CONNECTING SYSTEMS, DATA, AND PEOPLE: A MULTIDISCIPLINARY RESEARCH ROADMAP FOR CHRONIC DISEASE MANAGEMENT[1]

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Introduction

Chronic diseases (such as diabetes, asthma, heart disease, lung disease, cancer, depression, stroke, hypertension, and Alzheimer's) are responsible for seven out of ten deaths each year, and treating people with chronic diseases accounts for 86% of health care costs according to the Centers for Disease Control and Prevention. In the United States, more than 140 million Americans live with one or more chronic conditions, and the population is expected to grow by at least 10 million new cases per decade (Anderson 2010). Along with the growing patient population, the costs of chronic care have also escalated over the last decades, and account for over 75% of the total national health expenditures in the United States (CDC 2014). Of all Medicare beneficiaries, 68% suffer from two or more chronic diseases.[2] Readmission rates associated with chronic diseases have recently garnered attention from policy makers and healthcare providers due to their high cost burden on the healthcare system. As healthcare experts, care providers, and policy makers try to identify new ways to lower healthcare costs while improving care process and delivery, information systems and analytics research can play a pivotal role in suggesting new and innovative health strategies and solutions.

Technological advances such as the Internet of Things (IoT), sensors, wearables, social media, mobile apps, and genomics (Agarwal et al. 2020; Agarwal et al. 2010), along with widespread adoption of electronic health records (EHR), are changing the granularity, volume, velocity, and variety of patient and wellness data collected (Grewal et al. 2020). Along with advances in AI and analytics, they are also changing

> what care is being delivered (e.g., precision medicine); how and where care is delivered (e.g., remote monitoring); how patients interact with providers (e.g., patient portals, telemedicine), with caregivers, and with other patients (e.g., online patient communities); how patients receive medical information (e.g., conversational agents); and how organizations in the healthcare ecosystem exchange information and coordinate around patient care (Grewal et al. 2000, pp. 2-3).

For example, IoT, which includes a broad spectrum of connected devices ranging from medical devices in hospitals, to patient monitoring devices (Brohman et al. 2020), to wear-

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[1] All authors contributed equally to this editorial.

[2] http://www.cdc.gov/chronicdisease/

ables (Jiang and Cameron, 2020), to sensors in senior homes (Aramendi et al. 2018), and to ingestibles (such as a micro-bio-electronic device that can be used to monitor gut health; Mimee et al. 2018), is generating volumes of granular real-time data which can be analyzed and interpreted in real time to provide alerts and real-time interventions. This is facilitated by the changing nature of sensors—from carry-able to wearable and now to ingestible—and their evolving capabilities—from the ability to measure and record signals to sensor integration with the web and the ability to share and access data to passive data gathering, aggregation, and interpretation using AI.

Chronic disease management refers to "an integrated care approach to managing illness which includes screenings, check-ups, monitoring and coordinating treatment, and patient education."[3] Addressing chronic diseases requires new strategies, tools, and process of care to achieve what is referred to as the "triple aim" of healthcare: improving patients' health quality and outcomes and the quality of patients' lives; increasing access to healthcare services; and reducing healthcare costs by preventing or minimizing the effects of a disease (Berwick et al. 2008). These technological advances in tools and methods hold great promise in addressing these challenges through creative solutions. For example, tele-health applications can offer solutions to address mental and physical challenges of patients with chronic illnesses (Ayabakan et al. 2018). Wearable sensors and home devices can play a pivotal role not only in monitoring the status of chronic disease patients and predicting adverse events before they occur, but also in preventing the onset of chronic diseases. Wearables and apps can be designed to motivate patients to adhere to treatment protocols or individuals to lead a healthy lifestyle through, for example, gamification or social support. New business models may emerge around tracking, monitoring, and analyzing sensor data related to prevention and management of chronic diseases. Well-designed online patient communities can offer social and informational support to chronic disease patients, empower patients, influence the patient–physician relationship, and generate data that provides new insights into the experience of illness that can be mined for medical knowledge discovery.

Leveraging analytics also offers the potential to identify cost-effective treatments for chronic diseases by analyzing patient treatment data; to identify patients who can benefit from preventive care and lifestyle changes by analyzing patient profiles; to identify fraud and wastage in the treatment of chronic diseases; to collect and disseminate data on medical procedures that assist patients and providers in identifying

clinical protocols that provide the best value; and to profile diseases to predict and prevent adverse events. Payers can also harness the power of analytics to identify adherence to medications and other treatment programs and identify trends that are associated with benefits to population health and wellness. Leveraging computational advances through design science offers the potential to develop new methods and algorithms for aggregation of multi-scale clinical, biomedical, contextual, and environmental data about each patient and decision support tools to facilitate optimized patient-centered and evidence-based decisions. Other promising information systems design contributions could include developing robust knowledge representations and reasoning algorithms to support inferences based on individual or population health data and designing innovative technology for the secondary use of health data to support assisted and automated health-care discovery.

The objective of the special issue is to showcase research where the focus and contribution is on the role of IS and analytics in addressing chronic disease management and prevention. Below we provide a brief overview of emerging themes from prior research around the use of analytics in chronic disease management. We focus our discussion of prior research around analytics since research on health information systems has been reviewed in prior work (Agarwal et al. 2010; Baird et al. 2018; Chiasson and Davidson, 2004; Payton et al. 2011; Romanow et al. 2012), although the focus of these prior reviews is not confined to chronic disease management. We further leverage a framework of "connecting systems, data, and people" to provide a roadmap for future research in this space, and we end by highlighting the contributions of the nine papers in the special issue.

