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State Synergies and Disease Surveillance: Creating an Electronic Health Data Communication Model for Cancer Reporting and Comparative Effectiveness Research in Kentucky

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Innovation: We document and assess the statewide efforts of early health information technology (HIT) adopters in Kentucky to facilitate the nation's first electronic transmission of a clinical document architecture (CDA) from a physician office to a state cancer surveillance registry in November 2012. Successful transmission of the CDA not only represented a landmark for technology innovators, informaticists, and clinicians, but it also set in motion a new communication mechanism by which state and federal agencies can capture and trade vital cancer statistics in a way that is safe, secure, and timely. The corresponding impact this has on cancer surveillance and comparative effective research is immense. With guidance from the Centers for Disease Control and Prevention (CDC), the Kentucky Cancer Registry (KCR), the Kentucky Health Information Exchange (KHIE), and the Kentucky Regional Extension Center (KREC) have moved one step further in transforming the interoperable health environment for improved disease surveillance.

Credibility: This case study describes the efforts of established and reputable agencies, including the KCR, the state department of health, state and federal governmental agencies, and a major research university in leveraging existing networks, infrastructure, and federally awarded funding to implement interoperable health information systems for disease surveillance. Project assessment through quasi-qualitative interviews with key stakeholders facilitated evaluation of attitudes and beliefs for continued use of the cancer surveillance model.

Conclusion and Discussion: In Kentucky, the cancer reporting initiative leveraged and enhanced a solid foundation for statewide collaboration to achieve better health and improved disease surveillance through a learning health system. Leveraging the Meaningful Use (MU) program as an overarching policy and structural driver is imperative. The cancer reporting initiative in Kentucky suggests that future surveillance and reporting initiatives will require locally adaptable solutions and that there is a need for increased technical assistance in rural settings. Kentucky's experience also indicates that stakeholders should be diligent in identifying state-level criteria that align with MU for vetting EHR vendors.

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Keywords

health information technology, disease surveillance, comparative effectiveness research

Disciplines

Health and Medical Administration | Health Information Technology | Health Services Research | Medicine and Health Sciences | Oncology | Translational Medical Research

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Introduction

For rural communities and states, adoption of health information technology (HIT) presents specific questions, challenges, and opportunities. Will these rural populations, which often experience significant health disparities, be positively impacted through better care coordination for patients, and how do we translate HIT imple-

mentation into a learning health system that can support improved disease surveillance and patient health outcomes? Additionally, how can we replicate and expand innovative HIT initiatives in sustainable ways that enhance the operative capacity of clinicians and improve disease surveillance while gaining the cooperation and consent of a diverse body of health care stakeholders? For

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rural states, such as Kentucky, these questions become especially paramount as cost, quality, and efficiency are driving factors for improving the health of disenfranchised populations. While questions of implementation and replication are difficult to answer, addressing these challenges requires statewide collaboration for effective and sustainable disease surveillance.

This exploratory case study describes and assesses the collaboration between a state public health department, a major research university, and a health extension service funded as part of the Health Information Technology for Economic and Clinical Health (HITECH) Act to implement a disease-specific surveillance intervention (referred to as “the intervention”) through interoperable electronic reporting of systemic therapy data from oncology practices in Kentucky. This surveillance intervention resulted in the nation’s first electronic transmission of a clinical document architecture (CDA) from a physician office to a state cancer surveillance registry in November 2012. Successful transmission of the CDA not only represented a landmark for technology innovators, informaticists, and clinicians, but it established a new surveillance intervention through which state and federal agencies can capture and trade vital cancer statistics in a way that is safe, secure, timely, and sustainable. The corresponding impact that this intervention has on cancer surveillance and comparative effective research is potentially immense. The Kentucky Cancer Registry (KCR), the Kentucky Health Information Exchange (KHIE), and the Kentucky Regional Extension Center (KREC), with guidance from the Centers for Disease Control and Prevention (CDC), have moved one step further in transforming the interoperable health environment for improved disease surveillance.

For purposes of this case study, “sustainability” is defined as a participatory process that produces long-term, institutionalized support for an intervention through engagement of rural health stakeholders, use of federal and state policy levers, and identification of locally appropriate, consensus-based solutions.¹ Sustainability therefore includes consideration of intervention design, organizational culture, and imbedded characteristics of the surrounding community in order to be replicated throughout a variety of settings.

Through the use of electronic health records (EHRs), health information exchanges (HIEs), and cancer registries, Kentucky stakeholders have developed a process for a surveillance intervention that can be used as a sustainable strategy for future adopters and innovators in registry-based organizations, regional extension center (REC) programs, and state HIEs that are working to implement and improve EHR usage for disease surveillance. The following case study documents the innovative approach used in this cross-network collaboration and the communication vehicles used to leverage EHR for cancer surveillance in Kentucky. Specifically, this case study addresses three questions:

1. How are state organizations in Kentucky collaborating to improve cancer surveillance?

2. What are the challenges to collaboration and implementation of the surveillance intervention?
3. What are the processes and variables of the interorganizational partnerships that contribute to successful collaboration and implementation of the surveillance intervention?

The experience of the Kentucky cancer surveillance system revealed that strong existing networks between collaborating entities, efficacy across institutions, malleable implementation strategies, and shared commitment to innovation empowered stakeholders to overcome challenges and leverage the state’s HIT foundation in conjunction with federal levers for improved and sustainable disease surveillance and health outcomes. This case study can help other local and state entities achieve greater effectiveness and sustainability in designing similar interventions to increase usage of EHRs and HIEs for disease surveillance to meet new and evolving HIT standards in patient care. Packaging and replicating this surveillance intervention can greatly contribute to achieving the tripartite aim of increasing the efficiency of care, decreasing costs, and improving population health, especially for rural communities and states.

