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Perspective

Envisioning health equity for American Indian/Alaska Natives: a unique HIT opportunity

Theresa Cullen, ¹ Jan Flowers, ² Thomas D. Sequist, ³ Howard Hays, ¹ Paul Biondich ⁴, and Maia Z. Laing ⁵

¹Center for Biomedical Informatics, Regenstrief Institute, Inc, Indianapolis, Indiana, USA, ²Biobehavioral Nursing and Health Informatics, School of Nursing, University of Washington, Seattle, Washington, USA, ³Division of General Medicine, Brigham and Women's Hospital, Boston, Massachusetts, USA, ⁴Global Health Informatics, Center for Biomedical Informatics, Regenstrief Institute, Inc, Indianapolis, Indiana, USA, and ⁵Office of the Chief Technology Officer, U.S. Department of Health and Human Services, Washington, DC, USA

Corresponding Author: Theresa Cullen, MD, MS, Regenstrief Institute, Inc, 1101 West 10th Street, Indianapolis, IN 46202, USA (thcullen@iu.edu)

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ABSTRACT

The Indian Health Service provides care to remote and under-resourced communities in the United States. American Indian/Alaska Native patients have some of the highest morbidity and mortality among any ethnic group in the United States. Starting in the 1980s, the IHS implemented the Resource and Patient Management System health information technology (HIT) platform to improve efficiency and quality to address these disparities. The IHS is currently assessing the Resource and Patient Management System to ensure that changing health information needs are met. HIT assessments have traditionally focused on cost, reimbursement opportunities, infrastructure, required or desired functionality, and the ability to meet provider needs. Little information exists on frameworks that assess HIT legacy systems to determine solutions for an integrated rural healthcare system whose end goal is health equity. This search for a next-generation HIT solution for a historically underserved population presents a unique opportunity to envision and redefine HIT that supports health equity as its core mission.

Key words: equity, health, health information technology, Indians, North American

INTRODUCTION

The Indian Health Service (IHS), an agency of the U.S. Department of Health and Human Services (HHS), provides care to remote and under-resourced communities in the United States. American Indian/ Alaska Native (AI/AN) patients have some of the highest morbidity and the mortality of any ethnic group in America. AI/AN communities have high rates of poverty and social risk. Lack of fiscal and human resources contribute to these statistics; limited effective strategies have been identified to impact these numbers.

However, 50 years ago, these disparities led to an IHS strategic and core commitment to health information technology (HIT) to help improve efficiency and quality. HIT was designed to increase access to

care, provide early situational awareness for public health emergencies, and achieve the goal of health equity. Starting in the 1970s, this investment in HIT created support and knowledge for a population health approach to health care—decades before population health was recognized as a critical part of the healthcare delivery cycle in the broader U.S. health system. This perspective reports on the current Resource and Patient Management System (RPMS) evaluation process undertaken to support modernization of RPMS in the pursuit of health equity.

HISTORY OF RPMS

The IHS HIT system, RPMS, was designed to support the first-ofits-kind community-oriented primary care model. Over the last five

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decades, this open-source platform has met the increasing and diverse needs of AI/AN patients, communities, and healthcare teams. Commitment to the community-oriented primary care model continues today as evidenced by a commitment to all facilities being patient-centered medical homes certified by 2021.

From inception, RPMS integrated clinical and administrative data to create a longitudinal record and supported innovative HIT functionality. RPMS relied on and integrated core HIT components from VistA, the Veterans Administration (VA) (now the Department of Veterans Affairs)^{7,8} HIT solution. The electronic diabetes audit (diabetes registry), developed in the late 1980s, supported management of the diabetes epidemic among AI/AN communities.⁹ The RPMS suite included eClinical Quality Measures starting in 2001; an expansive population health software application platform (iCARE) was released in 2007.

RPMS development was and continues to be dependent upon a collaborative relationship with tribal communities. An early commitment to human-centered design occurred before the discipline was formalized. Tribal consultation ensured tribal input into decisions that affect Al/AN health care. Clinical quality measure reports and data are available to communities in accessible formats, allowing communities to use their health data to make decisions about local health priorities.

CASE FOR CHANGE

Despite the aforementioned achievements, the RPMS platform in-adequately supports health equity. There is limited funding to address change requests, no functioning enterprise interoperability solution, a poorly designed and underutilized patient portal, and graphical user interface designs that are inconsistent. These constraints result in an inability to create comprehensive longitudinal records that include external data, loss of productivity due to healthcare team documentation inefficiencies, and an inability to share information with patients and healthcare team members. This impacts access to care delivery as well as clinical quality and limits access to comprehensive information for patients who receive care at multiple facilities.

