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INTRODUCTION

The transformation of this country's health information technology (HIT) and health data landscapes have been well documented, with considerable attention paid to the potential for these changes to drive and support healthcare reform.[1,2] Observers caution, however, that despite the need for and promise of health data, the actual, real-world experience suggests we have a long way to go before we can fully harness the power of health data for health system transformation.[3] Documenting the "on-the-ground" challenges faced in using data to inform – and ideally drive – health system transformation is an essential step, therefore, in the learning process, as we collectively work toward an effective and sustainable health data infrastructure capable of supporting informed clinical care and delivery system re-design.

In 2011 the Maine Health Access Foundation launched its Advancing Payment Reform initiative to stimulate innovative payment and delivery system reform strategies in Maine. This policy paper reports on the health data experience of the 14 program grantees, using interviews conducted in 2013-14 and other information garnered from the evaluation of the initiative. The paper focuses on the role and impact of health data in supporting implementation and monitoring of specific components of the projects' reform strategies; the data infrastructure challenges the projects have faced and how those have been addressed; and the generalizable lessons learned so far for improving data usefulness, access, analysis, and integration to support payment and delivery system reform.

BACKGROUND

The term "health data" is broadly conceived to include: 1) **clinical health data** found in electronic health records (EHRs) and data submitted to health information exchanges (HIE); 2) **claims data** reported by private and public payers; and 3) **consumer reported data**, such as Health Risk Assessments (HRA) and the CAHPS survey (Consumer Assessment of Health Providers and Systems). Physicians, hospitals, health plans, and purchasers need access to reliable, timely, and secure data for planning, contracting, and providing clinical care. Health data are essential, for example, for identifying key target populations, evaluating patterns of care and expenditures, predicting health risk, utilization, and costs and understanding their drivers, and modeling the effects of delivery system restructuring and new payment approaches. Selecting and aligning quality and cost measures to inform practice and improve systems has become a key strategy in health system transformation efforts. As delivery and payment reforms continue, with a focus on creating incentives for higher quality and better value,[4,5] access the right data and appropriate analytic tools is critical to organizational and clinical performance.[6]

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While access to timely and complete data is essential, turning data into actionable information has become an even more important priority. Persistent administrative roadblocks and limited analytic experience hinder users' abilities to aggregate and analyze cost and clinical data, especially within smaller healthcare practices and organizations. Finally, the flow and sharing of data across providers and systems continues to challenge most healthcare transformation efforts.

MeHAF's Advancing Payment Reform Initiative

This initiative includes 14 projects, each with different reform strategies. All share, however, a common goal of changing the incentive, payment, and delivery systems in which they operate to improve value and outcomes with an additional emphasis on the needs of uninsured and underserved individuals in the development of the projects. The projects generally fall into four categories according to their focus on: (1) delivery system reform; (2) payment/insurance design; (3) data infrastructure and analytics; or (4) consumer/provider engagement. Delivery system reform grantees are focusing on effecting clinical changes within practices and/or care management programs. For example, Eastern Maine Medical Center, part of a large integrated health system, is assessing the return on investment of patient activation in their care management programs for individuals with chronic conditions. Maine Quality Counts is implementing a system of regional Community Care Teams to provide wrap-around care management and other services for high-cost users within three public initiatives: Maine's PCMH Pilot, the Medicare Advanced Primary Care Practice demonstration, and the Medicaid Health Homes demonstration.

Grantees in the payment/insurance design group are creating new models of provider payment and insurance design. Examples include Maine Health, the state's largest integrated health system, which is developing and piloting a new physician compensation model in selected primary care practices, to align with the new structure and incentives of their Accountable Care Organization (ACO) initiative. Another grantee, the Maine Primary Care Association is partnering with Maine Community Health Options, Maine's ACA-funded CO-OP insurance plan, to implement new value-based insurance design features.

Among projects in the data infrastructure and analytics category, two grantees, HealthInfoNet, (the statewide Health Information Exchange) and the Maine Health Management Coalition, are building data warehouses and associated analytic capacity to support care coordination, and provide data modeling tools for clinical and cost management to support ACO development and new contracting approaches.