Replicating Effective Programs (REP) Model

As a national change agent, the CDC facilitates dissemination of various health communication interventions, many aimed at rural and disenfranchised populations and involving outreach focused on disease prevention, vaccinations, screenings, safety, and disease surveillance.² In 1990, the CDC developed a particular model, the Replicating Effective Programs Model (REP), to disseminate interventions for implementation in community-based settings.³ The REP outlines a framework by which health service organizations can readily utilize tested interventions that maximize transferability. Designed to be a strategic, community-based tool that uses evidence-based research to improve health service implementation, the REP has been empirically tested and provides an appropriate road map for nonacademic settings and stakeholders (including providers, purchasers, patients, and other health care affiliates present in the continuum of care) to collaborate for successful implementation of a surveillance intervention such as the one described here.³ While the Kentucky case was the first transmission of a CDA for cancer surveillance in the country and therefore did not itself utilize the REP model, the REP provides an ideal framework for other states’ HIT stakeholders to sustainably replicate the cancer surveillance intervention process developed in Kentucky.

The REP framework is comprised of four phases: pre-conditions; pre-implementation; implementation; and maintenance and evolution. In the pre-conditions phase, assessments of needs, training, and the local setting takes place. In this phase, the intervention package is also assessed and tested for effectiveness according to the unique needs of the population.³ Next, the pre-implementation phase requires a close examination of the key elements that will result in a customized delivery of the intervention. Additional training, planning of logistics and team orientations to the intervention package and execution compose this phase.

When correctly executed, the pre-implementation phase begins to yield a technical assistance method that is reinforced by the distinct needs of the members of the local setting.³ The implementation phase utilizes the momentum of the pre-implementation phase and helps stakeholders evaluate and refine the intervention package. Here, the inclusion of new community groups and organizations takes place in addition to ongoing training to streamline the delivery of the intervention.³ Finally, in the maintenance and evolution phase, sustainability is addressed. The intervention is repackaged for replication among like groups in other settings. While the intervention has been tested, consistent tweaks and customization will occur based on the nuances of each locale the intervention is used in.³

Overall, the REP model relies on identification of barriers, effective empirical interventions, and selection of community work groups that, once trained and provided the proper amount of technical assistance, have proven to be effective in delivering a formative intervention.³ Fundamentally, this framework creates accountability and a mechanism for follow-up by representatives across all levels of the innovation process. Due to this functionality of the REP, change agents like the CDC and other early adopters have the capability not only to be invaluable technical guideposts at the outset of an intervention process, but also to continue to provide oversight and guidance in how to turn comparative effectiveness research into best practices that fit a wide variety of public health stakeholders and settings.³

While the REP model calls for utilizing an empirically tested intervention, there are no quantitative analyses using randomized, controlled testing for the type of collaboration and data transmission involved in Kentucky's surveillance intervention because it was the first of its kind in the country. Nevertheless, the conceptual pillars of each phase of the REP framework readily lend themselves to replicating the process and partnership activities that resulted in this successful surveillance intervention in Kentucky. Furthermore, the experience of cancer surveillance intervention in Kentucky suggests that future surveillance and reporting initiatives will require locally adaptable solutions, consistent with the REP framework's emphasis in community-specific diffusion and locally adaptable solutions to support sustainability. The REP is therefore an ideal framework to increase efficiency and dissemination of the intervention in future rural CDA transmission cases, and has the potential to play a large role in the sustainability of future cancer reporting models.

This case study examines the Kentucky cancer surveillance intervention and addresses three main questions: (1) how stakeholders are collaborating for a cancer surveillance intervention in Kentucky, (2) the barriers to implementation, and (3) key processes and variables to overcome those barriers—in terms of the REP framework, in order to suggest how other stakeholders can replicate the intervention process through the distinct phases outlined by the REP.

Background

Burden of Cancer in Kentucky

Currently, cancer is the second leading cause of death in the United States.⁴ While national mortality rates are decreasing, incidence and mortality rates among rural populations continue to climb. The burden of cancer is particularly severe in Kentucky. According to the 2008 United States Cancer Statistics (USCS) report, Kentucky had both the highest incidence rate and mortality rate for males and females of any state in the country.⁵ This rate topped more than 560 incidents per 100,000 people, with a staggering total of 9,400 deaths statewide.⁶

While these trends have a crippling effect on rural public health, EHRs, HIEs, and disease surveillance registries are vital to the monitoring and reporting of these cancer statistics. Real-time data transmission provides a crucial tool in tracking cancer and applying subsequent interventions, especially in rural patient populations. This interaction represents a major turning point in disease monitoring and control and in the use of a new, locally adaptable surveillance intervention. Moreover, the impact of this innovative surveillance intervention process cannot be undervalued in a rural state with limited resources. As federal HIT mandates evolve, cancer reporting will remain a priority well beyond the established federal benchmarks, making the Kentucky case a potentially valuable model for future use in other states and communities.⁷

As will be discussed, the KCR, in collaboration with the CDC, NIH, and CMS, made significant contributions to the evolution of cancer surveillance by developing this new, national model.

The HIT Foundation and Stakeholders

At the federal level, HIT has been a priority for over a decade. Through executive order in 2004, President George W. Bush created the position of the National Coordinator for Health Information Technology. In 2009, a legislative mandate led to the Office of the National Coordinator for Health Information Technology (ONC) established through the HITECH Act. From its inception, the ONC was charged with developing and implementing an innovative, interoperable health network¹.

