eGEMs
Generating Evidence & Methods to improve patient outcomes

# Concordium 2016: Data and Knowledge Transforming Health

Beth Devine, PhD, PharmD, MBA[i]

## ABSTRACT

**Introduction and Context:** Concordium 2016 celebrated the potential for data and knowledge to transform health. Through a series of plenaries, presentations, workshops and demonstrations, the conference highlighted projects among four themes: effectiveness and outcomes research, health care analytics and operations, public and population health, and quality improvement.

**Papers in the Special Issue:** The eight papers that comprise this special issue of *eGEMs* provide exemplars of solutions to the Big Data problems faced in today's healthcare environment.

**Cross-Cutting Elements and Overlapping Themes:** Several of the papers contain elements of multiple overlapping themes. We integrate these into five overlapping themes: telehealth, user-centered design/usability, clinic workflow, patient-centered care, and population health management through prediction modeling and risk adjustment.

**Conclusion and Future Directions:** The effort to leverage all types of Big Data to improve health and healthcare is a monumental effort that will require the work of numerous stakeholders, and one that will unfold incrementally over time. This collection of eight papers reflects the current state of the art. Concordium 2017 will take a different form, inviting a small set of leaders in the field to focus on the next round of exciting and provocative research currently underway to improve the nation's health.

[i]Department of Pharmaceutical Outcomes Research and Policy Program, Department of Health Services, Department of Biomedical Informatics, Department of Surgery at the University of Washington

## Introduction

Academy Health's second annual Concordium conference was held on September 12 and 13, 2016 in Crystal City, VA. Concordium is the evolutionary merger of two of Academy Health's established and highly successful annual conferences held earlier this decade – the Electronic Data Methods (EDM) Forum's[1] Stakeholder Symposium and the Delivery System Meeting. With support from the Agency for Healthcare Research and Quality (AHRQ), AcademyHealth, the California Health Care Foundation, Kaiser Permanente, and the Robert Wood Johnson Foundation, Concordium 2016 brought together experts in the fields of health data and delivery system transformation to showcase emerging science and promote collaboration in an effort to improve the nation's health. Judging from the innovative projects summarized in this special issue of *eGEMs*, all of which emanated from presentations at Concordium 2016, attendees were not disappointed. The papers highlighted in this special issue detail projects that embody inspiring ideas, innovative use of methods, and challenging implementation strategies. Through a series of plenary sessions; poster, podium and panel presentations; challenge workshops and demonstrations; the four themes of Concordium 2016 spanned projects encompassing effectiveness and outcomes research, health care analytics and operations, public and population health, and quality improvement.

Placing these in the current context of Biomedical Big Data and Data Science,[2] we describe the projects summarized in the eight invited papers that comprise this special issue. We categorize the papers by the theme under which they were presented at Concordium. We then explore the cross-cutting elements overlapping themes that appear throughout this collection of papers to arrive at an integrated whole that represents the current state of data and knowledge used to transform health and healthcare. We close with a look to the future.

## Context – Big Data and Data Science

Biomedical Big Data are more than just large datasets and multiple data sources. The National Institutes of Health defines biomedical big data as including data sources that are diverse, complex, disorganized, massive, and multimodal, and that are generated by researchers, health systems and patients' mobile devices.[2] Biomedical Big Data include many types of data – phenotypic, molecular, genetic, imaging, clinical, exposure, and patient-reported, among others. The potential for discoveries that lead to improvements in human health are almost limitless. Yet Big Data face many challenges – vast amounts of information, lack of ability to access that information using appropriate and efficient tools, and insufficient training. All of these make for a challenging environment. To make good on the promises that Big Data offer, the authors of the eight papers in this special issue are each deliberately and thoughtfully tackling these problems and addressing these challenges in unique and innovative ways.