Emergent Themes in Health Information Systems Analytics Research for Chronic Disease Management ▪▪▪▪

IS and analytics healthcare research has a long history. Earlier research often focused on health information technology[4] (HIT) adoption and use and on HIT impacts on quality of care, efficiency, and financial performance (for a review, see Agarwal et al. 2010). Specifically, a recent research curation of 41 HIT articles in the *MIS Quarterly* over the past 15 years identified a temporal progression of research themes (Baird et al. 2018). Prior to 2007, the focus of HIT research was primarily to evaluate traditional IT artifacts in a

[3]https://www.healthcare.gov/glossary/chronic-disease-management/

[4]Health IT is defined as "a broad concept that encompasses an array of technologies to store, share, and analyze health information" (Baird et al. 2018).

healthcare context (Dennis and Garfield 2003; Mitchell 2006; Ray et al. 2005). Healthcare was thus just the context for research with the focus of the research being on developing or testing generalizable IS theories (see Chiasson and Davidson's (2004) "IS-Only" category of HIT research). The government and policy-driven growth in HIT markets subsequently shifted the focus of HIT research toward explicitly considering HIT artifacts and their impacts, such as consumer decision-making processes associated with HIT use (Angst and Agarwal 2009), and HIT investment decision-making and governance (Xue et al. 2008). Since 2013, HIT has evolved from the hospital-based EHR to patient-centric mobile devices and assistive technologies, while health analytics methodologies have expanded from statistical models (e.g., econometrics-based models) to advanced computational models such as AI-based deep learning, which are suitable for chronic disease analysis. This has propelled HIT research to examine a more diverse set of topics, to examine traditional research questions but with more granular data or advanced methods, or to apply advanced analytical models based on emerging HIT and hospital and patient data (including chronic diseases) to identify more salient influencing factors or provide more precise health predictions (Chen et al. 2012). Through a review of this more recent literature, we identify three broad areas of HIT analytics research that have emerged: studies focusing on (1) leveraging EHR data; (2) online health communities and social media analytics; and (3) mobile and robotic assistive systems and the associated mobile analytics research.

First, among recent health IS and analytics research, hospital-based information systems such as EHRs have become a primary area of exploration into new methods and applications. For example, such hospital data have been adopted in health data analytics to predict adverse events (Lin et al. 2017), hospital readmissions (Bardhan et al. 2015), or patient mortality (Tabak et al. 2014), among others. Examples of analytical models adopted in this research include growth-mixture models (Angst, Wowak et al. 2017), sequence analysis (Angst, Block et al. 2017), and Bayesian multitask learning models (Lin et al. 2017). In chronic diseases, diabetic kidney disease (DKD) is one of the most frequent complications in diabetes associated with substantial morbidity and mortality. To accelerate DKD risk factor discovery, Song et al. (2019) developed an ensemble feature selection approach to identify a robust set of discriminant factors using EHR. Further, Shams et al. (2015) proposed a new readmission metric, based on administrative claims data, to identify potentially avoidable readmissions from all other types of readmissions. They developed a tree-based classification method to estimate the predicted probability of readmission, and validated their models with one year of data on approximately 3,000 chronic disease inpatients, across four

Veteran's Administration hospitals in the state of Michigan. Similarly, Singh et al. (2015) incorporated temporal EHR data into predictive models for risk stratification of renal function deterioration. Based on a study of chronic kidney disease (CKD) patients at Mount Sinai Medical Center, they observed that including temporal information in a patient's medical history can lead to better prediction of kidney function loss, and using multitask learning is an appropriate way to robustly capture the temporal dynamics in EHR data.

In addition to exploring EHR data, recent health analytics research aims to connect and analyze multiple systems and data. Recognizing the importance of connecting EHR with other critical patient medication usage information, Hoopes et al. (2018) developed an algorithm to link EHR prescribing to claims-based medication dispensing data and used the results to quantify how often patients with diabetes filled prescribed medications. Garcelon et al. (2018) developed a data warehouse framework to integrate 21 data sources (e.g., EHR, biological results, medical imaging results) and enable multiple views for clinicians to generate medical narrative reports. Based on deployment of their system within a single hospital in Paris, 96.6% of the users were satisfied and reported that system use reduced their time-consuming tasks (e.g., building a comprehensive profile for their patients). Connecting and analyzing hospital-based information systems and data with advanced analytical models continues to be an active avenue of research for IS and health informatics researchers.

Based on our review of the literature, we found a variety of deep learning techniques and frameworks have been applied on several types of clinical applications including information extraction, representation learning, outcome prediction, phenotyping, and de-identification of patient data. For example, Li and Yu (2019) evaluated the effectiveness of emerging deep learning models (e.g., capsule network, adversarial training) for single-domain and multi-domain relation extraction (medication and adverse drug event relation extraction) from EHR notes. Other researchers have explored the use of lagged linear methods to detect physiologic drug effects in EHR data. For instance, Levine et al. (2018) demonstrated significant improvements in prediction accuracy of detecting drug physiologic effects by using particular combinations of temporal reparameterization, time-series differencing, and regression models. Taslimitehrani et al. (2016) proposed a classification algorithm, Contrast Pattern Aided Logistic Regression (CPXR(Log)) with a probabilistic loss function, to develop and validate prognostic risk models to predict one-, two-, and five-year survival among heart failure patients using data from electronic health records at the Mayo Clinic.

Another use of EHR data involves data-driven phenotyping, where a core computational task is to identify medical concepts and their variations to stratify phenotypic cohorts. A conventional analytic framework for phenotyping uses a knowledge engineering approach or a supervised learning approach, wherein tasks associated with feature engineering and data annotation are computationally expensive and not appropriate for rare diseases where the data may be quite sparse. Chiu and Hripcsak (2017) used infectious diseases as the domain of study to demonstrate a hierarchical learning method based on ensemble learning that attempts to address these issues through feature abstraction. They proposed a sparse annotation set to train and evaluate many phenotypes at once, an approach known as bulk learning, based on which statistical models can be trained and evaluated.