The current limitations of RPMS is reflective of a multitude of factors, including the following:

- Budget: Balancing investments in direct healthcare with technological needs; many of the platform problems reflect lack of adequate resourcing.
- Infrastructure: Limited wide area and local area network IT infrastructure and the digital divide that continues to exist in rural/ underserved communities.
- Trained Workforce
 - Scarcity of a skilled and consistent rural workforce with adequate knowledge of RPMS. Some rural hospitals have no full-time clinical application support.
 - High provider turnover rates with limited access to HIT training and support.
- Interoperability: Immaturity and variance in interoperability capabilities with no supported enterprise wide solution.
- Usability: Lack of user-friendly functionality to improve quality and help ensure patient safety.
- Implementation Concerns and State Compliance: Varied approaches to immunizations, screening, and public health reporting by states, and payers for a geographically dispersed system.

Legacy systems have traditionally been defined as systems that still meet the majority of an organization's business needs, but are inconsistent with emerging architectural standards and unable to meet evolving needs. ¹⁰ RPMS, like VistA, is currently a legacy system. ¹⁰ This determination, coupled with the Department of Defense and VA's recent decision to transition to a commercial off-the-shelf (COTS) HIT solution, has created an opportunity and challenge for IHS. Significant database infrastructure and clinical components of RPMS are derived from VistA. Although most RPMS components, such as public and population health, child and women's health, and revenue cycle applications, were developed and supported by IHS, dependence on VA-supplied code remains for core applications. VA's plan to deprecate support for VistA, coupled with the previously mentioned limitations, have triggered IHS to reconsider its future HIT strategy.

This article reflects the process and goals of the team assembled to help answer this research question: should RPMS be modernized, and if not, what are the other alternatives? The team composition includes tribal representatives and end users as well as clinical informaticians, human-centered design experts, business analysts, full-stack engineers, and representatives from government and nonprofit organizations. Each team member is committed to helping the IHS identify the best HIT alternative to help achieve health justice for AI/AN people.

This team has defined IHS HIT modernization as an organizational endeavor to bring a health IT system to a new state. Modernization is people- and process-centric. Modernization is an adaptive and progressive process that aims to rethink and redefine the problem. Modernization will result in a system synergistic with the clinical vision for the healthcare system.

A PATHWAY FOR CHANGE

Addressing the research question for a complex broad-reaching HIT system requires a multifaceted approach. Decisions will affect over 400 facilities serving over 2.2 million patients across 37 states, with differing context and constraints across facilities. The approach must discern the strengths and shortcomings of RPMS, and understand the ability of commercial alternatives to "fit" within the challenging and often constrained settings within Indian country. These two "poles" must be considered within the context of the tribal communities, the population served, and the fiscal and human means that IHS has available.

The assessment itself requires an appropriate evaluation rubric to guide the legacy assessment and modernization and potentially provide guidance for other resource constrained communities. Scant information exists about processes that can be used to identify, prioritize, and assess environment and technical factors in a system with constraints such as the IHS. The majority of available publications on system evaluation or replacement have focused primarily on developing an appropriate RFP. System changes and selections have been based on cost, reimbursement opportunities, infrastructure, required or desired functionality, and ability to meet provider needs. 10–18 While these identified factors are important, additional evaluation criteria may need to be identified, such as organizational factors as well as a continuum of supportable architecture. 10,14

Principles and community engagement

The relationship to the community was identified as a key success factor in HIT redesign. Modernization principles (Table 1) were

developed through diverse stakeholder participation using human-centered design principles. The principles are based on the mission of IHS to raise the physical, mental, social and spiritual health of AI/AN to the highest level. ¹⁹ These principles ensure that users of the system and the population are at the center of the evaluation with their needs driving the assessment.

Assessment activities

Numerous activities have been initiated to evaluate multiple contexts, aspects, and perspectives including the following (Table 2):

<u>Literature Review:</u> Academic literature review of HIT in domestic resource constrained environments and identification of modernization frameworks.

<u>Facility Site Visits</u>: Hospital and clinic site visits representing the scope of IHS, Tribal, and Urban Indian healthcare. Visits utilize a human centered design approach to answer "What does modernization look like from the end-user perspective?":

- 1. What works well in the system for users?
- What about the system is frustrating and/or not working for users? and
- 3. What would users want or change in the system?

<u>Assessment Survey:</u> A quantitative survey to assess both context and perspective, designed to assess infrastructure, technological, and end-user support at the facilities as well as the operational network of the IHS.