Concerted efforts in HIT have been long underway in Kentucky, as well. In 2005, Kentucky established the E-Health Network Board, a governor-appointed panel of over 25 leaders in health care, government, business, and academia. The E-Health Board gained funding in 2007 with a \$4.9 million Transformation Grant from the Centers for Medicaid and Medicare Services (CMS). The leadership of the board chose to use the Transformation Grant dollars to begin work on the statewide expansion of HIT projects. The Governor's Office of Electronic Health Information (GOEHI), established in 2009, serves as the anchor point for strategic and operational planning across the state.⁸

The establishment of GOEHI not only signified the beginning of a cohesive effort among state players, it also yielded state funding and established a platform for improvements to the state's HIT infrastructure. Specifically, the build-up of a technical HIE, with RECs and expansion of registry programs, gained traction as new HIT initiatives received federal stimulus dollars in 2009 and 2010. These funds became the driver for more partnerships, opportunities, and idea generation.

Cancer Surveillance Intervention in Kentucky

In order to provide insight on how to replicate Kentucky's surveillance intervention using the REP framework, the following research questions and elements of the Kentucky experience are addressed with respect to the phases and concepts of the REP:

1. How are state organizations in Kentucky collaborating to improve cancer surveillance?
2. What are the challenges to collaboration and implementation of the surveillance intervention?
3. What are the processes and variables of the interorganizational partnerships that contribute to successful collaboration and implementation of the surveillance intervention?

1. How Are State Organizations in Kentucky Collaborating to Improve Cancer Surveillance?

In Kentucky, many of the preconditions articulated in the REP framework were met through existing collaborative partnerships between established and institutionalized entities that together identified the need for a new surveillance intervention, identified an effective surveillance intervention that fit local settings, and packed the intervention for training and assessment.

As the primary driver for the cancer surveillance intervention, the Kentucky Cancer Registry (KCR) was formed in 1986 as a voluntary cancer reporting system. In 1990, the KCR was mandated by Kentucky state law in an effort to track, study, and improve the health outcomes of cancer patients. Mandatory reporting began in January 1991. In 1994, KCR received funding from the CDC through the National Program of Cancer Registries (NPCR), and in 2000 KCR expanded as one of four Surveillance Epidemiology and End Results (SEER) registries. The cancer registry, housed at the University of Kentucky and its National Cancer Institute (NCI) designated Markey Cancer Center, has developed relationships with hospitals and clinicians across the state (including free-standing treatment centers, private physicians, or pathology labs that diagnose, test for, or treat cancer patients) in order for those entities to submit data to the cancer registry. KCR collects data on over 25,000 new cancer cases every year from over 35 pathology labs, which submit data in various manners including fax, mail and electronic submission. The collection of this diagnostic and outcome data is invaluable to evidence-based disease surveillance and control programs and related comparative effectiveness research.⁹

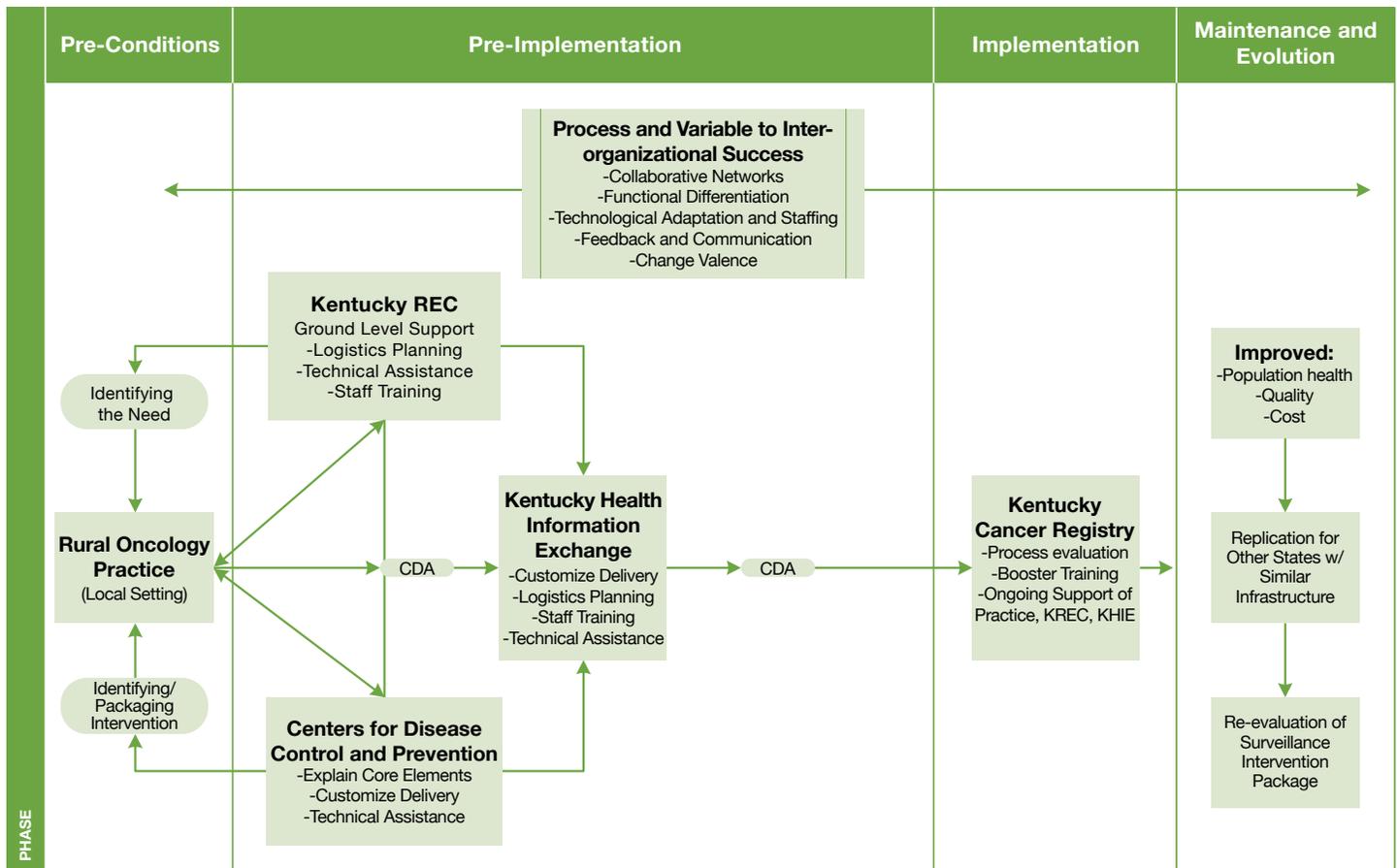
The Kentucky Health Information Exchange (KHIE), part of the Governor's Office on Electronic Health Information (GOEHI), was born out of the passage of HITECH in 2009.⁸ Kentucky received \$9.75 million in seed money to jumpstart the HIE initiative.¹⁰ Under the purview of the Kentucky Cabinet for Health and Family Services, the KHIE works with the KREC to help physicians and hospitals connect to the state exchange¹¹.