Several consumer and/or provider engagement grantees are engaging consumers and patients in health care decision making. For example, MaineGeneral Health System has created Patient Advisory Councils throughout its hospital owned practices, and is developing a peer navigator program. Medical Care Development Public Health (MCDPH) and its partner, the Somerset Public Health, have developed a micro-businesses wellness program for a small town in rural Somerset County, a model which has since been expanded to include communities across the state.

THE BEST LAID PLANS FOR ACCESSING AND USING HEALTH DATA

The health data access and use experience of each of the grantees varies depending on the payment reform strategies and interventions they are pursuing. Across the 14 projects, four key observations have emerged:

All 14 projects, while differing in their reform strategies, share a common goal of improving value and outcomes

- Although EHR, administrative claims, and HIE data are available, efforts to access and use them have required significant workarounds;

- Innovative data linkage and analysis strategies are creating powerful tools that often exceed the "on the ground" functional capacity of program and clinical users;

- Getting patient-reported data and incorporating patient/consumer perspectives in the analysis and use of health data are a priority but challenging; and

- Most organizations lack the analytic capacity to use data effectively.

Access to Data Often Requires Significant Workarounds

Data access challenges have occasioned many of the MeHAF projects to develop creative strategies to get and use the data needed to support key project functions and achieve core objectives. Data access problems have arisen at multiple levels. Some grantees have been challenged in accessing data and information within their own systems and across provider organizations in the face of incompatible or inaccessible EHR platforms. Access to timely and accurate EHR, HIE and administrative claims data present persistent challenges, including timeliness, costs, and data limitations (e.g. data are de-identified and exclude uninsured individuals). In the face of such barriers and with no short-term solutions, grantees have developed innovative "data workarounds" to enable them to move forward with the implementation of their projects.

Using institutional/internal data: Several grantees have faced significant problems accessing internal data from EHR and other systems. For example, The Aroostook Medical Center's project to reduce emergency room use has encountered the common problem of hospital and practice EHR systems that do not communicate easily with each other, complicating the project's ability to assign patients from the emergency department to a primary care provider. Similarly, efforts by Franklin Community Health Network (FCHN), a rural-based integrated health system, to provide nurse management services for uninsured patients have been complicated by the inability of FCHN's billing and other data systems to identify the charity care population and profile their health care use and costs. Both grantees have had to develop short-term "workarounds" by manually cross-referencing EHRs and by conducting manual chart reviews to identify targeted patients. One of the obvious lessons of these projects has been that challenges of data access are greater in environments with less developed EHR and other electronic data infrastructures.

Confronting EHR and data sharing challenges: Maine Quality Counts' Community Care Teams (CCT) support nearly 100 primary care practices in Maine's statewide Patient Centered Medical Home (PCMH) and Health Home (HH) initiatives. CCTs provide care management for high-risk, high-need patients in all PCMH and HH practices within designated geographic regions. They are housed in a variety of organizational entities, including home health agencies, Federally Qualified Community Health Centers, and hospital "Charity Care" programs, among others. Only some of these entities have experience extracting useful data from EHRs. Each CCT serves patients of multiple practice sites and each site can vary in the type, connectivity, and capacity of the EHR it uses.

This project has faced significant challenges accessing data across multiple EHR systems needed to identify and stratify the high risk, high need patients targeted for care management. In some cases, CCTs have been granted limited access to practice EHRs, enabling them to see and use some patient information and add notes into EHRs, which then can be shared with practice teams using internal flagging systems. Gaining such access has been a challenge for reasons having to do with data privacy and security as well as

because some CCTs are housed in organizations that are market competitors of the primary care practices they serve in their geographic area. In addition, substantial training of CCT staff on each of the different EHR platforms has been required. For practices without EHRs, CCTs must securely fax all referral information and communications about services provided.

In addition to EHR access, CCTs have access to Medicaid claims information through a specially designed data portal for Health Homes' patients and, in some cases have been able to get critical information from Maine's Health Information Exchange (HIE). For example, the Exchange provides real-time notification to care managers in some CCTs when patients are admitted to or discharged from the hospital.

Other projects have had a comparatively easier time successfully using their EHR and internal billing systems to support community-wide care management. Mercy Hospital's Medical Neighborhood project relies on Mercy's EHR and internal billing data to provide real time information for a utilization management (UM) initiative involving several hundred charity care patients. The project has created a seamless flow of information between the emergency department and primary care practices, supplying limited real time data for weekly case reviews by the UM team. In addition, the project has provided access to the hospital's EHR for clinical partners in the community, assuring timely, actionable data for all of the providers serving these patients.