<u>Legacy Technical Assessment:</u> Review of RPMS technology with full-stack engineers experienced in modernization of legacy systems and RPMS experts to answer:

- Technical feasibility to modernize RPMS architecture
- Costs, challenges, and barriers to modernize

<u>Technical Advisory Group:</u> An independent, multidisciplinary Technical Advisory Group to inform and review findings, and provide recommendations for the most effective way to modernize the IHS HIT platform.

Table 1. Guiding principles for modernization

- 1. Honor and respect Tribal communities and stakeholders
- 2. Focus on the people
- 3. Be Data Driven
- Embrace decision making that is impactful, community serving, evidence based, and incorporates a rigorous and repeatable process

<u>Analysis of Alternatives:</u> Options for modernization; recommendations to achieve a "modernized" state including the following:

- "Wrap and Renew": Develop a modern architecture; maintaining existing functionality; adding application program interface, allowing legacy components to be updated over time;
- "Rip and Replace": Replace with fully integrated or business line–specific COTS;
- Hybrid approach with best of breed COTS, while modernizing legacy components that serve IHS needs and meet unique requirements.

<u>Community of Practice:</u> Sharing of best practices across geographically and organizationally diverse enterprise, assisting optimal utilization of HIT to achieve improved clinical outcomes while supporting tribes and users.

DISCUSSION: REDEFINING HIT TO ACHIEVE HEALTH EQUITY

Many HIT requirements for IHS focus on functionality for ambulatory and inpatient EHRs, such as order entry and results retrieval, pharmacy, laboratory, radiology, and privacy and security. This functionality need is ubiquitous, and not unique to Al/AN communities. To achieve health equity, the next generation system must also include the ability to respond to unique needs—collect, aggregate, analyze, share and provide the opportunity to act on expanded patient, community, and population health data.^{20,21} This traditionally secondary use of this data cannot be an afterthought or done in "another system," but rather must become a primary data function if health equity is a goal of the HIT system.

A limited subset of social determinants of health data is currently collected both within RPMS and other COTS products. The next-generation system must support known and anticipated factors that impact health outcomes, integrate data from multiple datasets, provide holistic insight for individual patients, and document progress of health equity of communities. Additional data, such as adverse childhood experiences, are critical in providing cradle-to-grave care for families and communities. ^{21,22}

Datasets that provide critical insights into AI/AN community health include data from programs such as Head Start, WIC, the judicial system, and environmental health offices, including lead levels in wells and rabies vaccination penetration, as well as traditional healers. Patients and communities will benefit from having this information integrated into their health information, creating an integrated approach

Table 2. Pathway for change activities

Activity	Representation (Context, Aspect, or Perspective)	Informs
Literature Review	Historical data about HIT in resource constrained environments	Legacy Technical Assessment; AoA
Legacy Technical Assessment	Current RPMS technical stack and environment	AoA (eg, wrap and renew vs rip and replace strategies)
Facility Site Visits	System end-user perspectives	Discovery Sprint; AoA
Assessment Data Survey	Healthcare facility perspective	AoA
AoA	Multifaceted (all contexts, aspects, and perspectives)	Technical Advisory Group
		Final Recommendations
Technical Advisory Group	Evaluate all Activities	Final Recommendation
Community of Practice	Support for Change and Best Practices	Ongoing healthcare team needs

for the provider and patient. The current population health platforms, such as RPMS iCARE, that run on the transactional database, need to be expanded to meet known challenges, such as the suicide and opioid epidemics. ²³ Embedding population health data within the individual patient record is essential to "move the needle."

The IHS is "the little engine that could," providing care with the most limited resources of any federally supported healthcare system. There is little time to share the innovation, creative thinking, and impact of the technological work that has been done. For the future, IHS must commit to creatively integrating ongoing evaluation of any HIT interventions, and sharing lessons learned from successful disruptive approaches with other communities.²⁴

CONCLUSION

As a public health agency, the IHS has an enormous opportunity to lead the identification and incorporation of what and how data is included, displayed, and utilized in the next generation HIT systems to best achieve health equity. This user and population centered approach envision a new model for HIT within IHS; this model has the potential to move the needle forward on health equity beyond the borders of AI/AN communities. We should be watching. Opportunities to adopt IHS achievements in this area as a result of these modernization efforts may drive the larger HIT ecosystem to prioritize health equity as a core mission of HIT.

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AUTHOR CONTRIBUTORS

TC, JF, HH, PB, and MZL were involved in the conception and design of the overall approach to this work. TDS contributed to the design of a major part of the work. TC and JF prepared the first draft of the manuscript. TC, JF, TDS, HH, PB, and MZL engaged in subsequent drafting and revision of the content. All authors edited and approved the final manuscript.

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CONFLICT OF INTEREST STATEMENT

None declared.