The Kentucky Regional Extension Center (KREC), housed at the University of Kentucky, is one of 62 entities funded by the Centers for Medicare and Medicaid Services (CMS) to assist providers and hospitals in adoption, implementation, and upgrading of EHR systems to meet the measures of the federal Meaningful Use (MU) Incentive Program under the HITECH Act. The extension model was initially created as an agricultural model to support rural farmers, but in this case the extension model was applied to the rural health care setting for assistance with provider adoption of EHR technology because policymakers were concerned that major barriers to EHR adoption for small providers would be workforce and knowledge.¹² The KREC works with approximately 2,500 clinicians throughout the state and 100 percent of the independent critical access and rural hospitals. KREC consultants operate as local HIT advisors and community-centric public health liaisons.¹²

In 2011, the KCR was awarded \$1 million from the CDC's Enhancing Cancer Registry Data through Comparative Effectiveness Research (CER) program to initiate standardized data exchange efforts across the state, which corresponds to the REP preconditional task of identifying and packaging a new, effective intervention that fits local settings. In the wake of the award, the aforementioned stakeholder groups—the KCR, KHIE, KREC, and GOHIE—were able to leverage preconditional relationships, existing expertise, and codependent infrastructures to identify implementation barriers and recruit oncology practices with high-burden conditions for inclusion in the CER program. Collaboration between the KHIE and the KREC provided an optimal platform for technical assistance, ground-level connections, oversight, and vision alignment for cancer surveillance through electronic health data. These preestablished community work groups provided a vehicle for the creation of streamlined assessment tools used to select the milestones that took place in both the precondition and subsequent preimplementation phases of the project.

Preimplementation and Implementation: Project Planning, Milestones, and Timelines

After project initiation in the spring of 2012, milestones were specified in order to track and monitor significant benchmarks through the lifespan of the initiative. Many of these technological and logistical milestones correspond to elements of the REP preimplementation phase, including logistics planning, recruitment and training of personnel (identification of participatory oncology practices), establishment of reporting procedures, and technical

Figure 1. Creating a Cancer Surveillance Intervention in Kentucky Utilizing the REP Framework


assistance, particularly to customize intervention delivery to fit each practice setting (a key feature of both the Kentucky experience and the REP framework). The detailed work grid (Figure 2) illustrates the step-by-step project plan over the course of the three-year funding period.

This work plan also includes internal self-audits and periodic, in-person progress reviews with state partners, which correspond to the process evaluation component of the REP. Many of these tasks coincided over the three-year project timeline and involved a number of critical meetings in which the surveillance invention was continually redefined.¹⁰

Following the establishment of a contract mechanism, the recruitment and training of project managers, interface specialists, and systems program analysts occurred across the three participating organizations, a task that corresponds to the preimplementation phase of the REP. This coincided with the prioritization of targeted oncology practices in regions across Kentucky in order to fully establish the community work group. This group, once formed, was more apt to provide the much needed practice-level input that bridged the gap between the technical undertones of the surveillance intervention and the need for more applicable, everyday interpretation of the intervention, aiding in future model fidelity.

Additionally, when KCR applied for the funding from the CDC's Enhancing Cancer Registry Data through CER program, KCR had already identified 57 providers in 18 oncology practices who were interested in participating, however through the parameters of the program KCR could only sponsor KREC assistance for 10 providers a year (at the current American Recovery and Reinvestment Act (ARRA)-funded rate of \$5,000 for the provider). Existing HIT infrastructure and outreach avenues established by the KREC helped provide a tool for the work group to assess each practice's readiness to participate in the program. These organizational needs assessments, which correspond to the logistics planning element of the REP preimplementation phase, included the evaluation of EMR and EHR systems and internal resources that could be dedicated to technology development and other external partnerships with IT vendors in order to review and audit data feeds. Targeted providers who achieved MU of EHR technology would be eligible for up to \$44,000 in Medicare incentive funds, which improved the likelihood of recruiting targeted providers.

