An Evaluation of Computational Methods to Support the Clinical Management of Chronic Disease Populations

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Abstract

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Innovative primary care models that deliver comprehensive primary care to address medical and social needs are an established means of improving health outcomes and reducing healthcare costs among persons living with chronic disease. *Care management* is one such approach that requires providers to monitor their respective patient panels and intervene on patients requiring care. Health information technology (IT) has been established as a critical component of care management and similar care models. While there exist a plethora of health IT systems for facilitating primary care, there is limited research on their ability to support care management and its emphasis on monitoring panels of patients with complex needs. In this dissertation, I advance the understanding of how computational methods can better support clinicians delivering care management, and use the management of human immunodeficiency virus (HIV) as an example scenario of use.

The research described herein is segmented into 3 aims; the first was to understand the processes and barriers associated with care management and assess whether existing IT can support clinicians in this domain. The second and third aim focused on informing potential solutions to the technological shortcomings identified in the first aim. In the studies of the first aim, I conducted interviews and observations in two HIV primary care programs and analyzed the data generated to create a conceptual framework of population monitoring and identify challenges faced by clinicians in delivering care management. In the studies of the second aim, I used computational methods to advance the science of extracting from the patient record social and behavioral determinants of health (SBDH), which are not easily accessible to clinicians and represent an important barrier to care management. In the third aim, I conducted a controlled experimental evaluation to assess whether data visualization can improve clinician's ability to maintain awareness of their patient panels.

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Chapter 1: Introduction

1.1 Dissertation Introduction

Ensuring the delivery of primary and secondary preventative care to persons living with chronic disease is a critical aspect of efforts to improve health and reduce costs in modern healthcare systems.(1) A particularly promising approach, referred to as *care management* (CM), involves identifying patients with care gaps - unmet preventative screenings and chronic care needs - and arranging services to address those gaps.(2) This approach has been most prominently adopted in chronic disease settings, where secondary prevention is often life-saving.(3) The successful provision of such preventative care at scale has been associated with the availability of information technology (IT) tools that support components of CM including population monitoring, interoperability between care settings, collaborative care, and quality measurement.(4–6)

Despite claims that IT is essential to care management, there has been limited research focused on the ability of existing systems to satisfy the IT needs of clinicians providing such care.(7) In this dissertation, I detail findings from qualitative research that resulted in a set of design requirements for IT systems that support the management of large groups of patients with chronic disease. I then assess whether computational methods such as natural language processing and information visualization can satisfy the aforementioned needs and requirements. Throughout the thesis, I use the management of human immunodeficiency virus (HIV) as an example but assert that these findings are generalizable to other care settings.

1.2 Dissertation Overview

The goals of this dissertation can be generalized into 3 specific aims that together demonstrate how health information technology (IT) can improve the delivery of care management. In Aim 1, we characterized the IT needs of clinicians and evaluated whether existing IT systems satisfy those needs in the context of CM. The shortcomings of the systems observed in Aim 1 motivated Aims 2 and 3, which identified computational approaches that may better support healthcare providers in care management settings. Aim 2 attempts to provide insight into how social and behavioral determinants (SBDH) - factors important to the management of patients with complex care needs - are expressed in the patient record and leverage those insights to improve approaches to automated inference. Aim 3 addresses clinician’s inability to maintain awareness of patients with complex needs - a paramount task not supported by contemporary IT systems. Towards this goal, an experimental study was conducted to assess whether data visualization can improve provider’s awareness of patients compared to patient registries. The visual interface evaluated in the experimental study was informed by the findings of Aim 1, which yielded a set of requirements for population monitoring, and Aim 2, which suggested that information on patient SBDH can be inferred from patient records and included in population monitoring systems.