REFERENCES

- Disparities | Fact Sheets. Newsroom; 2019. https://www.ihs.gov/newsroom/factsheets/disparities/. Accessed March 1, 2019.
- Adakai M, Sandoval-Rosario M, Xu F, et al. Health disparities among American Indians/Alaska natives – Arizona, 2017. MMWR Morb Mortal Wkly Rep 2018; 67 (47): 1314–8.

- Dickman SL, Himmelstein DU, Woolhandler S. Inequality and the healthcare system in the USA. *Lancet* 2017; 389 (10077): 1431–41.
- Kaiser Family Foundation. Health and Health Care for American Indians and Alaska Natives. Washington, DC: Kaiser Family Foundation; 2016.
- Sequist TD, Cullen Y, Acton KJ. Indian health service innovations have helped reduce health disparities affecting American Indian and Alaska native people. *Health Aff (Millwood)* 2011; 30 (10): 1965–73.
- Timbie JW, Mahmud A, Buttorff C, et al. Patient-Centered medical home implementation in Indian Health Service direct service facilities. Rand Health Q 2018; 8 (2): 2.
- Curtis CA. Using DHCP technology in another public environment. In: Kolodner RM, ed. Computerizing Large Integrated Health Networks: The VA Success. New York: Springer; 1997: 405–25.
- Habiel S. History of RPMS. Seattle (WA): VISTA Expertise Network; 2018. http://smh101.com/articles/Hx_RPMS_final.html. Accessed January 2019.
- Acton K, Valway S, Helgerson S, et al. Improving diabetes care for American Indians. Diabetes Care 1993; 16 (1): 372–5.
- Alkazemi B, Nour M, Meelud A. Towards a framework to assess legacy systems. In: 2013 IEEE International Conference on Systems, Man, and Cybernetics. Manchester, United Kingdom; October 13–16, 2013. https:// ieeexplore.ieee.org/document/6721915. Accessed March 1, 2019.
- Kannry J, Mukani S, Myers K. Using an evidence-based approach for system selection at a large academic medical center: lessons learned in selecting an ambulatory EMR at Mount Sinai Hospital. *J Healthc Inf Manag* 2006; 20 (2): 84–99.
- Levy G, Moghadas K. Strategies for picking the best EHR system for your practice. Med Econ 2013; 90 (20): 70–1.
- Legacy System Modernization: How to Transform the Enterprise for Digital Future. Carlsbad, CA: AltexSoft; March 17, 2018. https://www.altexsoft.com/whitepapers/legacy-system-modernization-how-to-transformthe-enterprise-for-digital-future/. Accessed March 1, 2019
- Aversano L, Tortorella M. An assessment strategy for identifying legacy system evolution requirements in eBusiness context. *J Softw Maint Evol* Res Pract 2004; 16 (45): 255–76. http://csis.pace.edu/~marchese/CS775/ Proj1/aversano_legacy.pdf. Accessed March 1, 2019.
- Anonymous. Selecting an electronic health record—one coalition's journey. Mich Medi 111 (4): 6.
- Daigrepont J, How to select a vendor based on practice-specific requirements: developing your RFI and RFP. J Med Pract Manag 2006; Suppl: 6–10.
- Adler KG. How to select an electronic health record system. Fam Pract Manag 2005; 12 (2): 55–62.
- McDowell SW, Wahl R, Michelson J. Herding cats: the challenges of EMR vendor selection. J Healthc Inf Manag 2003; 17 (3): 63–71.
- U.S. Department of Health and Human Services. About IHS. Updated March 18, 2003. https://www.ihs.gov/aboutihs/. Accessed March 4, 2019.
- 20. Federal health care: increased information system sharing could improve service, reduce costs. Government Accountability Office Report Briefing Report to the Chairman, Committee on Veterans Affairs, House of Representatives, June 1993; Updated November 16, 2014. http://www.gao.gov/ assets/80/78677.pdf. Accessed January 3, 2019.
- Thornton RL, Glover CM, Cene CW, et al. Evaluating strategies for reducing health disparities by addressing the social determinants of health. Health Affairs 2016; 35 (8): 1416–23.
- Sequist TD, Cullen T, Bernard K, et al. Trends in quality of care and barriers to improvement in the Indian Health Service. J Gen Intern Med 2011; 26 (5): 480–6.
- Indian health service: actions needed to improve oversight of quality of care. U.S. Government Accountability Office, January 9, 2017; Updated February 11, 2017. https://www.gao.gov/products/GAO-17-181. Accessed January 3, 2019.
- Sequist TD. Urgent action needed on health inequities among American Indian and Alaska Natives. *Lancet* 2017; 389 (10077): 1378–9.