The practice-level work group participant's choice in EHR was also an influencing factor as these vendors would ultimately be included in the community work group. As a result, KCR also helped identify EHR vendors who were willing to develop a system robust enough to handle the code specifications required to transmit a message in the correct CDA format, working around the technical logistics of disseminating the surveillance intervention.

Project assessment with key stakeholders, an element in the implementation phase of the REP, took place in the summer of 2013. Fifteen stakeholders across six organizational entities were identified for conversations: the CDC, KCR, KREC, KHIE, one EHR vendor, and an oncology practice in Western Kentucky. The assessment used a quasi-qualitative method to evaluate the attitudes and beliefs of stakeholders for continued use of the cancer surveillance model. Conversations were structured around significant milestones, challenges, situational factors that had an impact on success, and efforts toward creating a replicable and sustainable model. Themes emerged regarding the nature of the challenges, as well as processes and variables of the partnerships for overcoming them.

2. What Are the Challenges to Collaboration and Implementation of the Surveillance Intervention?

Understanding the challenges inherent in a cancer surveillance intervention such as the one described here can help replicators more efficiently prepare for and overcome these challenges in the intervention process. Challenges were identified throughout the precondition, preimplementation and implementation phases of the project. Intermittent assessments of the project yielded information regarding barriers specific to data exchange, vendor recruitment, internal clinic management, and patient compliance and reporting.

Figure 2. Detailed Work Plan

Task	Yr 1 Qtr 1	Yr 1 Qtr 2	Yr 1 Qtr 3	Yr 1 Qtr 4	Yr 2 Qtr 1	Yr 2 Qtr 2	Yr 2 Qtr 3	Yr 2 Qtr 4	Yr 3 Qtr 1	Yr 3 Qtr 2	Yr 3 Qtr 3	Yr 3 Qtr 4
Recruit, hire, train Project Manager												
Identify and prioritize targeted oncology practices												
Recruit oncology practices for participation												
Audit and validate provider data feeds												
Provide summary reports, feedback and data to IFC Macro/CDC												
Recruit, hire, train Interface Specialist												
Develop KCR interface to KHIE												
Assist oncology practices with EHR/EMR to KHIE interface development												
Meet with KHIE/KY-REC in person												
Recruit, hire, train Systems Analyst Programmer												
Meet with CDC LinkPlus team (in-person)												
Develop record linkage use cases												
Develop new LinkPlus features												
Conduct LinkPlus integration testing												

Source: Kentucky Cancer Registry. (2011b). Grant application for comparative effectiveness research funding. Available from <https://careweb.ukhc.uky.edu/ky-rec/Shared%20Documents/KCR-Markey-Grant/KCR%20CER%20Narrative%20FINAL.pdf>

Onerous Data Exchange

HIT relies on data sharing. While data transfer is a seemingly straightforward task, it is complex and requires a common language that is difficult to package. Prior to EHR systems, registrars relied on the manual abstraction of cancer data from clinics. This was arduous, time-consuming, and disruptive to the practice because personnel had to manually select information from hundreds, if not thousands, of paper charts at a single practice.¹⁰ Following the implementation of electronic systems, collecting vital health data became simpler. Running a report became the function of a computer system, and most systems are infinitely faster and more accurate than manual abstraction methods, allowing for a more complete picture of patient cases.

Nevertheless, transferring data from one point to the next in a unified way requires a specific code. Correct interpretation of transferred data is critical to successfully accessing and understanding the message being disseminated. Without the appropriate tools and programs, the burden on clinicians to format the content and structure of a medical message would be immense.¹³ In addition, data are proprietary, originating from providers on both the individual-practice and hospital levels. To protect the private nature of these data, they are encrypted.

In most cases, at the onset of a transfer, data are sent from a provider into a community master patient index (MPI). This index is populated with information outlining basic patient information such as labs, radiology reports, and patient demographics. The data are de-identified of patient-specific as well as clinic-specific information. The process allows recoding in a tradable format. Once shared in the proper format, the data reside in a central HIE—in this case, KHIE. Upon request, patient information is obtained through a record locator service inside of an HIE. Providers are able to request or query the previously inputted information and access visit-specific data from clinical encounters, including when, where, and what type of visit the patient had.^{11,13}

A critical need in cancer reporting is the ability to capture therapeutic information. This process requires a particular type of transport structure via a transmission called a “continuity of care document” (CCD).¹⁴ One version of this format is the CDA. Dolin, Giannone, and Schadow elaborate,

[The CDA] is a core data set of the most relevant administrative, demographic, and clinical information facts about a patient’s healthcare, covering one or more healthcare encounters. It provides a means for one healthcare practitioner, system, or setting to aggregate all of the pertinent data about a patient and forward it to another practitioner, system, or setting to support the continuity of care. The Health Level Seven, Inc. CDA is a document markup standard that specifies the structure and semantics of clinical documents for the purpose of exchange. From its inception, CDA has supported the ability to represent professional society recommendations, national clinical practice guidelines, and standardized data sets.¹⁵

In short, utilizing the CDA allows providers to communicate with registries in order to trade and understand vital population health information across a variety of EHR systems. While case studies on use are limited, research has indicated the CDA is a complex structure that requires implementation guides or technical manuals, as it covers general medical documentation. As the federal oversight agency, the CDC helped to vet computing code used for these types of transmissions based on rigorous tests of technical standards.