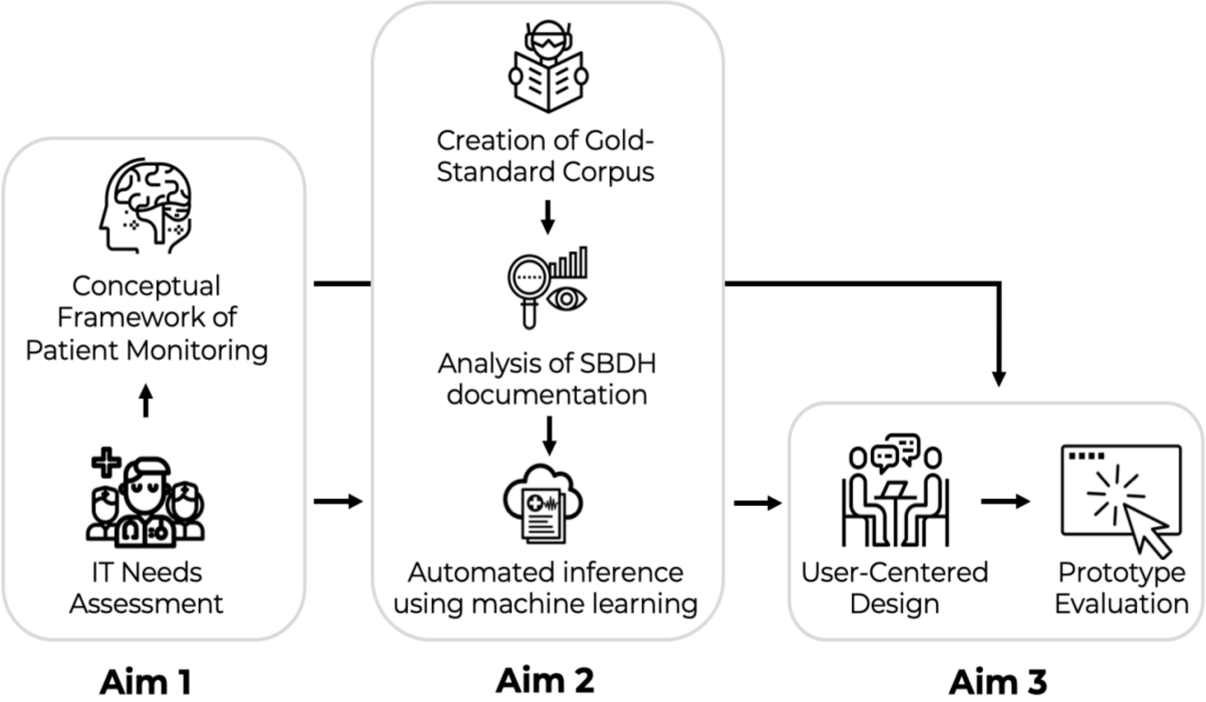


Figure 1.1 Overview of dissertation

Aim 1: Assess the IT needs of clinicians and identify inefficiencies and bottlenecks associated with care management provided to populations of HIV patients

The research conducted in Aim 1 advances a comprehensive understanding of the IT needs of providers delivering care management and a conceptual framework that describes the process of population monitoring. Research findings were generated through a qualitative study conducted in two HIV primary care clinics that included semi-structured interviews and direct observation. The qualitative inquiry focused on the following research questions which were related to the ability of existing health IT systems to support care management: 1) what information is required to successfully perform activities related to care management delivered to HIV populations, 2) how do information requirements vary across different staff roles in ambulatory HIV practices, and 3) what components of existing IT systems support or undermine complex care management delivered to HIV populations?

Aim 2: Extract from clinical data the information required for HIV care management, including relevant social and behavioral determinants of health

Aim 2 consisted of multiple studies that together advance knowledge related to automated classification of social and behavioral determinants (SBDH) from clinical data. First, we developed a gold-standard corpus of clinical notes annotated with an array of SBDH using semi-supervised learning. This was necessary due to the low prevalence of notes with documentation of SBDH, and this approach significantly increased the yield of the manual annotation process. Second, the sizeable annotated corpus was used to analyze the longitudinal manifestation of SBDH within individual patient records. This analysis yielded insight into the frequency changes in patient SBDH status as well as data quality issues in SBDH documentation. Third, we used the aforementioned insights to inform our approach to automated classification of patient SBDH status, which leveraged unstructured and structured data and supervised learning to infer a range of distinct SBDH factors from clinical data.

Aim 3: Design and evaluate an interface that supports monitoring and prioritization of patient panels

Aim 3 entailed the development and evaluation of an interactive tool designed to improve a healthcare providers' situational awareness of their patients and respective panels. First, user-centered design was employed to develop an interactive tool that leveraged data visualization to support population monitoring. A within-subjects experimental study assessed whether the this interactive visualization improved healthcare provider's awareness compared to a simulated patient registry. Subjects participated in 15-minute trials, in which they performed a series of tasks related to population monitoring.

1.3 Knowledge Gaps

This dissertation is motivated by the need for the informatics community to better understand the requirements of clinicians delivering care management and the computational tools that could support these requirements. While health IT is considered an essential component of modern primary care, there is limited research on the ability of health IT to support care management and more specifically, the important task of monitoring and intervening on large populations of patients with complex needs.(8,9)

Aim 1 attempts to address the fact that little is known about the IT needs of clinicians delivering care management, reflecting the relatively recent emergence of this care model. To our knowledge, no previous studies have conducted a comprehensive assessment of clinicians' needs associated with delivering care management to large patient groups.(3,7) As a result, the most dominant approach to providing clinicians with information on care gaps among their respective patients has been exceedingly simple; *patient registries* are simple unsorted lists of patients with a specific care gap.(10) Despite being endorsed for use in primary care by the American Medical Association, patient registries have not been evaluated for their ability to support population monitoring.(11) The volume of patients presented on these registries is likely to be overwhelming; contemporary primary care providers are responsible for more than 1,500 patients on average.(12) An improved understanding of the requirements for IT systems designed to support such activities could enable the development of interfaces more sophisticated than patient registries and thereby improve the ability of clinicians to provide care management.

Aim 2 attempts to provide insight into how social and behavioral determinants are expressed in the patient record and leverage those insights to improve approaches to automated inference, with the ultimate goal of providing this information at the point-of-care. Previous research on extracting SBDH from clinical data has primarily employed Natural Language Processing (NLP) techniques and have achieved modest performance. (13) However, structured data elements in the EHR can also be utilized to infer SBDH. It has been established that alcohol abuse, drug abuse, and homelessness are represented by International Classification of Diseases (ICD) codes which exhibit high specificity but poor sensitivity for the determinants they represent.(14–17) Despite the potential utility of this information in systems for extracting social and behavioral determinants, no previous study has leveraged heterogenous clinical data to improve information extraction compared to one data source alone. Moreover, previous experiments related to retrieval of SBDH from patient records have not considered the characteristics of clinical documentation related to SBDH. This creates an opportunity to develop a better understanding of how patient SBDH status is manifested in clinical data and thereby inform the design of novel approaches to automated inference.