## Papers in the Special Issue

### Effectiveness and Outcomes Research

In an effort to improve the effectiveness of care and incorporate the outcomes most relevant to patients, Zheng and colleagues at the University of Massachusetts explored the use of mHealth technology in medical decision making for patients with advanced knee arthritis.[3] Using patient focus groups and clinician interviews, the authors examined the content and design of a mobile health app to facilitate daily symptom capture and summary feedback reporting to help inform treatment decisions, including the use of total knee replacement surgery. Feedback about important

symptom capture included that patients prefer easy tap user interfaces to multi-tap or slider methods, and vertical question layout to horizontal orientation. Patients also enjoyed receiving educational tips. Moreover, both patients and clinicians found a trended outcome summary report helpful in providing more precise details on whether and how symptoms are changing over time.

## Health Care Analytics and Operations

Two papers describe the work of research teams that undertook optimization of risk prediction to improve patient care.[4,5] Using a retrospective cohort study design, Ehlers and colleagues[4] at the University of Washington, Seattle employed machine learning techniques and a naïve Bayes algorithm to characterize health care utilization prior to surgery to predict risk, and found their methods improved upon the Charlson comorbidity index, a commonly used risk estimator.[6] Further, they found that the performance of a machine learning algorithm applied to their claims database approached that of the American College of Surgeon's National Surgical Quality Improvement Program (ACS NSQIP) Calculator; ACS NSQIP being a much more resource-intensive program in that it requires manual chart abstraction.[7] The authors state that precisely predicting the risk of adverse events and death following surgery can better inform patient-centered decision making and health care quality improvement interventions, and can support care organizations' activities that rely on accurate estimates of population risk.

Wrathall and colleagues at Intermountain Healthcare also used a retrospective cohort study design to create a model to predict patients at risk for remaining high cost users over subsequent years.[5] Formerly having used the average of the publically available Charlson Comorbidity Index[6] combined with two proprietary risk scores available within their health system (together called their Cost Ranking algorithm), their new risk-adjusted algorithm incorporated key variables readily available in electronic health records, supplemented by additional clinical data and estimates of socioeconomic status to facilitate identification of already high cost, complex patients eligible for more intensive care management. The authors found their new risk-adjusted algorithm outperformed the traditional cost-ranking algorithm in predicting patients' future cost status, thereby facilitating identification of those eligible for intensive care management.

## Public and Population Health

In the spirit of providing an educational health intervention, Arcia of Columbia University analyzed how pregnant Medicaid recipients perceived or engaged with maternity education delivered through their patient portals and personal health records.[8] Gestational age was captured from the electronic health record and a research tool called Maternity Information Access Point (through Care Guide by Maternity Neighborhood) was used to push online maternity educational resources and anticipatory guidance via weekly emails to pregnant women at appropriate times during fetal development. This qualitative study used focus groups and usability testing feedback obtained through self-report instruments. Arcia discovered that usage varied widely, and that popular features of the portal included push emails and reminders, while forgetting passwords and lack of technological experience were barriers to use. She noted that users desire easy-to-access content, but that this ease must be balanced against the need to safeguard protected health information.

Coordinating care continuity for Medicaid patients as they transition between the hospital and their patient-centered medical home (PCMH) is also

important, and requires reliable communication between providers and care settings, as well as an understanding of the social determinants that influence patients' recoveries. In this study, Hewner and colleagues at SUNY Buffalo describe the Coordinating Transitions project, wherein they demonstrated that developing informational and clinical workflow that incorporates both social health determinant and traditional health record data is key in creating solutions that improve continuity during transitions.[9] The project pivoted on New York's health information exchange – HEALTHeLINK.[10] The social determinants of health were collected by administering the Patient-Centered Assessment Method. Other central components of the intervention included real-time care alerts and care coordination outreach. In addition to assessing the impact of the complex intervention on inpatient admissions, emergency department visits, and outpatient utilization rates, the authors also reported results of a concurrently conducted comparative effectiveness analysis wherein they compared outcomes from their PCMH study to those estimated from regional data contained in the New York State Medicaid Data Warehouse. While additional work is needed to develop managerial continuity, such as shared comprehensive care plans across settings, this complex intervention revealed that transition workflows that incorporate social determinants of health data improve patient outcomes.