The second major area of research related to health IS and analytics involves online health communities and health social media analytics. Instead of relying on clinical data from healthcare providers, these online social media systems often help connect patients, caregivers, and health professionals in an open and virtual environment. Online health communities (OHC) change the way that people learn about health and illness (Yan and Tan 2014; Ziebland et al. 2004). They have significant social, organizational, and economic importance (Yan et al. 2015). For example, Goh et al. (2016) showed that technology-mediated OHCs are able to alleviate rural–urban health disparities. OHCs can also support the most vulnerable family caregivers (Friedman et al. 2018). There is a growing trend for patients to share their medical conditions and treatment experiences through social media (Agarwal et al. 2010), thus attracting many IS researchers to leverage social media in health analytics (Goh et al. 2016; Yan et al. 2015). For instance, patient comments and sentiments in forums have been used for drug safety surveillance (Mao et al. 2013), medical error monitoring (Nakhasi et al. 2012), treatment comparative effectiveness research (Cho et al. 2013), and infectious disease surveillance (Dredze 2012).

Goh et al. (2016) examined an online patient community, aiming to discover the disparities of social support in urban and rural areas. Kallinikos and Tempini (2014) used patients' postings to construct a patient network and analyze the health status of patients. Yan et al. (2015) utilized health social media to understand the driving forces behind patients' social network formation and evolution. With greater impetus on broad post-market surveillance, the "Voice of the Customer" (VoC) has emerged as an important source of information for understanding consumer experiences and identifying potential issues. Abbasi et al. (2019) proposed a framework to detect adverse health events based on VoC listening platforms, connecting multiple disparate health social media systems and

data, including millions of tweets, forums postings, and search query logs pertaining to hundreds of adverse events related to the pharmaceutical and automotive industries. Such research demonstrates the value of connecting and analyzing patient-centric, health social media systems and data.

The last and emerging area of health IS and analytics research is related to the increasingly popular mobile and robotic assistive systems and associated mobile analytics research. People in the United States and elsewhere are enjoying longer life expectancies due to healthy lifestyles and advances in medicine and health services. The life expectancy in the United States was 78.87 years in 2019.[5] Population aging, however, presents challenges and has become a growing concern for the nation. Senior citizens face many challenges in terms of independent living, including a decline in mobility or cognition and chronic physical and mental health conditions.   Such conditions and adverse events include frailty, diabetes, Parkinson's disease, dementia, stroke, falls, etc. Despite active research using hospital-based information systems and patient-based OHCs, mobile health systems design and analytics remains an under-explored but increasingly critical area of health IT research.   Some interesting research in this area has begun to emerge. For example, Hamm et al. (2019) designed a mobile 3D measurement guidance application to help senior citizens measure the dimensions of their daily-use furniture (e.g., bath, toilet, chair, and bed). The accuracy of measurements critically affects the result of the home environment fall risk assessment process. Šumak et al. (2019) developed a hands-free human–computer interface mechanism for users with motor disabilities. They collected input from multiple systems, including on-head motion sensors, EEG readers, and a computer monitor-mounted camera to navigate the on-screen cursor and execute computer commands. Disabled users found the touchless interaction solution significantly more useful than the current interface.

Aramendi et al. (2018) conducted a long-term ADL (activity of daily living) monitoring experiment on 29 independent-living senior citizens to assess their health decline. Passive infrared (PIR) sensors were used to collect activity data in each room (e.g., kitchen, bedroom). The researchers developed activity-specific features (e.g., sleep pattern, overnight activity, mobility) for their classic machine learning-based methods. Kheirkhahan et al. (2019) designed and evaluated a smartwatch-based framework for real-time mobility assessment and monitoring. In addition to collecting data from the on-watch sensors, they leveraged the smartwatch as a user interface to collect self-report data (e.g., pain level) and dis-

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play analytic results. More recently researchers have begun to explore deep learning techniques for mobile health analytics. For example, Zhu et al. (2018) developed a sequence-to-sequence deep learning model to recognize ADL for senior care. The model was used to identify senior citizen's daily activity patterns, such as drinking coffee and opening drawers, with different environmental and personal motion sensors. We anticipate significant research opportunities and activities in this nascent area of mobile and robotic assistive systems research.

Future Opportunities and Challenges ∎

The need for significant transformations in medical, public health, and healthcare delivery approaches has been recognized by numerous organizations and captured in a number of national reports and programs, including the NSF Smart and Connected Health Program (NSF SCH 2018; see also Leroy et al. 2014). Technological and methodological innovations are key to achieving such transformations which involve not just technical challenges, but also sociocultural, economic, legal, political, and ethical challenges, that may amplify or ameliorate the development, deployment, use, and effects of such innovations. Achieving these transformations would, therefore, benefit from multidisciplinary teams that leverage diverse perspectives and methods to address the problems and derive innovative approaches and solutions.

The long-standing academic tradition in health IS and analytics research and the critical societal needs in addressing chronic diseases present unique opportunities for high-impact IS health research. A multidisciplinary research agenda to address chronic disease prevention and management requires contributions from social, behavioral, organizational, economic, and design science scholars in the IS community. We leverage the components of NSF's Smart and Connected Health Program, "connecting data, people, and systems" (NSF SCH 2018, p.1), as a framework to discuss possible directions for future research (see Figure 1). Our discussion is meant to be illustrative of themes and opportunities, rather than exhaustive. Further, it should be noted that, although we have organized our discussion around each component (systems, data, and people), these components are interrelated and discussion of one component often involves discussion of one or both of the other components.

Connecting Systems

In light of new health IT development trends and emerging healthcare community needs, we identify the following research opportunities and challenges in connecting systems for health IS and analytics research for chronic diseases.