Aim 3 provides insight into ways that interactive systems can improve healthcare provider's awareness of their respective panels. It has been established that EHRs are unable to support providers in monitoring populations, as EHR systems are designed to support information retrieval for individual patients.(18–20) To complement EHRs, many providers use patient registries (11,21) but due to the limitations of registries, clinicians often must create 'homegrown' tools such as paper-based lists and Excel spreadsheets that can better satisfy their needs related to population monitoring.(4,22–24) Although both the American Academy of Family Physicians and American Academy of Pediatrics have asserted that new IT tools are required to support population monitoring in ambulatory care (25), little research has been conducted in this area. Increasingly, information visualization is being considered as a means to support healthcare providers utilize large volumes of clinical data.(26–28) Research is needed to assess whether visualization can support providers delivering care management.

1.4 Contributions

This dissertation makes several contributions to the informatics community that can inform the design interactive systems for clinicians and improve approaches to automated inference of social and behavioral determinants of health from electronic health records. In addition, the research described herein contributes to the international community of HIV care providers a better understanding of how information technology can improve the quality of HIV care.

First, we establish a comprehensive set of IT needs for clinicians managing large groups of patients. Our study suggests that existing IT tools may not adequately support care management and that the information contained in these systems may be insufficient to identify patients requiring enhanced attention. To inform the design and evaluation of novel systems, we introduce a conceptual framework of population monitoring in care management that is grounded in the theory of *situational awareness*; this framework can inform researchers as they strive to better understand the process by which clinicians monitor and prioritize patients on their panels. In addition, the conceptual framework also advances a set of design requirements and evaluation metrics that may guide the development and evaluation of novel systems that improve the ability of healthcare providers to deliver care management.

Second, we advance the science of extracting social and behavioral determinants from clinical documentation. This is an important contribution because it is well established that providers who lack access to this information provide worse quality care.(29,30) First, we present a means of accelerating the process of generating an annotated corpus of clinical notes annotated for SBDH. In addition, we advance a set social and behavioral determinants of sexual health such as sexual orientation and safe sex practices that may be used in future inquiry. Second, I present a longitudinal analysis of the aforementioned gold-standard corpus, which provides insight on how a patient's documented SBDH status changes over time. This analysis suggests that there may be data quality issues in SBDH documentation. Third, we demonstrate that structured EHR data provides indicators of patient SBDH status and that classifiers attempting to infer patient SBDH status should leverage both structured and unstructured data .

Third, our study findings provide evidence that data visualization exists as a useful paradigm to support population monitoring. A convenience sample of physicians and nurse practitioners overwhelmingly preferred an interactive visualization to patient registries - which are the most commonly used IT tool for monitoring – when asked to complete several tasks related to population monitoring. The informatics community should assess whether such tools can successfully be integrated into clinical practice among providers responsible for monitoring large populations of chronic disease patients.

Fourth, many of the findings enumerated in this dissertation propose several ways in which the provision of HIV primary care can be improved through the use of IT. In Aim 1, interviews with clinical staff suggested that HIV care providers would benefit from novel systems that better enable population monitoring, facilitate communication between providers, and help address psychosocial barriers to treatment. Aim 2 explores the feasibility of automatically inferring the presence of SBDH. Our findings suggest that some SBDH related to sexual health can be inferred from patient records, which may provide an opportunity to build clinical decision support systems that help providers identify patients at risk of contracting HIV. Aim 3 provides evidence that data visualization can improve healthcare provider's awareness of patients with complex care needs. These findings raise the possibility that visualization may improve the quality of HIV primary care and support providers as they attempt to ensure that all patients achieve continuous adherence to HIV antiviral therapy.(31)

1.5 Limitations

The findings of Aim 1 were drawn from two HIV primary care programs in New York City. As a result, study findings may have limited generalizability to clinical settings other than HIV management. In addition, data collected via semi-structured interviews and observation of multidisciplinary care team meetings; we did not directly observe clinicians during clerical work. As a result, the qualitative data collected may have been impacted by participant's recall bias.

The studies of Aim 2 related to SBDH documentation have several limitations that should be considered. In the longitudinal analysis of SBDH documentation, we were unable definitively distinguish legitimate changes in patient SBDH status from status due to data quality issues. Future studies should attempt to capture unassailable information on changes in patient SBDH status (likely direct report from patients) to ascertain the proportion of changes in SBDH documentation that reflect true changes in the patient state. In addition, for our approach to automated SBDH inference we chose to obtain document-level annotations rather than mention-level annotations because we observed that SBDH are not typically expressed as named entities. However, this precludes comparison of our results to the majority of other studies of using NLP for SBDH documentation that leveraged named-entity recognition.

Aim 3 has several limitations that should be considered. First and foremost, the experimental evaluation was conducted with dataset of synthetic patients. In actual practice, clinicians would be familiar with most or all of the patients on their panels and thus some of the study tasks are more challenging to accomplish in a laboratory setting. Second, the user-centered design and experimental evaluation was conducted in a simulated HIV primary care setting and thus results may not be generalizable to other healthcare settings. The components of the interactive solution may support the management of HIV but not be relevant to the management of other chronic diseases. Third, we used datasets containing 500 patients in study trials, but the actual caseload of providers may vary given different clinical settings. Third, our visualization tool was a prototype, and we expect that usability would improve with further refinement.