In the case of Kentucky surveillance intervention, the CDC provided direct guidance to regional and state partners through “implementation specifications,” a set of programmatic standards that helped the Kentucky partnership navigate the creation and testing of the actual code used in the CDA transmission. This general format creates an added level of intricacy and complication for technologists working with the design.¹⁶ The Kentucky stakeholders expressed doubts about the sustainability of the CDA as a transport mechanism, noting that until the flow of data was proficient they would continue to explore alternate avenues of transmission and further redefinition of the intervention package for future test cases.

Recruiting Vendors

Due to the complexity of CDA code, the project required an abnormally arduous vetting process of vendors, hindering the complete formation of a fully functional work group that could maintain the packaged intervention. The work group often found themselves actively recruiting multiple vendors for participation in the initiative.¹⁷ This meant increased pressure from senior leadership to engage other high-level, like-ranked decision makers outside of the collaborative group to enlist vendor companies qualified to implement the technical specifications of the CDA.¹³ Conversations with stakeholders indicated that there was little or no impetus on the part of the vendors if a favorable business argument was not presented. That is, if a clear return on investment was not identified, many vendors considered the endeavor too costly. Despite the potential positive impact on population health, these tenuous business relationships revolved around slack resources and excess time. As Kilbourne et al. reference, these multilevel barriers are common among REP utilizers.³

Multilayered technical issues also presented certain vendor challenges. Upon completion of a successful CDA test case, accessibility issues arose at the registry level. Specific software programs, called “Public Health Information Network Messaging Systems” (PHINMS), were designed to bridge information and act as a secure pipeline to move information.¹⁴ These industry-standard tools are implemented by the CDC to assist registries in capturing messages. Following the transmission of the CDA from the practice to the KHIE, technical limitations surfaced, forcing the KHIE, KREC, and KCR to request more assistance from vendors who could develop a tool to finalize the delivery of the message from HIE to the registry. This process was prohibitive, as the necessity of recruiting more specific expertise had an impact on the timely completion of project milestones.^{11,13}

Internal Clinical Management

Two distinct roles dominate clinical operations: care delivery, and the outlying support of clinical operations. Care support often refers to direction of clinical staffing, billing, system maintenance, and advisement of practice operations. In the clinical world, these are regarded as dichotomous positions, yet they are inextricably linked when addressing the speed of innovation, adoption, and assimilation. Contingent upon the number of clinicians operating in a practice and the cash flow from reimbursements, support roles can be stretched. Nurses and administrators often take on multiple roles, expending more time and commitment for what is often diminished practice reimbursements.¹⁷ When this challenge exists, it has the propensity to have a negative impact on the way these community work groups develop package content, plan the logistics of implementation, and provide other input relative to making the surveillance intervention actionable and relevant in the practices.

When safety and regulatory reporting standards are added to the mix, formatting and reporting specific cancer data presents an additional challenge. Research indicates that in certain clinical settings, providers are tasked with reporting up to 30 different quality measures assessing one single intervention.¹⁸ When individuals in support roles are charged with completing these tasks, the probability of burnout and turnover increases.¹⁷ Overwhelmingly, there is a significant challenge to create consistency and find high-value quality measures that align across all reporting spectrums.

Patient Compliance and Data Collection

Complete and holistic therapy information requires patient compliance. Patient adherence to treatment protocols and clinician recommendations is generally low.¹⁸ Due to this trend, obtaining a sufficient amount of complete data requires a critical mass of practices and high levels of patient compliance. While consumer engagement and patient health literacy were not fundamental parts of the collaborative strategy, increasing the level of compliance among the general patient population was cited as a need by the clinical teams overseeing the implementation in order to make the initiative truly sustainable. Bottom-up momentum is not easily achieved due to the newness of the innovation process, but was earmarked as a needed area for expansion as the model is maintained and evolves. For a fully operational REP model to flourish, this component can be especially important, as patient compliance supports the long-term fidelity of the surveillance intervention.

3. What Are the Processes and Variables of the Interorganizational Partnerships that Contribute to Successful Collaboration and Implementation of the Surveillance Intervention?

Despite challenges related to the Kentucky cancer reporting model, distinct processes and variables existed that contributed to successful utilization of the surveillance intervention amongst rural health stakeholders. Contiguous network subgroups, sustained

and repeated technical assistance, and a constant reaffirmation of the need for fidelity of the surveillance intervention all contributed to effective implementation.

Collaborative Networks

Progress on the work plan and the ultimate transmission of the CDA required distinctive organizational and individual network structures. Among the KHIE, KCR, and the KREC, strong horizontal social networks produced a cohesive direction among organizational leadership. In fact, prior to the formation of these grant-funded entities born out of HITECH, much of the senior leadership across the project had been previously affiliated with other companies, boards, consortiums, and advisory groups, making the propensity for likeminded, innovation-centered idea generation more likely. These mutual bonds prompted more steadfast feedback and refinement amongst the community work groups. The homophyllic groups, through the university and state political setting, were more prone to sharing goals, financial and staff resources, as well as organizational structure and governance, ultimately ensuring model fidelity.

Furthermore, close rural networks, predicated on trust and integration, aided in the cohesion between the KREC, KHIE, and KCR. This rural dynamic produced more inflective tendencies, yielding carefully planned and executed project elements. Inherently, the actions of one group had an impact on the outcomes of the others in a direct manner and, as such, these groups became acutely aware of the process and the corresponding needs of the community that drove that process. This intimate, holistic sense of collaborative effort facilitated quick problem solving and complementary solutions when obstacles arose. It can be argued that it was precisely because of the rural setting that this composite of groups worked together as well as they did.