Health Sensing: From EHRs and Social Media Systems to Mobile Sensing

Health conditions are multifaceted and long-term, especially for chronic disease prevention and management. Although increasingly popular motion sensors can be used as an important input for senior care, many chronic diseases cannot be detected or predicted by motion sensors alone. There is a critical need for connecting multiple health systems and data, including physiological signals (heart rate, blood pressure, blood glucose, etc.), genomic biomarkers, EHR, radiology and imaging data, and even patient-reported social media content. In addition to developing and evaluating the emerging mobile and robotic assistive systems, there will be increasing opportunities and challenges to improve the interoperability and interfaces in the complex health IT landscape (Bates and Samal 2018). In addition to system interoperability, it is also critical to develop human-in-the-loop systems such that health information systems and data are firmly grounded with a person's (patient's, caregiver's, and health professional's) needs, conditions, and preferences in mind.

Advancing Analytics and Assessing Impact: From Econometrics Models to Deep Learning

With the increasing availability of health IS and data for chronic disease prevention and management, there are significant opportunities for advancing health analytics research, especially for multiple data sources and multiple health outcomes. Most of the extant healthcare predictive analytics studies focus on one specific event (e.g., congestive heart failure, type-2 diabetes), and develop analytical models to best capture the characteristics of the event. Multiple co-morbidities are a common phenomenon among patients (especially senior citizens) with chronic diseases. Hence, there are future opportunities to achieve better risk profiling with multiple events and data sources being considered and modeled simultaneously. To this end, multitask learning (Lin et al. 2017) is an underutilized modeling strategy in health research and practice. Developing and utilizing multitask learning strategies to predict multiple patient outcomes remains a research gap. In addition to econometrics-based models, deep learning has recently emerged as a viable computational approach for selected health applications, such as medical image analysis and physiological signals processing.

With the explosion of patient clinical and administrative data, researchers have developed extended deep learning applica-
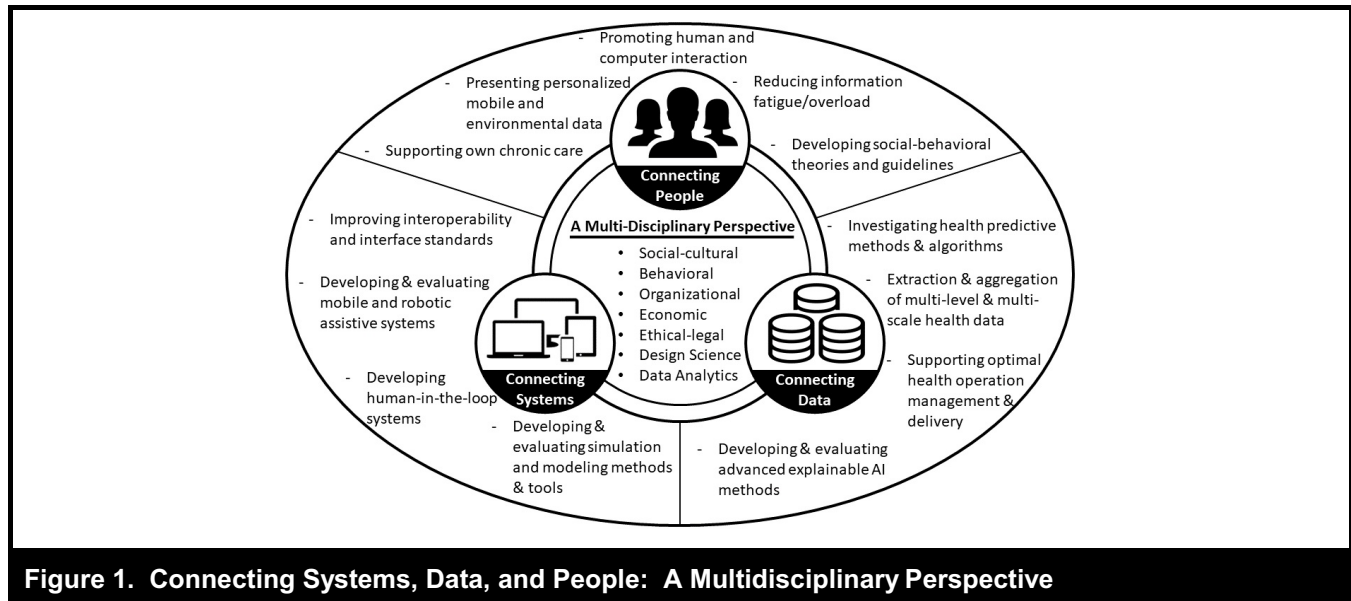
Figure 1. Connecting Systems, Data, and People: A Multidisciplinary Perspective

tions moving from structured to unstructured data including text, image, and video analytics (Shickel et al. 2018). Some examples of deep learning applications on EHR data include prediction of heart failure, hypertension, and diabetes, as well as temporal outcomes such as readmissions and post-operative outcomes. Miotto et al. (2016) developed a novel unsupervised deep feature learning method to derive a general-purpose patient representation from EHR data that facilitates clinical predictive modeling. Rasmy et al. (2018) recently developed an RNN (recurrent neural network) model, RETAIN using heterogeneous EMR data, for heart failure onset risk prediction. Their deep learning model achieved significantly greater predictive accuracy compared to logistic regressions, demonstrating the power of deep learning models for EHR predictive modeling. Choi et al. (2017) also developed an RNN model, based on leveraging temporal relationships within EHR patient records, which improved predictive performance for detection of incidents of heart failure with a short observation window of 12 to 18 months. Reddy and Delen (2018) developed a hybrid RNN-LSTM deep learning model to predict hospital readmissions for lupus patients, and demonstrated significantly better predictive performance compared to traditional classification methods.

Despite the promising overall performance for complex health analyses, such deep neural networks based models often suffer from interpretability issues (Rai 2020). For many health conditions (including chronic diseases), health professionals, patients, and their families often need to understand how and why a critical medical decision or recommendation was made or suggested. An important future research direction is to develop selected explainable artificial intelligence

models, which can offer insights about the salient features or parameters that contribute to health analytics results or recommendations. Last, regardless of the nature of the computational or algorithmic methods, empirical assessments and careful field studies are still required to demonstrate the practical value of these new approaches. Different patient groups often have different needs and perceptions of new health IT systems. For example, in this special issue, Savoli et al. (2020) identify three different patient views of the same self-monitoring portal (viewing the portal as facilitator, protector, and imposer) that explain patients' variations in use of the portal and in self-managing their chronic condition. Understanding patients' unique perspectives can provide guidelines for future health IT development and potentially improve adoption and use of these novel health IT systems. This research gap plays well into the strengths of the interdisciplinary IS community.