Chapter 2: Background & Literature Review

2.1 Care Management

2.1.1 The Triple Aim

In the past decade, it has been oft-repeated that the American healthcare system is plagued by high costs and poor outcomes; the United States spends more per capita on healthcare than any other nation on the globe.(32) However, American have little to show for it, as disease burdens and age-adjusted mortality rates are worse compared to other developed countries.(33) This has resulted in the pursuit of the so called ‘Triple Aim’ - controlling healthcare spending, securing high-quality patient experiences, and improving the health of the general population.(34) The central notion that underpins the Triple Aim is that by increasing the health of the population, population-wide healthcare care costs decrease thereby resulting in affordable healthcare costs for all. Policymakers have spawn a host of initiatives to achieve the Triple Aim; these include the Affordable Care Act and more recent initiatives that leverage financial incentives to compel healthcare providers to provide higher-value care.(35,36)

2.1.2 The Role Of Preventative Care

Health systems have several means of controlling costs and improving the health of the population and such as increased rates of screening and preventative care, targeting intensive care to ensure that persons with chronic disease patients can control their diseases, and using non-medical interventions that remove barriers to care such as social and behavioral determinants of health.

A recent nation-wide study observed that only 8 percent of US adults had received all of the preventative care recommended for them. This includes screening for common cancers, hypertension and cholesterol, and determinants of health outcomes such as tobacco and alcohol use, and depression.(1) Without proper diagnosis and management, these medical problems can lead to the development of chronic diseases which require lifelong care and exert an outsize impact on healthcare systems. 25% of adults have 2 or more chronic conditions such as heart disease, diabetes, or chronic obstructive pulmonary disease (COPD) and despite the availability of medical treatment, many persons with chronic disease do not achieve desirable health outcomes.(37) This reflects the patient's burden which involves altering their health-related behavior and taking medication and interacting with medical care over extended periods of time.(38)

Finally, the widespread absence of services for persons with social and behavioral needs also contributes to the incidence of acute and chronic illnesses. Social and behavioral determinants (SBDH) are environmental and behavioral factors that impede disease self-management and lead to or exacerbate existing comorbid conditions.(39) The impact of determinants such as unstable housing and substance use disorders on medical and cost outcomes has resulted in health systems being increasingly attuned to these determinants.(40,41) ED usage is disproportionately higher among persons with low socioeconomic status, who are more likely perceive the ED as the most convenient source of care.(42)

2.1.3 Delivering Preventative Care: The Emergence of Care Management

The achievement of the aforementioned goals has been hypothesized by policymakers and clinical thought leaders as being predicated on the delivery of high-quality care delivered in primary care and office settings (aka ambulatory care).(43,44) Innovative care models that deliver comprehensive care to address both medical and social needs can improve health and reduce healthcare costs among this vulnerable population.(2,6) One such model, *care* *management* (CM), involves using clinic-based staff, often referred to as care managers or care coordinators, who monitor patients' health outcomes, prioritize allocation of care and resources, and communicate directly with patients who require assistance.(45) In contrast to more 'reactive' care models that require patients to seek care, CM emphasizes the delivery of proactive care that requires clinicians to monitor and intervene on patients with unmet care needs.(45) There are many distinct styles of care management that reflect the care settings in which they are used; a care manager in a chronic disease program might be responsible for a small number of highly complex patients and thus sustain frequent contact with each patient while a care manager in a large family practice may contact patients infrequently to schedule screenings and visits.(2,6) Regardless of the type of care management deployed, transitioning to such care models requires changes in clinic staffing and organization. For example, CM employs care coordinators and additional non-physician staff that are often organized into multidisciplinary care teams(46). While not specific to chronic disease care, by definition CM includes the care coordination activities associated with the management of chronic illness.

The 2010 passage of the Affordable Care Act (ACA) facilitated this rise by making it easier for healthcare providers to be reimbursed for care management services delivered to Medicaid and Medicare recipients.(47) National initiatives such as the Comprehensive Primary Care program sponsored by the Center for Medicaid and Medicare Services have further established care management as a strategy for improving patient care.(48)

Moreover, evidence suggests that care management achieves its goals. Population health approaches that leverage care managers to provide healthcare navigation and education and also address social determinants have been shown to decrease the likelihood of ED visits and reduce costs.(49,50) Care management also is well suited to the management of co-occuring social and behavioral problems; engaging vulnerable patients with social workers and behavioral health clinicians can effectively address such determinants.(51,52)

2.1.4 Care Models Used In Care Management

Care management is most typically performed by multiple collaborating clinicians, although different care models are used to organize such collaboration. In many settings, a nurse-provider *dyad* is used to deliver care management: the nurse monitors the provider's panel and contacts any patients with care gaps, thereby freeing the physician from the time-consuming task of scheduling clinic visits. In other settings where patient needs are more complex, *multidisciplinary care teams* are composed of clinicians, including, but not limited to, physicians, nurses, behavioral health specialists or social workers, and case managers.(53) In this model, the nurse is often referred to as a 'nurse care manager', and monitors the providers panel similar to a nurse in a provider dyad.(54) This role is also referred to as a 'care coordinator'.