Similarly, Eastern Maine Medical Center (EMMC) is successfully using Maine's HIE to evaluate the return on investment of care management for patients with chronic disease.

Making the Most of Health Data: Advanced Data Linkage and Analysis Strategies

While some grantees are struggling with accessing data from single sources such as EHRs, several MeHAF-supported projects are extracting greater value from existing data by linking data from multiple sources and building new data analysis and application platforms.

Linking and using HIE, claims and other data to model risks and costs: Several projects are piloting data linkage and analysis strategies designed to support risk and cost analysis. HealthInfoNet (HIN), Maine's statewide HIE has successfully tested the linkage of clinical HIE data with Maine's all-payer claims database. They have worked with contractors to develop a predictive modeling tool using clinical data in the HIE to identify at-risk patients based on clinical and service use profiles. The goal has been to design a data linkage and modeling approach to support care managers and providers, population health management, and risk-based financial analysis by hospitals and health systems. This predictive risk modeling initiative is currently being piloted at four Maine hospitals. HIN has developed algorithms for each hospital to identify risk for admission and readmission, emergency room utilization, and prevalence of chronic conditions.

In its MeHAF-supported project, MaineHealth is designing new primary care and specialty care payment arrangements that align with its new ACO. In the design process the system has worked with practices to evaluate the financial implications of new payment models such as a partial or total capitated rate for a specific set of primary care services. To accomplish this, the project has combined practice-level claims, EHR, and other data (e.g. size and provider mix), to examine, among other things, variations in patient populations and patterns of service use across practices. Harmonizing the definitions of full time equivalents, panel size and other key data elements across practices and the system has been an unexpectedly critical step in building the analytic models.

Data linkage strategies support risk and cost analysis as well as population health management

Using health risk assessments to target interventions: Medical Care Development Public Health and the Somerset Public Health are demonstrating the viability and impact of micro-worksite wellness programs for micro-employers. To target wellness and health promotion interventions, the project is relying on Health Risk Assessments (HRAs) completed by employees that describe their health and health behaviors. Some challenges of using HRAs are similar to problems with communication among EHR platforms. Different proprietary HRA products are not compatible with each other and do not share common data elements and measures. These challenges suggest that wellness indicators and prevention activities are not yet an integrated part of the health data continuum. In addition, while self-reported data are useful, the project has not been able to link these data with claims experience to examine patterns of health service use.

Patient Access to and Perspectives on Health Data

The development of patient-reported outcomes that reflect the experience and priorities of healthcare consumers has become a national priority.[7] Innovations to develop and test the use of patient reported outcomes are expanding rapidly as a result of the Affordable Care Act.[8] Patient reported measures of satisfaction and outcomes of care are critically important in evaluating the clinical effectiveness of treatments and interventions as well as the 'human effectiveness' of delivery system restructuring. In addition to the limitations described above regarding clinical and cost data, patient health information is even less available and is still an emerging field with relatively limited tools and measures to capture patient experience, engagement, and clinical, functional, and health outcomes.

One common strategy for encouraging patient engagement has been to create and promote patient access to information in the EHR. Most EHR systems allow patients to access information in their EHR and to use other functions available in the EHR system (e.g. appointment scheduling). Maine's Health Information Exchange has been creating a portal that would allow patients to see their own information. Recently, however, the HIE discovered that meaningful use requirements - stipulating that patients be able to access their information through their provider's EHR - limit the HIE's ability to create an aggregated, single patient record. Through the state's State Innovation Model grant, however, the HIE hopes to overcome these challenges in part by developing an integrated patient portal across EHRs.

There are also efforts underway in the MeHAF initiative to pilot consumer engagement in using available health data to identify quality improvement opportunities. As part of their ACO development, MaineGeneral Health, a medium-sized health system in central Maine, is using MeHAF funding to pilot Patient Advisory Councils (PACs) in its primary care and pediatric practices. PAC members, including patients and staff, are provided analyses of consumer experience survey data (CG-CAHPS) collected for each practice. The PACs use this information to develop practice-level services and quality improvement goals and initiatives. MaineGeneral has found that patients bring a different perspective to data interpretation than providers and payers. For example, after reviewing the survey instruments and results, one PAC concluded that communication, respect, and trust between patient and provider are more important to a positive patient experience than waiting time, which had been the practice's key focus in improving patient satisfaction.