Addressing Risk and Fairness in Health IS and Analytics Research

Healthcare data analytics research has been using big data derived from a large volume of electronic health records in combination with claims data and a variety of health-related sources. It is widely believed that health data analytics can improve the access to, quality of, and cost of health care. However, these efforts can be foiled by patients or their families if they perceive more harm than benefits. A major risk is the exposure of their personal health information, especially in the era of data breaches within the "Dark Web" (Chen 2012), where health data are highly valued by cyber

criminals. Although much of the research can be conducted with de-identified data (i.e., HIPAA compliance), aggregation of information into large data sets increases the potential for patient data to be re-identified and used in ways patients never would have intended. There is growing concern about the legitimate use of health data due to the very real risks of discrimination in health insurance, life insurance, and employment based on preexisting health conditions. Although these practices are now largely limited by law, existing laws are being challenged and the sophistication of big data use by commercial entities suggests that these concerns are not unfounded (Cassel and Bindman 2019). Recently, we have witnessed the design of standards concerning security and privacy of patient data. However, more work is needed to adopt new regulations and deploy health data analytics with privacy and fairness in mind.

Connecting Data

The past decade has seen an explosion in the amount of digital information stored in EHRs and "in the wild" data from mobile devices and other types of sensors. Over the same period, research has seen widespread advances in the field of artificial intelligence (AI), and specifically, the development and deployment of AI applications. In recent years, deep learning techniques have achieved greater success in many domains through deep hierarchical feature construction and capturing long-range dependencies in data in an effective manner.

Use of Artificial Intelligence for Disease Prevention, Detection, Diagnoses, and Treatment

AI can use large data sets available to hospitals and healthcare providers not only to identify and predict patients who are at risk of disease, but also to detect changes in patients' health status and medical outcomes, enable more accurate and faster diagnoses, and support personalized treatment planning, especially for chronic disease patients (AHA 2019). AI's knowledge of the disease state is based on its learning algorithm and clinicians' experience in treating patients with the same signs, symptoms, diagnoses, treatments, and outcomes. While most clinical data are recorded in limited, broad categorizations that omit specificity and may be limited by potentially biased sampling, future research is needed on the development of well-accepted criteria and standards that will allow AI algorithms to "learn" within the data, and enhance the creation of "reinforcement learning loops." AI healthcare applications are expected to have an impact at three different levels: for clinicians, via rapid and accurate image interpretation; for health systems, by improving workflow and the potential to

reduce medical errors; and for patients, by enabling them to process their own data to improve their health engagement, use and accountability (Topol 2019).

Similarly, evidence-based medical protocols and established clinical pathways work for most patients because they are based on the "average treatment effect" established by statistical estimation models. However, what works for most patients may not work for an individual patient. Future research needs to explore how AI can personalize treatment decisions for individual patients to a clinician. The quality of data that AI learns from is also important and a potential barrier to widespread adoption of precision medicine. The scale of data required for deep learning and the diversity of techniques used makes it difficult to obtain a clear picture of how accurately AI systems may work in real-world practice or how reproducible they may be in different clinical contexts. Future research opportunities need to address "social bias" in AI algorithms and adequate steps must be taken to avoid exacerbating healthcare disparities when using AI tools in vulnerable patient populations (Topol 2019). Patient privacy must be protected and greater transparency into algorithmic fairness is needed to ensure acceptance of AI by providers and patients.

Integration of Nontraditional Data with Traditional Data Sources

In recent years, there has been significant interest in developing a human-centered approach to integrate electronic health records with data collected in-the-wild, including crowd-sourced data streams using (1) mobile and sensor-based sources as well as external databases such as users' social networks, environmental pollution, and weather data, and (2) developing methods and a framework to evaluate their usefulness for predicting patient engagement and health outcomes. The growing interest in IoT-like monitoring of humans in the wild, when combined with an explosion in increasingly higher quality wearables, provides a unique opportunity to monitor patients (and potential patients) over time and study changes in patient behavior through natural and quasi-natural experimentation (Bao et al. 2020). Future research opportunities include addressing the lack of a coherent integration framework between these data sources and a scalable approach for real-time collection and analysis of such data. New interoperability standards, such as the Fast Healthcare Interoperable Resources (FHIR) standards, provide an avenue to exchange patient data across electronic health records and data collected across mobile devices. New analysis methods and approaches to process and evaluate the accuracy of such data need to be developed to support clinicians in real-time decision-making applications.

Connecting People

Technological advances and regulatory shifts are transforming healthcare practices from being provider-centered to being patient-centered,

> providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions (Institute of Medicine Report 2001, p. 3).

As of 2017, there were over 318,000 mobile health apps available for use (IQVIA Institute for Human Data Science 2017), ranging from fitness and wellness to disease-specific apps (such as monitoring glucose levels for diabetic patients), mobile medication reminders, education, and interacting with medical providers. These have an estimated installed base of 3.35 billion worldwide and are used by 48% of healthcare consumers (*ibid.*). Online health communities such as *Mayo Connect* and *Patients Like Me* provide a supportive space for chronic disease patients and caretakers to share their daily experiences and narratives about their illness, to provide and receive emotional support, and to learn from other patients. Online health resources, such as Mayo.org, provide patients with a wealth of educational information. Patient portals, telehealth apps, and monitoring devices facilitate patients' access to providers. These IT-enabled capabilities have expanded patient-to-patient and patient-to-provider connections and are empowering patients to be active participants in their own chronic care health management and treatment. They have also created a wide spectrum of research opportunities to address chronic disease prevention and management, some of which we highlight below.