2.1.5 The Challenges of Care Management

Despite the established effectiveness of care management, it is not without challenges. First, the volume of patients that care managers are required to provide care for is large. Second, care managers do not have access to all of the information that is required for effective patient outreach.

Contemporary primary care panels consist of 1,500 or more patients and it has been estimated that physicians would require 18 hours per day to deliver recommended care to all of their patients.(55,56) Previous research has demonstrated that clinicians with large panels provide care of lower quality compared to those with lighter caseloads.(53,57) This may reflect the fact that providers with large panels struggle to maintain adequate awareness for all patients for whom they are responsible and inevitably neglect some patients who require care. The volume of messages that care managers receive from patients can quickly overwhelm their ability to respond in a timely manner.(58)

Another aspect that increases the difficulty of providing preventative care to large groups of patients is the outsize impact of social and behavioral determinants of health (SBDH) on chronic disease outcomes.(2,59) SBDH are environmental and behavioral factors such as unstable housing and substance use disorders and often impede disease self-management and lead to or exacerbate existing comorbid conditions. For instance, environmental factors such as food insecurity and neighborhood poverty are associated with adverse health outcomes, while housing instability and unmanaged substance use disorders can impede the delivery and efficacy of care and result in nonadherence to medication.(40,60–63) Due to the established impact of SBDH on health outcomes for persons living with chronic disease, health systems are increasingly attuned to these determinants. Although information on social and behavioral determinants of health provide clinically meaningful information and can lead to tailored care plans, they are typically recorded in clinical notes and thus not easily accessible.

A critical aspect that increases the difficulty of providing preventative care to large groups of patients is the outsize impact of social and behavioral determinants of health (SBDH) on chronic disease outcomes. Although information on social and behavioral determinants of health provide clinically meaningful information and can lead to tailored care plans, they are typically recorded in clinical notes and thus not easily accessible. There is evidence providers often struggle to retrieve information related to SBDH, and that those who are unaware of SBDH provide worse quality care.(29,30)

2.2 Health IT Systems in Care Management

Health information technology (IT) is an established requirement for care management and other care models that aim to coordinate the care of complex patients.(7,64,65) The Agency for Healthcare Research and Quality (AHRQ) Care Coordination Framework outlines several activities essential for achieving coordinated care, most of which rely on health information technology (HIT).(4,66) For example, electronic handoff tools, continuity of care documents, and interoperability are critical for *facilitating transitions*, *linking patients to community resources*, and *communication between care providers*.(67–69) Tools for electronic clinical quality measures can facilitate the *assessment of needs* and the *alignment of resources* with patient and population needs by providing insight into population health outcomes.(70) *Monitoring and follow-up* is most commonly performed using population registries, IT tools that list disease outcomes and gaps in preventative care for a defined patient panel (71–73) which are widely used by alternative practice organizations such as Accountable Care Organizations.(74) Care management is closely related to care coordination and thus relies on the aforementioned health IT – with the added emphasis placed on tracking and monitoring patient populations.(45)

Despite calls from clinical thought leaders and professional associations to improve IT tools for population monitoring, limited research has been conducted in this area. This is an area I focus on in Aim 3 of this dissertation, so I will describe existing IT solutions designed to support monitoring of large patient populations and potential opportunities to improve those systems.

2.2.1 Existing Systems Used in Care Management

The most frequently used IT tool in healthcare settings is the electronic health record (EHR). However, several studies have found EHRs inadequate for population monitoring –

defined as the process by which providers review their respective patient caseloads and intervene on any patients with unmet primary and secondary preventative care needs. Goetz et. al. reported that primary care physicians and staff perceived that their EHR does not adequately track patients and their disease status.(20) Berry and colleagues evaluated PCMHs in Louisiana and observed that EHRs did not support monitoring of adult and pediatric patients.(18) Alyousef and colleagues reported that systems that do not support efficient access of patient-related information create inefficiencies in clinical care, and that population monitoring systems that were challenging to use increased their perceived workload.(19)

The most basic form of care management interfaces are patient registries; these IT tools list all empaneled patients in a tabular format and present disease outcomes and health-related information in 1 or more columns. The American Medical Association recommends that primary care providers use disease registries to monitor patients for whom they are responsible, and the Meaningful Use program requires that certified EHRs generate registries.(11,75) For example, a diabetes registry might identify patients with high HbA1c values and relevant risk factors such as whether the patient is a smoker. Evidence suggests that providers deliver improved quality of care when utilizing registries. In addition, preventative care registries are also recommended; instead of disease outcomes such registries present care gaps – which represent missing screenings or evidence-based interventions appropriate for a given patient (e.g. overdue colonoscopy if patient is older than 50 or referral to a behavioral health provider if the patient has unmanaged depression).(11) Registries are widespread across Accountable Care Organizations and other advanced practice models; 65% used such tools in 2017.(74)