### Quality Improvement

Telehealth is a fast-growing sector in health care that uses a variety of technologies for doctors, patients, caregivers, and others to exchange information across locations to improve access, quality, and outcomes across the continuum of care. However, no systematic, policy-relevant framework yet exists to integrate regulatory, operational, and clinical factors and to guide future investments in telehealth research and practice. In this paper, Edmunds and coauthors present such a framework based on input from a multidisciplinary group of 21 experts from AcademyHealth, the American Telemedicine Association, Kaiser Permanente Institute for Health Policy, and the Physician Insurers Association of America.[11] The framework is an adaptation of the classic Donabedian framework for assessing health services and quality of healthcare: structure, process, outcome.[12] In the telehealth adaptation, there are two major components in the structure section: Regulatory and Payment. The second component is Delivery; it replaces process. Delivery includes the elements of population and modality. Outcomes include prevention, access, quality, utilization and costs. The authors seek for their framework to be a tool that can be used to educate policymakers, payers, and health systems about the value of telehealth and to frame discussions about implementation barriers, including risk management concerns, technology costs, and organizational culture. The authors are anxious to disseminate their framework broadly to additional audiences.

With the rising use of patient reported outcomes (PROs) in clinical practice, there is an increasing need to understand the data visualization needs of clinical teams to support their effective use for both individual patient decision making and broader population health applications. In this paper, LeRouge and coauthors present their experience as the first investigator group to use an heuristic evaluation to enhance the design of a PRO dashboard in the context of a human-centered design approach to optimize the visual design of an interactive PRO system.[13] The authors offer several recommendations to improve the display, accessibility, and interpretability of the dashboard data.

The third paper categorized under the theme of quality improvement, and the final paper in the special issue describes the work conducted by Hamlin at the National Committee for Quality

Assurance to address a leading cause of death in the United States – cardiovascular disease.[14] Expenditures for this disease continue to be higher than for any other diagnostic group. At the same time, strategies for assessing the effectiveness of care quality improvement initiatives aimed at addressing cardiovascular disease are limited. Hamlin presents a new approach to quality measurement meant to reduce avoidable cardiac events and improve overall population health. Specifically, this group employed a standardized technical specification to define a process to collect data from the electronic clinical data systems representing four disparate health care organizations, and reliably generate predicted outcomes scores. The combined data were processed using Archimedes, Inc. Global Outcomes calculator,[15] and generated a cardiovascular event probability for each provider's patient population. The resulting Global Cardiovascular Risk (GCVR) scores indicate the gap between current and optimal care, for each provider's patients. Data quality and completeness were evaluated in the process. The author suggests this is the first time predictive models have been proposed for national quality measurement, and proposes a shift in the current quality measurement focus from population assessments of individual indicators such as smoking status, hypertension management, and hemoglobin A1C control to one of patient-centric assessment using a model that conveys the likelihood of future adverse events.

## Cross-Cutting Elements and Overlapping Themes

Several of the papers contain elements of multiple themes. In this section, we integrate these findings into a whole new set of five themes.

### Telehealth and mHealth

The work of both Edmunds and Zheng illustrate the importance of telehealth to gain efficiencies and lower costs of care. Edmunds points out that, although a plethora of peer-reviewed studies and systematic reviews has been published about various aspects of telehealth, an overarching framework has been lacking. The impact of their work is to propose a framework with which the nation can move forward to demonstrate the value of telehealth. mHealth technology, the use of text messages and mobile apps, is considered an important tool in the toolkit of telehealth. mHealth technology is readily embraced by patients and provides a viable way to engage them in their ongoing treatment strategies. There is a growing body of research that establishes patient preferences for app design and use. Zheng and colleagues contribute to this important work, noting that patients and clinicians each view apps from a unique perspective; successfully deployed apps must incorporate both perspectives.