Online Health Communities as Hubs for Medical Innovation

While the last decade has witnessed significant interest in research on OHCs, such as *Patients Like Me* and *ParkinsonNet*, it is important to evaluate how such patient-generated content and data can be harvested to improve research on the development of new drugs and therapies to improve patients' quality of life. For example, some communities curate and integrate patient feedback about the efficacy of therapies, their side effects, and disease progression to generate medical knowledge that can benefit patients, clinicians, and policy makers (Kallinikos and Tempini, 2014). Complementing clinical knowledge with patients' lived experiences, identifying challenges in daily experiences of illness and creative solutions, and observing feedback from patients and caregivers on product attributes, can spawn medical innovation and creative insights. Patient-driven research (where patients collect data from others in the community) can serve as the seed for future randomized clinical trials. How can these be best achieved? What analytical tools, community design practices, and governance mechanisms can be leveraged to do so? In addition, research needs to be conducted on the quality, integrity, and privacy of such patient-generated data to assess their relevance and use for clinical and healthcare process innovation.

AI in Mobile Apps and Wearables

AI is increasingly being used in mobile apps and wearables to promote healthy lifestyles and to facilitate management of chronic conditions. Such uses may range from monitoring of symptoms to detect potential adverse events (e.g., atrial fibrillation) to virtual coaching to managing diabetes. For example, the virtual care company, Onduo, integrates physical activity data with glucose sensor data and AI image recognition of food to provide real-time coaching via text messages (Topol 2019). Given that chronic conditions are frequently associated with poor lifestyles, understanding how and why people modify their behaviors and the role of technology in this process will be paramount in designing effective interventions through AI. For example, behavioral theories of feedback may inform the timing, frequency, form, and framing of feedback to provide effective digital nudges and to avoid reminder and alert fatigue, desensitization, and information overload that may negate the benefits of such interventions.

New AI-based conversational interfaces also provide an important avenue for future research. Such interfaces, especially voice, enable broader access, especially for those with lower literacy (Bickmore et al. 2010, 2016), for the elderly, and for those whose health conditions may prevent them from interacting via clicks. Research has explored use of conversational agents for mental health conditions (Fitzpatrick et al., 2017; Park et al. 2019; Suganuma et al. 2018), autism (Tanaka et al. 2017), education (Bickmore et al. 2010), searches for clinical trials (Bickmore et al. 2016), and engagement of the elderly in conversations (especially those suffering from dementia), among others. Research avenues for behavioral and design research involve identifying design features for different application contexts, diseases, goals, and groups of users that make the use of such conversational agents effective. These include choices in terms of text versus voice, embodiment, anthropomorphization (e.g., gender, age, race, etc.), whether to use homophilous anthropomorphism or not, personality, emotional intelligence, personalization mechanisms, and conversational structures and flow (for a discussion see Thomaz et al. 2020). Ethical considerations, privacy, and long-term effects (intended and unintended) of using such

medical personal assistants are also fruitful areas for research in this domain.

Coordinating Care in Multidisciplinary Care Teams and Across Transitions

While we have acknowledged the importance of connecting patients with patients and patients with providers, seamlessly connecting providers with providers is a critical aspect of patient care. Coordinating care for chronic diseases is likely to involve multidisciplinary care teams. The knowledge boundaries across these teams must be transcended, sometimes in real-time, informed by insight on the distinctive characteristics of the patient. While EHR systems provide a level of visibility to help develop shared understanding about the patient, how can insights from doctors' notes and patient-generated data (e.g., sensor-based continuous data streams) be meaningfully culled and proactively shared with providers across specialties involved in the patient's care? With the expansion in the volume and velocity of data and in the number of sources of data, how can information overload be managed and curated while sharing the relevant information across specialties so the care is effectively coordinated?

Chronic disease patients are also likely to undergo transitions across a series of providers—from providers at ambulatory care centers to providers at another hospital to providers of outpatient and rehab care to providers of home care. Transitions between providers, especially those spanning very different organizations, are critical points of coordination failure—which escalate costs, risks of adverse medical events, duplicate tests, and extreme stress for patients (Ayabakan et al. 2017). Coordinating care with technology does not end with interoperability; it begins there as the system-level technical constraints are addressed with interoperability across diverse systems sourced from diverse vendors (Bao and Bardhan 2018). The more challenging, and arguably consequential, need is developing highly nuanced models to augment provider decision-making for their specific role at any point in time: How can these models be developed to incorporate the needs of the patient, what works and what does not work for the patient, and how can the provider intervene effectively at a particular point in time given the history of care? These models are necessarily ones that augment the provider's decision-making about how to intervene with the patient's care given a situational need and the history of their care spanning providers that play different roles and are associated with different facilities. The well-recognized issues of HIPAA and information-sharing constraints that can constrain the development of such active process models fuel the need to understand the patient calculus on information

sharing across providers under different care settings that can be rendered.

Addressing the Digital Divide in Health IS and Analytics

We have begun to witness a potential digital divide in the emerging world of connected health systems and data. As health devices and systems become more sophisticated (and expensive), they may widen the digital divide, separating a portion of the world's population who do not have easy access to the internet and health IT, due to cost, literacy, or political barriers, from those who do have such access. Although some evidence suggests that certain HITs, such as OHCs, which connect patients to other patients (Goh et al. 2016), and telemedicine, which connects patients to providers (Zhang et al. 2018), may reduce urban–rural health disparities, it is important for IS researchers and healthcare professionals to understand this divide in the context of relevant health research and practices and the conditions (technological, social, cultural, etc.) that may propagate or ameliorate it. For example, there is wide agreement that one of the most effective pathways to drive down healthcare costs and improve quality of life for individuals is for them to engage in a wellness lifestyle that prevents chronic diseases. However, wellness initiatives may not be pursued by individuals due to the digital divide and disparities in health access that result in lack of awareness or lack of resources and capabilities. How can digital awareness-building programs effectively promote wellness initiatives such as nutrition, exercise, and regular health checkups in a way that bridges the digital divide and health disparities? How should these programs incorporate the real-time awareness of the individual, the context in which the person lives, and his/her changing risk to chronic diseases? Information technologies need to be provided to individuals and their caregivers in a way that contributes to their health and well-being, taking into account their social, economic, political, and cultural contexts. We hope the IS community can have an impact on this often neglected area of research.