Despite these challenges, there has been limited research focused on addressing the needs of clinicians who manage large volumes of chronic disease patients. Because providers are often attentive to multiple disease & quality indicators, clinics typically use several registries. Despite their ease of use, basic registries do not support surveillance across large groups of patients or multiple conditions.(76) While interfaces have been developed to consolidate multiple disease & preventative indicators, these systems have the potential to elicit information overload and have not been formally evaluated. In 2014, a consortium led by the American Academy of Family Physicians (AAFP) and American Academy of Pediatrics (AAP) asserted that existing IT systems lacked many components necessary to support primary care.(25) This included not supporting coordination by lacking dashboards that 'synthesize and prioritizes information about panels of patients', and failing to support population management by lacking tools that 'identify and reach out to patients overdue for care'. Reflecting on these shortcomings, multiple studies have reported that clinicians often use paper-based lists and Excel spreadsheets for monitoring patient panels. Richardson and colleagues observed that the use of 'homegrown' tools such as spreadsheets reflected the inability of existing systems to generate patient panels and use real-time clinical data to monitor patients with complex conditions.(4) Cifuentes and colleagues studied EHR challenges in 11 primary care and behavioral health practices and found that multiple clinics also used Excel spreadsheets to facilitate close monitoring of patients.(22) In addition, when patient information was challenging to access in the EHR, clinicians were more likely to rely on recall, which is problematic because clinicians do not always remember information. In these studies, nurses and other non-physician staff were the primary creators of these homegrown systems and use them to target patients requiring outreach.

2.2.2 Approaches to Patient Prioritization in Care Management

Prioritization of patients who require enhanced attention is a growing need among clinicians in primary care settings who have, on average, between 1,500 and 2,000 patients.(55)

Risk-stratified care management was one of the fundamental components of the nation-wide Comprehensive Primary Care Initiative (CPC) launched by the Centers for Medicare and Medicaid Services (CMS).(48) This care model required primary care practices to identify high-risk patients such as those with high ED utilization rates or multiple chronic conditions and assign them to care managers, who would assist the patient in navigating medical and non-medical services. However, some participating practices reported that they had insufficient health information technology to support care delivery.(77)

A variety of risk-stratification approaches have been implemented in primary care but all have limitations. Prioritization based on manual screening are considered too labor-intensive to administer to be practically useful.(78,79) Acuity-based scales such as the Elixhauser comorbidity index are the most commonly used stratification techniques but are as imprecise due to their reliance on diagnosis codes and don’t accurately represent clinician’s conception of medical complexity.(80) Predictive models are increasingly used by health systems and clinics to stratify patient populations and assign different intensities of care. Models typically predict cost-related outcomes such as risk of hospital admission and typically have modest performance and perform similar to physician judgement.(81)

Moreover, several studies have observed that clinicians object to the use of predictive models because they restrict their autonomy over clinical decision making. Ross and colleagues observed that more than 80% of clinicians implementing risk-stratification were mistrustful of automated stratification and incorporated human review into the process.(82) Two other studies reviewing multiple sites implementing risk-stratification found that physicians often rejected approaches that were unable to incorporate clinical intuition and had limited interpretability.(83,84) Another limitation that all the aforementioned prioritization approaches share is that they only account for a single outcome. Clinicians often make decisions by considering multiple criteria when assigning interventions to patients to receive intensive case management, clinicians must take several patient dimensions into account including treatment adherence, unmanaged behavioral health problems, the duration the patient has been receiving care, and other factors.(85,86) The availability of stratification methods that could engender transparency while accounting for multiple disparate outcomes could address the noted shortcomings and allow clinicians to have more control over which patients are targeted for enhanced care. This could further the ‘doctor-in-the-loop’ paradigm, which dictates that the clinical intuition of a provider is supported by machine-driven stratification and subsequently reviewed by the clinician.(87)

2.2.3 Novel IT systems for Care Management

There have been a limited number of dashboards created specifically for care management. Studies by Loo et. al. and Zhou et. al. describe the development of basic interfaces for care management.(88,89) These two papers were the first to assert that a consolidated view of a provider’s panel has utility and to leverage color-coding to represent varying degrees of priority for patient problems. Use of data visualization can reduce cognitive load and improve comprehension, thereby increasingly the likelihood that clinicians are attentive to all patients for whom they are responsible. However, these interfaces use rudimentary stratification and sort empaneled patients on the number of ‘care gaps’ (e.g. required colonoscopy = 1 care gap) associated with each patient. This representation is undesirable given that some patient problems are far more critical to a patient’s quality-of-life (and/or the health system’s bottom line) compared to others. These studies both represent the ‘state-of-the-art’ for consolidated panel views, which aggregate the information contained in relevant disease and preventative registries.

The development and evaluation of such tools have been described by Zhou and Loo. Such tools have several general features: 1) tabular representation of entire patient panels, 2) presentation of preventative care & disease indicators tailored to clinic population, 3) generate automated reminders (e.g. texts & emails) to patients to schedule preventative screenings, 4) use colors to highlight key care gaps, 5) enable sorting of panel by basic prioritization.

Despite these advances, important features are still lacking. First, care management tools must enable tailoring to the clinical environments in which they are implemented; out-of-the-box systems have had poor uptake.(23,90) Second, clinicians require high-quality, continuously updated information on their empaneled patients.(23) Moreover, existing tools do not include key disease risk factors that would inform patient outreach.(4,22,91) Third, there is a lack of monitoring tools for prioritizing high-risk patients.(4,25) Fourth, care managers have previously described the need for a IT system to use visualization to reveal patients who may be in need of outreach.(4) Fifth, there is momentum towards including patient-generated data into EHRs from patient portals or mHealth applications.(92,93) It is unclear how these requirements can be met by interactive systems.