### User-Centered Design and Usability

Three studies incorporated the themes of user-centered design and usability. Zheng and colleagues employed user-centered design principles when conducting their work, as described above. Arcia used focus groups of patients, coupled with patients' self-completed surveys of user satisfaction and usability to solicit feedback about pushing online maternity education via patient portals and personal health records. She suggests this work is generalizable to pushing content for other health conditions. LeRouge's team investigated the addition of heuristics to human-centered design to improve attributes of a dashboard to present patient reported outcomes to both clinicians and patients at the point of care. These approaches are paramount for 'getting it right' when developing technology intended to engage and inform patients and clinicians.

### Clinic Workflow

Two sets of investigators were acutely aware of the impact their interventions would have on clinician workflow and, to some extent, patient engagement. Zheng learned that patients were amenable to sharing information about their symptoms of knee osteoarthritis twice daily, but that their clinicians preferred to see the trends in summary symptom reports on a monthly basis. Separately, the complex intervention to improve care transitions implemented by Hewner and colleagues required use of the regional Health Information Exchange (HIE). At the same time, the information that was presented in the HIE was augmented to include data about social determinants of health captured via administration of a patient survey. The investigators took care to ensure the results of this patient survey were presented in a novel way that was simple yet meaningful. Specifically, they displayed the summary score as a laboratory report that was minimally disruptive to workflow. Elements of LeRouge's project could also be construed to have an impact on workflow. These investigators worked to ensure their display of dashboard information would be quick and easy to interpret.

### Patient-Centered Care – the Importance of Socioeconomic Status (SES) and Social Determinants of Health (SDH)

Four studies centered on providing patient-centered care and soliciting direct input from patients: Zheng's mobile app, Arcia's maternity education, LeRouge's dashboard, and Hewner's care transition project. Moreover, three sets of investigators incorporated measures of SES or SDH into their studies; two of these studies (Arcia and Hewner) targeted Medicaid patients. Hewner, specifically, took a novel approach in administering the Patient-Centered Assessment Method survey to capture measures of SES to inform and improve care transitions. When creating their prediction model, Wrathall and colleagues incorporated estimates of SES into their new prediction model, and found it out-performed the model without SES information.

### Population Health Management through Predictive Modeling and Risk Stratification

Three of the eight studies focused on development of prediction and risk stratification models. Prediction models are becoming increasingly popular to better target patients who stand to benefit from specific interventions. Prediction models lend nicely to addressing problems of treatment heterogeneity and personalized medicine that are so important in today's healthcare environment. There is widespread interest in the machine learning techniques employed by Ehlers' group to improve prediction models for adverse surgical events over what can be accomplished using traditional regression methods. As artificial intelligence, of which machine learning is a part, takes hold across sectors of the economy, healthcare stands to benefit from these techniques, but only if studies that use them are well-designed and conducted so that patient safety is preserved and enhanced. Using a simpler approach, Wrathall and colleagues also created an improved prediction model for identifying high cost patients. Finally, Hamlin collected clinical data across four health care organizations to create a Global Cardiovascular Risk Score - a patient-centric assessment that conveys the likelihood of future adverse events. With further development, this model holds promise for use as a national quality improvement measure. In sum, these methods emphasize that identifying high risk, high cost patients is important as health care providers focus on population health management. By allowing for earlier interventions, care management programs, or pre-screenings, these tools may lower healthcare costs while improving patient safety. Not mentioned in this special issue is the notion that prediction models can enhance the information

provided in clinical decision support (CDS) alerts; a 2015 special issue of ***eGEMs*** was devoted to the topic of CDS alerts.[16]

## Conclusion and Future Directions

In summarizing these eight papers using two different approaches to thematic categorization, we have highlighted the many dimensions of data and knowledge and their role in improving health. This work requires commitment from many and diverse stakeholders, from patients to clinicians, data analysists to Bayesian statisticians, network specialists to implementation scientists, outcomes research scientists to operations specialists. The effort to leverage all types of Big Data to improve health and healthcare is a monumental effort, and one that will unfold incrementally over time. This collection of eight papers reflects the current state of the art. Concordium 2017 will take a different form, inviting a small set of leaders in the field to focus on the next round of exciting and provocative research currently underway to improve the nation's health.

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