IT can also play a major role in improving the visibility of health disparities at the level of communities, so that there is broad-scale awareness of the extent of the problem. With shortages in nutrition for children at school, both in developed and much more so in developing and underdeveloped countries, with lack of potable water in many parts of the world, with expectant mothers engaging in practices that put infants' lives and wellness into risk, there is a strong need for a comprehensive perspective on how we look at community health in relation to the chronic disease challenge (Venkatesh et al. 2016; WHO 2016). How can community-level IT systems

provide visibility of health disparities and dysfunctional behaviors that can catalyze chronic diseases, and how they are trending? How can such digital platforms serve as test-beds for the implementation, evaluation, and refinement of policies and public–private partnerships to address these problems?

Although we have discussed the proliferation of health data from EHRs, sensors, social media, and mobile devices, health disparities and the digital divide would suggest that data are not generated equally across the population. The exclusion of certain vulnerable populations (such as racial and ethnic minorities, low income individuals, or individuals living in rural areas) from data generation processes may give rise to algorithmic biases. Such algorithmic biases may result, for example, when groups are underrepresented in EHR data and in data from clinical trials (Downing et al. 2016), especially when diseases may occur or manifest differently in such populations (Agarwal et al. 2020). Detecting and correcting such biases in data generation practices requires research attention as algorithm-driven recommendations and processes become more prevalent in healthcare delivery.

Papers in this Special Issue ▰▰▰

The special issue includes nine papers that reflect the richness and multifaceted nature of using information systems and analytics to manage and prevent chronic diseases. The nine papers provide different theoretical (e.g., feedback theory, attribution theory, etc.) and methodological perspectives, focus on addressing different problems (e.g., readmissions, self-monitoring and third-party monitoring, health costs, emergency room visits, patient–provider relationships, engagement in educational videos, etc.), leverage different data sources (e.g., EHRs, social media, online communities, patient portals, YouTube videos), and examine different chronic conditions (e.g., asthma, diabetes, COPD, depression, chronic heart failure, etc.).

Ofir Ben-Assuli and Rema Padman, in their paper, "Trajectories of Repeated Readmissions of Chronic Disease Patients: Risk Stratification, Profiling, and Prediction," examine the longitudinal risk stratification, profiling, and prediction of multi-morbid, heterogeneous patient populations based on trajectories of repeated readmissions of chronic disease patients. They study how readmission risk may progress across multiple emergency department visits, their early stratification into distinct trajectories with related frequencies, and the relationship of these trajectories to patient characteristics. They further extend this analysis to investigate the impact of time-stable and time-varying covariates in predicting future

readmission conditional on latent class membership. Results indicate that longitudinal risk stratification can enable early identification of specific patient groups following distinct trajectories based on their presentation for emergency care.

Steve Thompson, Jonathan Whitaker, Rajiv Kohli, and Craig Jones, in their paper "Chronic Disease Management: How IT and Analytics Create Healthcare Value Through the Temporal Displacement of Care," introduce the notion of temporal displacement of care (TDC), in which IT and analytics can create healthcare value by displacing the time at which providers and patients make interventions to improve healthcare outcomes and reduce costs. Their theoretical development identifies TDC mechanisms through which IT and analytics displace later high cost interventions in favor of earlier preventative procedures. They test their hypotheses using four years of data on 45,000 cardio-metabolic patients from the state of Vermont, which implemented a Patient-Centered Medical Home (PCMH) program. Their results provide insights into how TDC effects develop over time and reveal that the use of analytics and data quality sprints are associated with an increase in the use of preventive procedures, lowering emergency department utilization and overall patient treatment costs.

Few studies have identified evidence-based digital therapeutics with technology-enabled interventions to improve the ease with which patients can retrieve medical information to manage chronic conditions. Xiao Liu, Bin Zhang, Anjana Susarla, and Rema Padman, in "Go to You Tube and Call Me in the Morning: Use of Social Media for Chronic Conditions," propose an interdisciplinary lens that synthesizes deep learning methods to examine user engagement with encoded medical information in YouTube videos. They first use a bidirectional long short-term memory (BLSTM) method to identify medical terms in videos and then classify videos based on whether they encode a high or low degree of medical information. Their study provides healthcare practitioners and policymakers with a better understanding of how users engage with medical information in videos, and contributes to enhancing current public health practices by promoting normative guidelines for educational video content to improve management of chronic diseases.

Three papers in the special issue, focus on asthma patients as their context of study. Asthma is a prevalent respiratory chronic disease. Patients diagnosed with asthma may experience significantly reduced quality of life if their asthma is not properly controlled. In the first of these papers, "A Data Analytics Framework for Smart Asthma Management Based on Remote Health Information Systems with Bluetooth-Enabled Personal Inhalers," Junbo Son, Patricia Flatley

Brennan, and Shiyu Zhou present a data analytics framework for smart asthma management based on remote health information systems with Bluetooth-enabled personal inhalers. Asthma specialists and engineers have developed the smart asthma management system (SAM), which provides Bluetooth-enabled inhalers and collects time stamps of every rescue inhaler use. Taking advantage of the patient monitoring capability of the SAM system, the authors developed a data analytics framework for detecting abnormal inhaler use that is out of the patient's normal usage pattern. This proposed framework can address the key features of the data collected from the SAM system such as the heterogeneous impact of environmental factors on inhaler usage behavior and the correlation structure governed by the patient's repetitive routines. The authors demonstrated the performance of the data analytics framework through rigorous comparison with various statistical and machine learning benchmark methods.