2.3 Interaction Design for Care Management

The following section provides an overview of methods that are likely relevant to the design of novel IT systems that can support healthcare providers in care management settings. First, I provide an overview of how conceptual frameworks and theories are relevant to this dissertation and describe how frameworks have been used previously to inform the design of novel systems. I then describe systems that have been developed in various application domains that may inform the design of novel systems that support care management.

2.3.1 The Role of Theory in Human-Computer Interaction Research

The scholarly disciplines of human-computer interaction (HCI) and computer-supported collaborative work (CSCW) have often adopted theoretical constructs to advance a more detailed understanding of how humans make decisions as well as design and evaluate novel applications. Christine Halverson (2002) enumerated four specific areas where theory is helpful in these domains(94):

1. A theory should be **descriptive** and help us make sense of the world without applying needless reductionism. Theories often "shape the object of study" and enable a more intimate understanding of complex situations by bringing certain important objects into focus.
2. Theories should be **rhetorical** and enable stakeholders to more easily describe the situation being studied.
3. Some theories are **inferential** and enable stakeholders to make predictions about decision agents, although these are less important in the early stages of design.
4. Designers often utilize theories to support **application design** by highlighting important aspects & considerations for interaction design.

Conceptual frameworks have been widely used in health informatics research to explain complex problem domains (95) and incorporate critical human and institutional characteristics into technology design.(96) Frameworks have been often used in informatics research to understand the elements of success for informatics interventions; the RE-AIM framework developed by Bakken and Ruland.(97) Another common application of frameworks in health informatics research is in modeling the cognitive processes used by healthcare providers. One such theory is *distributed cognition*, which posits that actions are coordinated between persons and devices which constitutes a “cognitive ecosystem” that supports decision making.(98) Finally, frameworks such as the *technology acceptance model* (TAM) have also been applied to healthcare consumers to understand their usage and acceptance of informatics interventions.(99)

2.3.2 The Theory of Situational Awareness

Situational awareness (SA) is a critical skill in high-risk industries such as aviation and disaster response. It asserts that perceiving and understanding all elements in one’s immediate environment enables successful decision-making.(100,101) Situational awareness has been informally defined as “knowing what’s going on” but more formally can be understood as describing how individuals anticipate future events. SA segments a decision-maker’s environmental understanding into 3 components; 1) perception of environmental elements in time and space, 2) comprehension of the meaning of these elements, and 3) projection of their future status.(102) For example, SA is often applied in air traffic control settings, where a controller must have adequate perception of all aircraft in a given airspace, comprehend potential traffic control problems, and project each aircraft’s location in the near future. SA has been applied in other settings where decision agents must develop and maintain a deep understanding of their environments, such emergency response and nuclear power plant management.

Across industries and applications, the human-computer interaction (HCI) community has explored interaction modalities that support situational awareness of stakeholders responsible for monitoring populations. Perhaps the most well-researched settings application domain is education, as teachers are responsible for tracking the scholastic progress of students in one or more courses. Many teacher dashboards use tabular visualizations wherein each student is represented by a single row.(103,104) In these applications, color-coding is used almost universally to improve a decision-maker’s situational awareness by focusing attention on urgent and/or extraordinary persons..(108,110,111) While color-coded tabular visualizations are the most common paradigm, other innovative systems exist. One such system uses *risk quadrants* to isolate students at risk of both academic underachievement and poor attendance.(112) Multimodal interfaces (e.g. text and image) have also been observed to improve situational awareness of severe illness within a simulated patient population.(113)

2.3.3 Situational Awareness in Healthcare

As a result, there have been several previous applications of SA to healthcare settings where physicians and nurses must maintain longitudinal awareness of groups of patients.(114,115) Situational awareness has been used to describe the administration of anesthesia(116) and monitoring of patient status during surgery(117–119) and in intensive care units.(120,121) SA is also commonly used as a means of assessing the quality of team-based care in both ambulatory and hospital settings.(122–124) The concept of SA has also been applied in public health for monitoring population health.(125,126) To our knowledge, SA has not been applied to chronic disease care or CM, and we hypothesize that such application is appropriate given how clinicians delivering care management are required to maintain longitudinal awareness of the state of their respective panels and the patients for whom they provide care.

SA can also be used as a means of assessing the quality of team-based care in both ambulatory and hospital settings. Singh et. al used SA to examine diagnostic errors among primary care clinicians.(127) Among the 86 errors studied, analysis of interviews related to those errors revealed deficits in the three levels of SA: information perception, information comprehension, forecasting future events, and choosing appropriate action based on the first three levels. In cases without error, the application of the SA framework provided insight into processes involved in attention management.

2.3.4 Visualization of Patient Records

Now that I've described how conceptual frameworks inform the design and evaluation of novel systems, I'll provide a broad overview of systems that may inform the design of IT solutions for care management.

Interactive systems have been previously developed to improve healthcare provider's awareness of clinical data. Many systems have been developed to visualize data from multiple patient records and support two general tasks: 1) exploration of patient cohorts and 2) therapeutic decision making. Systems that support therapeutic decision making by comparing an individual to similar patients are not well suited to care management activities. In contrast, tools that visualize multiple patient records such as the widely cited "Lifelines" system typically visualize a single patient's longitudinal record on parallel lines with a common time axis.(128) Such visualizations provide an overview of event sequences extracted from multiple patient records and generally do not process data to support decision making. Several aspects of the aforementioned tools might provide useful paradigms for care management solutions. First, published systems have emphasized querying, sorting, aggregating, and clustering of patients using both query-by-example (IPBC and Similan) and more expressive queries (Lifelines2).(129,130) Gravi++ and TimeRider color-code patients based on shared attributes to create visually distinctive patient groups.(131,132) The LifeLines tool groups related items in facets (eg. medications in one facet, test results in another facet) and such facets are collapsible, enabling users to expand only facets that are important to them.