The collaboration of entities across existing networks further increased the long-term sustainability of the model, including providing robust process evaluation and feedback for future maintenance and model evolution.

Functional Differentiation

Studies also indicate that organizational determinants such as functional differentiation, or the division of autonomous subgroups inside an organization, decentralized decision-making power, attitude toward change, or change efficacy, most always have a positive, significant impact on programmatic success.¹⁹ In Kentucky, subgroups of the overall community work group structure emerged within each organization and were motivated and encouraged to operate independently, outside of more global project-management decisions. While the management of each stakeholder group was tapped into significant project accomplishments, the teams avoided the one-size-fits-all mentality, as was the case with vendor selection. This improved the relay of information among the groups and the achievement of core and menu elements during the project. Indeed, a professional culture of experimentation, like that often found in the academic medical center setting, proved to be an asset to the work group. The

intrinsic motivation of individual entities within the project will also support long-term investment in the success of EHR cancer reporting in Kentucky.

Technological Adaptation and Staffing

In certain cases, the design of an innovation might indeed be a drastic departure from the intended use of the innovation by early adopters.¹⁹ One major challenge was the technical complexity of the CDA. In fact, the development of the code by Health Level Seven, Inc., and overseen by the CDC, utilized chunks of code that were largely untested amongst technology experts, let alone providers. Even the most tech savvy required a trial and error period of testing to ensure effective connection and compatibility between sending and receiving teams. Basic competency was built up over time instead of being previously established. This mandated a unique subset of early adopters who not only addressed the complexity issue, but advanced pragmatic agendas with assistance from the change agents, ultimately increasing trialability to confront technological issues. The project leadership identified, early in the process, a need to staff and recruit personnel that could understand the intricacies of the reporting process. These staff resources quickly identified deficiencies in the implementation process and proposed realistic and culturally specific resolutions that promoted the implementation of the intervention. These technically specific team members of the community work group were often proactive in problem solving, and encouraged realistic feedback in order to rework the intervention package when necessary. Ultimately, they were of great value in ensuring that the project rested on a sustainable and usable technological foundation.¹³

Feedback and Communication

These technological hurdles necessitated formalized feedback loops as well. In the case of Kentucky, the KREC was established for this purpose, taking the shape of a hub-spoke model of communication to bring new and relevant information to frontline adopters. The communication between the KREC and the frontline workforce was key to project implementation. To that end, a fundamental strength of the extension center work group was the ability to create malleable strategies that could be applied to the different features of interested parties. Overall, the interactions that drove innovations compelled appropriate communication methods between rural clinicians and academics—that is, understanding a local context and how to approach and emphasize the importance of such a project among technology vendors and providers.²⁰ Furthermore, the KREC is now an established entity, one that has gone through a host of organizational and financial changes to provide sustainable HIT support and facilitate ongoing communication between cancer reporting stakeholders, among others. This is directly in line with the REP-based tenet of continual adaptation and aids in the maintenance and evolution of the intervention package for further national dissemination, per the REP framework.

Change Valence

Throughout the project, the KHIE, KREC, and KCR also demonstrated a high level of change valence, or the inherent organiza-

tional value placed on implementing change.²⁰ This progressive attitude toward innovation and model fidelity aided the work group in making a stronger business case for the surveillance intervention. After encountering problems recruiting vendors, the groups recommended a collective, practice-level approach that would have required clinician champions to approach technology vendors as a cohesive group and encourage the build-out of a system that achieved the desired reporting procedures. While this effort was never officially mechanized, it demonstrated a forward-thinking attitude and an effort to recustomize intervention delivery in the face of logistical setbacks, a key element of the REP framework.²¹

Implications and Recommendations

As indicated, population-based central reporting registries and HIEs operate as a clearinghouse for high quality data that, when analyzed correctly, create a sustainable learning health system with a tremendous impact on how population health is understood and managed. The specific challenge in this project was not only properly positioning the technical expertise of developers, coders, and clinicians to format a CDA transmission, but knowing what policy levers to rely on to reinforce a congruent vision, or model fidelity, across a diverse constituency and diverse set of resources. As a strategy executed in a rural setting, Kentucky's cancer reporting initiative provides long-term value as a management tool for executives, clinicians, and state-level policy advisors, particularly when combined with the REP framework. These implications are described below.

Use of Federal Policy Levers

Under the HITECH Act, the CMS have been integral in helping facilitate the sharing of data in an effort to improve population health.⁷ The MU Incentive program offered through CMS is, and will continue to be, the launching platform for future data-sharing initiatives. While these programs are effective for encouraging rapid adoption of EHRs, they are also equipped to more thoroughly address interoperability standards for sustainability. As such, leveraging the MU program as an overarching policy and structural driver is imperative. Kentucky has been a proving ground for HITECH and is exemplary of a state that has successfully used the MU program to develop sustainable interoperability initiatives such as the one described here.²⁰ Placing other surveillance interventions against this backdrop, while ensuring that the intervention fits the local setting as emphasized in the REP, is likely to yield programmatic success for future adopters of EHR. In fact, diffusion studies indicate that cohesive policy put in place at the infancy of innovation projects has a strong statistical tie to the success of the project. This is generally due to steady funding and external mandates that yield motivation and fidelity.²²

Applying MU as a development tool also has implications for vendor recruitment. As discussed, the process of creating software to understand and translate the cancer CDA required an exigent team strategy. This meant that recruitment of vendors, development of specifications, and implementation were ongoing activities, often perforated by business decisions on the part of the

vendors. Unfortunately, the vendors were largely unmotivated by population health concerns, federal incentive programs, or other overarching national HIT policies.