In the second paper, "A Comprehensive Analysis of Triggers and Risk Factors for Asthma Based on Machine Learning and Large Heterogeneous Data Sources," Wenli Zhang and Sudha Ram introduce a data-driven framework, which adapts and integrates multiple machine learning techniques, and perform empirical analysis to (1) derive characteristics of self-reported asthma patients from social media, (2) enable integration and repurposing of highly heterogeneous and commonly available datasets, and (3) uncover the sequential patterns of asthma triggers and risk factors, and their relative importance, both of which are difficult to achieve via retrospective cohort-based studies. Their methods and results can provide guidance for developing asthma management plans and interventions for specific subpopulations and, eventually, have the potential to reduce the societal burden of asthma.

In the third paper, "Examining How Chronically Ill Patients' Reactions to and Effective Use of Information Technology Can Influence How Well They Self-Manage Their Illness," Azadeh Savoli, Henri Barki, and Guy Paré focus on the use of self-management (SM) portals for asthma patients as a means to help them manage their condition. Leveraging attribution theory and learned helplessness theory, the paper examines how patients' causal attributions of their success or failure in self-managing their chronic condition tends to influence how they perceive and use the SM portal. The paper identifies three SM attributional styles (reliant, engaged, and autonomous) and three patient views of the SM portal (facilitator, protector, and imposer) that help explain variations in how chronically ill patients use the SM systems, as well as variations in the consequences of such use to self-managing their condition. Although the empirical context of the study focuses on asthma patients, the theoretical framework likely generalizes to use of SM systems for other chronic conditions.

Although much research has focused on online patient health communities for managing chronic diseases, less attention has been devoted to online health communities involving physicians. Qianqian Ben Liu, Xiaoxiao Liu, and Xitong Guo, in "The Effects of Participating in a Physician-Driven Online Health Community in Managing Chronic Disease: Evidence from Two Natural Experiments," examine physician-driven online health communities for managing diabetes and depression that engage both patients and physicians. Drawing on the "patient–physician partnership" paradigm for managing chronic disease (Bodenheimer et al. 2002), they suggest that physician-driven OHCs facilitate patient–physician collaborative care and self-management support, which may improve the patient's relationship with the physician as well as the patient's wellbeing. Leveraging two natural experiments, they find that physician participation significantly increases patients' participation for both diabetes and depression, but patients' participation only increases physicians' participation for depression. Although both patients' and physicians' participation significantly improve patient wellbeing and the patient–physician relationship, there are interesting nuances in these effects over time. The variability of results across chronic conditions and over time provide interesting directions for future research on physician involvement in OHC.

With the increasing presence of sensors, telemonitoring technologies have the potential to provide continuous feedback of a chronic patient's condition either to the patient or to their healthcare providers (Kitsiou et al. 2015). This can enable early detection of problems and early intervention resulting in more effective and efficient chronic disease management (Kalankesh et al. 2016; Peters et al. 2015). In this vein, Kathryn Brohman, Shamel Addas, Jeff Dixon, and Alain Pinsonneault, in their paper "Cascading Feedback: A Longitudinal Study of a Feedback Ecosystem for Telemonitoring Patients with Chronic Disease," develop a theoretical model to examine how telemonitoring, mediated through care providers, influences patient behavioral outcomes. Specifically, leveraging feedback intervention theory, the paper examines the cascading effects of two types of telemonitoring technology feedback (medical and compliance alerts) received by the care providers. These two types of telemonitoring feedback influence the provision of three types of feedback (outcome, corrective, and personal) given to patients by care providers, which in turn is related to patient adaptation and ultimately calls to 911. The authors test the model using longitudinal data from 212 patients with chronic obstructive pulmonary disease (COPD) and/or chronic heart failure (CHF) over 26 weeks. Their results showed differential effects of the two types of telemonitoring technology feedback on care provider feedback to the patient. Further, the three types of provider feedback had differential effects on patient adaptations and emergency calls. Time effects suggest that

the frequency of care provider feedback decreased over time while the number of patient adaptations increased over the same period, which suggests that patient self-management improved over time. The study has significant implications for the design of telemonitoring technology feedback ecosystems where such feedback is mediated by a third party.

While Brohman and her colleagues focus on telemonitoring mediated by third parties, Jinglu Jiang and Ann-Frances Cameron, in "IT-Enabled Self-Monitoring for Chronic Disease Self-Management: An Interdisciplinary Review," provide a multidisciplinary literature review and synthesis of studies focusing on IT-enabled self-monitoring (ITSM) for chronic disease management. They develop an overarching framework and organize their findings from 159 studies published in 108 journals and conferences around four emergent themes: ITSM functionalities that enable self-monitoring affordances; effects on ITSM system use; effects on the achievement of chronic care goals; and achievement of intermediary outcomes. The synthesis provides a significant stepping stone to integrating work from multiple disciplines holistically and to suggesting research directions for ITSM research in the context of chronic disease management.

Special Issue Process

We received 149 extended abstracts for the special issue. We used three criteria to evaluate the abstracts: whether chronic disease was a salient aspect of the paper, whether the paper had the potential to make a significant scholarly contribution, and whether the research was at a stage of development advanced enough to meet the deadline for the special issue. Based on these criteria, we invited 32 papers for full submission. These papers were each reviewed by at least two members of our editorial board for the special issue. Eleven of these papers were invited for resubmission. We subsequently held a workshop for the special issue at the University of Texas at Dallas to provide authors with additional feedback on their revision strategy. The editorial board members were also invited to participate in the workshop. The special issue editors integrated the workshop feedback and provided authors written and specific guidance on how to leverage this feedback in revising their papers. Nine papers were accepted for publication in the special issue.

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