Future work with Greater Plains Collaborative (see PCORI)

The CIC assisted Dr. Kanaan in search strategies, providing data upon request, and notification of new data and functionality within HERON.

Linda D'Silva, PhD candidate

The CIC introduced Linda D'Silva to searching HERON, which resulted in a request for data to analyze. The data from her initial research request prompted her to narrow the research focus, thus taking her research in a unique direction. For her second data request, she tested and provided feedback on the process of providing data via a REDCap project. She was able to use Graphical Data Views & Stats functionality which significantly reduced her analysis time. To date, her research resulted in two presentations and a paper submission.

Seamus Murphy, Research Coordinator

This is an example of training the trainer. Seamus Murphy works with researchers within the Emergency Medicine (EM) department. Initially, the CIC spent time training Seamus on various aspects of HERON. Seamus, in turn, trains the researchers in EM. He also helps researchers format and integrate their REDCap projects into HERON to limit cohorts to a specified patient population. He serves as a contact for HERON questions from outside EM on the intricacies of EM data.

Frontiers Research Participant Registry Researchers

Patients consenting to be contacted regarding eligible studies at KUMC are added to the Frontiers Research Participant Registry. The CIC teaches researchers how to limit HERON population sets to those in the Frontiers Research Participant Registry. Once a patient population is defined in HERON, the researcher submits a request to the Data Request Committee (DRC) for review. The CIC serves as the honest broker and answers questions for the committee regarding HERON data and search structures. Once approved by the DRC, the CIC provides researchers with the patient contact information procured from EMR and billing systems.

PCORI

The Greater Plains Collaborative (GPC), a network of 10 institutions within 7 states, received a PCORI CDRN contract in 2014.

The CIC will serve as the GPC honest broker coordinating with honest brokers across the network to ensure searches are executed properly and data requests are fulfilled.



Figure 8: GPC sites and locations

The GPC will:

- Establish Governance
- Measure EHR Meaningful Use standardization and align for 3 use cases
- Develop Patient Reported Outcome Measure Methods
- Develop Comparative Effectiveness Research Trial infrastructure embedded in EHRs
- Enhance Patient Recruitment
- Support Biospecimen Requests

In figure 9, the yellow highlighted boxes involve the CIC.

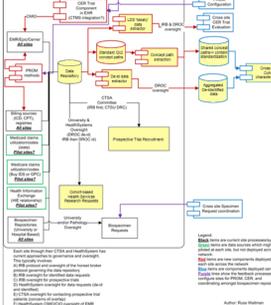


Figure 9

Observation & Results

The Clinical Informatics Coordinator position has existed 26 out of the 40 months (65%) since HERON's implementation.

- 18,726 searches conducted Nov. 2010-Feb. 2014, while 78% (14,533 searches) occurred since the CIC joined the team in Jan. 2012.
- 82% (72/88) of data use requests and 75% (121/161) of sponsorship requests occurred 2/2012-2/2014.
- With the help of the CIC, HERON usage is notably increasing.

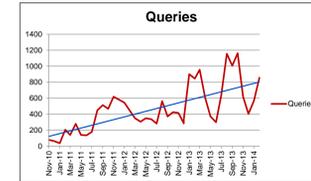


Figure 10

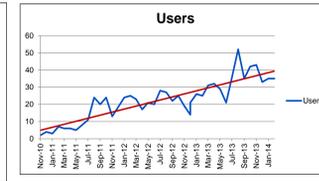


Figure 11

Figures 10 and 11 show a steady increase in HERON users and queries executed. The large spike around August 2013 is a result of the HERON workshop.

Figure 12 illustrates the Frontiers request and the HERON research data requests. Both request types increased but not significantly since HERON debuted. Note: 12 data requests included return requests where the researcher changed a query or desired follow-up data.

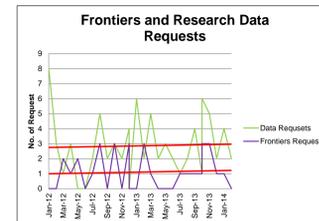


Figure 12



Figure 13

Figure 13 shows a continuous increase in sponsorship requests for access to HERON. This exemplifies the increase in usage for non-faculty members, such as students, study coordinators, etc.

Summary of Conclusions

While HERON provides translational researchers with unprecedented access to a variety of data sources through a single self-service query interface, it does not completely shield them from the underlying complexity of clinical research data or the concerns of the health systems and patients that contribute the data. The clinical informatics coordinator is a crucial guide to getting results out of all these data.

As the capabilities available through HERON increase and the goals of the HERON user community diversify, the importance of the CIC role continues to grow.

Acknowledgements

This project is supported in part by NIH grant UL1TR000001 and PCORI Contract CDRN-1306-04631.

Boyd, AD, Hunscher, DA, Kramer, AJ, Hosner, C, Saxman, P, et al (2005). *The "Honest Broker" Method of Integrating Interdisciplinary Research Data*. AMIA 2005 Annual Symposium, 902.

Waitman, R., Warren, J., Manos, L., & Connolly, D. (2011). *Expressing Observations from Electronic Medical Record Flowsheets in an i2b2 based Clinical Data Repository to Support Research and Quality Improvement*. AMIA 2011 Annual Symposium. Improving Health: Informatics and IT Changing the World. Washington, DC.

We would like to acknowledge the work of Saddam Kanaan and Linda D'Silva.