The immediate concern for most vendors was direct profit, and because of low data volumes, this turned out to be a limiting factor throughout the project. Arguably, though, the continuing MU program will provide more opportunities for new technical specifications. As the data flow becomes more regular, future adopters and state agencies can use computing standards and quality reporting measures that are part of the MU program to approach vendors about development of new and unique service lines that would produce sustainable profit. While the sheer number of EHR vendors and systems is overwhelming, stakeholders should also be diligent in identifying state-level criteria that align with MU for vetting these technology groups, as in the Kentucky case.

Increasing Technical Assistance in the Rural Setting

In line with REP's emphasis on locally appropriate solutions, conversations with stakeholders also indicated a distinct need for increased technical assistance and recruitment of change champions in the rural setting.¹⁷ Indeed, implementation of EHRs has been a basic building block for this progress. Shifting from a paper-based operation to an electronic system has advantages, especially when trying to synthesize information and improve the delivery of patient care. It's quicker, more easily interpreted, and the data are more often complete. Research has indicated that the return on investment for EHR implementation increased revenue by close to \$100,000 over a two-year period for practices, and led to an average billable gain per patient of about \$26.^{23,24} Additionally, HIE connectivity has been shown to decrease hospital readmission, the largest source of Medicaid spending, and to help reduce emergency costs by over \$1.07 million annually based on select volume, acuity, and patient populations.²⁵ This impact is significant for rural providers. However, nurses, practice managers, and even doctors are lacking in the expertise needed to optimize these systems.¹⁷

For sustainable and maximized use of EHRs, especially for disease surveillance, new care models should take into account the importance of staffing informaticists, technologists, and public health professionals who have the experience and knowledge to not only develop and work with complex codes, but to also be able to understand the impact these procedures have on population health. Such staffing, training, and technical assistance concerns are addressed in the pre-implementation phase of the REP and are integral to implementation, maintenance, and evolution of the intervention. Recently, Ryan et al. found that the support from technical experts at the RECs in New York had a direct, positive impact on patient health outcomes.²⁶ Through a longitudinal study the researchers discovered that after eight technical assistance visits by REC staff, there was significant and measureable quality improvement. Accessible, competent, and ongoing support for EHR adoption and use in disease surveillance is critical in establishing and maintaining sustainable systems.

The Value of Change Agency and Reproducing the Model

There are many structural similarities between the REP and the model used to execute the cancer reporting partnership in Kentucky. The prior work with oncology practices via the KCR allowed for a quick identification of interventions among a targeted population. Coincidentally, the KREC and the KHIE were strong assets that operated as a boots-on-the-ground workforce to ensure adaptability and feasibility in select oncology practices. The value of this workforce should not be understated as these teams were a critical component in drafting and refining a locally customizable intervention package, including a method of transmission that was explained against the backdrop of MU, general EHR implementation, and other federal reporting initiatives. This method was built on strong existing networks that valued trust as a key factor of success.

Indeed, the very essence of the Kentucky experience – implementing a technological innovation for disease surveillance via federal and state health IT policies – allows for further deployment of the REP and provides rural health stakeholders with a tool to create and maintain CDA transmissions. While the Kentucky surveillance intervention model is far from being empirically proven, or quantitatively tested in accordance with the recommended REP pre-conditional phases, and an analysis of the impact it has on care quality is still far down the line, similar stakeholders, social mechanisms, and increasing public health need for cancer surveillance is found in rural settings across the country, suggesting the Kentucky experience could be successfully replicated

While these evaluations will occur in the near future, the stakeholders involved in this project continue to exhibit a proactive approach to quality improvement, HIT development, and disease surveillance in the state. The KHIE and the KREC plan to establish additional partnerships to help additional critical accesses and rural hospitals with technical assistance in clinical quality-measure reporting. Additionally, the KCR, part of the Markey Cancer Center at the University of Kentucky, was recently awarded the only National Cancer Institute designation in the state. This designation comes with increased funding for ongoing research, current project evaluation, and a focus on sustaining unique efforts like that of the aforementioned partnership.

Conclusion

Under the American Recovery and Reinvestment Act, and through the scope of HITECH, state entities in Kentucky were able to reevaluate their approach to service delivery to incorporate new and innovative public-health reporting models for a novel cancer surveillance intervention that can be replicated in other states using the REP model. Despite alignment and service integration, technical interface issues arose in addition to practice- and vendor-level issues. As evident from conversations with stakeholders, many parts of the collaborative functioned efficiently precisely because they took place in a rural setting. The social networks were strong, the groups exhibited a high degree of efficacy across institutions, and the cross-functional relationships remained intact despite roadblocks. Resource sharing symbolizes

a unified and sustained effort, but EHR implementation, HIE facilitation, and registry reporting are just the start. Newly established federal HIT rules call for a more arduous data-exchange process, more robust transmission of patient care summaries, and a push for more patient-controlled health information.

In Kentucky, the cancer reporting initiative leveraged and enhanced a solid foundation for statewide collaboration. Through further use of the REP model, this initiative has the ability to expand and improve, and to potentially spread to other states. Strong HIE implementation and surveillance will result in better health, more affordable care, and healthier communities for Kentuckians both now and in the foreseeable future, and they provide a model for leveraging HIT in a sustainable learning health system.

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