Most Organizations Lack Analytic Capacity for Using Data

Many of the grantees in this MeHAF reform initiative noted the lack of trained staff needed to turn data into information to support executive, administrative, and clinical decision making. There is a distinct misalignment between expectations and the analytic capacities available both within and outside of the grantee organizations to enable them to meet their

projects' needs. This problem reflects the nascent and evolving structure and capacity of health data systems and related analytic expertise in healthcare organizations across the state. Maine is a leader among states in having developed the country's first All-Payer Claims Data System, a successful, state-wide Health Information Exchange and multiple, large data warehousing and analytic initiatives. Yet, little attention has been paid to the development of a workforce needed to use these data. For example, the Maine Health Management Coalition (MHMC), another MeHAF grantee, has developed a large, all-payer claims data warehouse and analytic/reporting platform for its member organizations (many of the state's larger purchasers, payers, and providers) and has concluded that most of their members want less *data* and more *information*. While members are able to access many reports generated by MHMC, few actually do so. Lacking time and skills to do actual analysis of the data, some members just want to know about financial risk and simply want guidance on actions they can take to reduce risk.

IS THE GLASS HALF FULL OR HALF EMPTY?

The experience in Maine and elsewhere demonstrates the critical importance of health data to efforts by healthcare providers and organizations to improve clinical care and population health. Clinicians need data to guide clinical decision making. Organizations, practices, and health systems need data to assess patient risk and target services and care management; understand comparative cost and quality performance; and model or evaluate the financial and other effects of changes in payment and other system transformation initiatives. Many also believe patient access to data and health information is critical to engaging patients in their care and in efforts to improve care delivery.

In the course of this assessment we were struck by the intensity of data activity across grantee organizations. The effort and sophistication of initiatives like MaineHealth's practice payment modeling project, the Maine Health Management Coalition's cost and quality reporting system, and HIN's project to test the merging of clinical and claims data and to create a predictive modeling platform demonstrate this. As noted earlier, however, the sophistication of these initiatives generally outstrips the capacity of most organizations and the people who work in them to take advantage of the important information they could generate. It was also striking, though hardly unexpected, that each of these initiatives has constructed its own ways to meet a specific organizational purposes triggered by needing to better understand or have immediate access to their own data. This reality, however, raises the important question of whether and how Maine will build a common core of health data that can support the needs of smaller provider organizations and others who need access to various types of data that may reside in other (potentially competing) organizations. While early adopters and relatively data-savvy users are developing creative data and health information workarounds to meet their operational, planning, and evaluation needs, smaller, non-health system-affiliated organizations and healthcare providers often lack the capacity and financial and technical resources to pursue these creative solutions. Building a comprehensive inter-organizational health data infrastructure that can support the critical functions described in this brief will require special efforts targeted at smaller and rural hospitals, practices, and other health providers.

Although Maine is a leader in developing a functional statewide health information and data infrastructure, the experience of the MeHAF payment reform grantees suggests that Maine's health systems are still very much a work in progress. Many hopes are pinned on the continued build-out of Maine's statewide Health Information Exchange, yet many providers and systems currently lack functional access to the data in the HIE. While greater access to the HIE and other data is clearly a priority in supporting health system transformation, the

organizational and workforce development needed to enable the effective use of this data remains a critical priority. In truth, we know very little about the actual capacity among health plans, state government and research organizations to use data. Many larger health organizations use consultants for data analytics, contracting with insurance companies or other organizations with more robust capacity. For other organizations, however, the long-term solution may be to build a shared capacity that can allow for real-time access to the analytic resources needed to support an increasingly data driven health system. Finally, it is critically important that our public and private educational institutions build the capacity of health professionals to effectively use health data to inform decision-making and action.

The experiences of MeHAF's payment reform grantees in creating, sharing, and analyzing data highlight today's frontline challenges in using data to transform health care payment and delivery systems. The creation of "workarounds"; the need for data sharing and security; and the wide variation in analytic capacity across institutions, are likely similar to what other states—particularly rural ones—are currently experiencing. Maine's experiences may point the way—or connect the dots—for others elsewhere. We invite questions and suggestions, and look forward to continuing to work with colleagues across the country to find new ways to harness the power of data to transform health and healthcare.

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