2.3.5 Clinical Dashboards

Similar to patient record visualizations, *dashboards* offer useful paradigms that can be improve provider's awareness of clinical data. Dashboards provide "summary data on performance measured against care quality or productivity metrics” in a visual format.(26) Many dashboards have been described in the literature. Franklin and colleagues developed a system to visualize all admitted ED patients and their disposition across time. Such “electronic whiteboards” are increasingly used in emergency departments (EDs) by physicians and nurses list the names and status of the entire population of patients on the ward and were developed under the assumption that these displays would improve situational awareness and result in rapid decision-making.(133) Such tools have had mixed results adoption due to limitations in information timeliness, quality of data and lack of customization for different user groups.(134,135) Croon et. al. developed an interactive visualization to enable general practitioners to identify patients requiring follow-up; however, the tool was basic and solely used filtering on patient characteristics (e.g. systolic blood pressure, BMI, etc.) and did not recommend specific tasks.(136) Waitman et. al. developed a surveillance tool for monitoring hospitalized patients treated with medications with likely adverse effects.(137) Riad Alharbey developed a remote monitoring tool for patients with COPD that used an ANN algorithm to identify individuals at risk of flare-ups.(138) Badgeley and colleauges developed a clinical dashboard for monitoring lab values of patients in ICU wards but visualize only 1 longitudinal physiologic indicator per patient and do no evaluate their tool.(139) Bakos et. al. describe the development and implementation of a patient safety dashboard at a large hospital, although the amount of information is overwhelming and the authors conduct no evaluation.(140) Tan et. al. developed a dashboard to mitigate information overload wrought by a CPOE system in a Singapore hospital and observed broad adoption.(141)

The success of visual dashboards in clinical settings motivates continued inquiry into interactive tools that use data visualization to support healthcare providers. Novel systems can follow the paradigm set by these systems; the majority of the aforementioned systems present data in a table format with color coding in the ‘traffic light’ format; wherein green indicates no action is required and red indicates that action is required.(26) In addition, many of these systems leverage simply table-based visualizations, which have been observed to be widely accessible to care providers with minimal computational and numerical literacy.(142)

2.3.6 Prioritization of Multidimensional Data

As described in section 2.2, prioritization is an important aspect of alternative primary care models such as care management. Although in contemporary systems prioritization is achieved through the use of algorithms that use either simple rules (e.g. Elixhauser comorbidity index) or more complex equations (i.e. predictive analytics), there is an opportunity to give users direct control of prioritization. In the seminal 2008 paper “Grand Challenges of Clinical Decision Support”, Dean Sittig and colleagues recommended the development of clinical decision support systems that could prioritize recommendations using an explicit value model, thereby accounting for multiple decision criteria such as “expected mortality, cost to the individual or organization, etc”. (143) The main challenge is to “appropriately account for competing influences and values impacting clinical decision-making while reducing the number of computer-generated recommendations into a manageable number”.

Methods known as *multi-criteria decision methods* have been used to prioritize patient’s access to limited care resources, such as selecting patients for elective surgery and assigning patients to receive liver transplants.(144,145) Longaray and colleagues conducted a systemic review of multicriteria decision making applications in healthcare management and identified 22 papers describing the use of such methods for clinical decision support.(146) The review also found that Analytic Hierarchical Process to the most frequently used MCDM method, followed by utility-based methods. This latter finding was corroborated by an earlier review by Adunlin et. al.(147) These findings may be explained by Weernink et. al.'s finding that relatively simplistic methods are adequate in clinical decision making because they have low cognitive burden and are easy to administer. There is a general consensus that the MAGIQ technique requires less user input than commonly-used alternatives such as SMARTER and Analytic Hierarchical Process.(85,148) While MCDM methods have not been evaluated in the context of care management, three studies have demonstrated that MCDM methods can be applied to the problem of ED triage, whereby clinic leaders must enumerate a set of preferences (e.g. mortality prevention is 1st priority, resource utilization is 2nd, etc.) to create a ranked list of patients to be admitted.(86,149–151) MCDM methods have been used for patient prioritization in other realms including prioritization of patients awaiting elective surgery in New Zealand, and allocation of organs among patients awaiting transplantation.(144,145)

2.3.7 Visualization of Prioritization

A range of visual interfaces have been developed to make multi-criteria decision making methods more accessible to end-users. Wall and colleauges develops a tool called Podium, which allows decision makers to drag rows in a table of multi-variate data points and the tool then infers a weighting model using Ranking SVM.(152) The authors reason that decision makers cannot often specify attribute weights accurately. Pajet et. al. contributed an interactive visualization technique that allows users to explore distinct combination of criteria weights for multi-criteria decision making.(153) Dimara et. al. used pair plots to provide decision support over multi-attribute rankings.(154)

Other tools have been developed for visualization multi-attribute data without relying on MCDM methods, and best practices for visualizing multidimensional data have been established.

Plots that visualize multidimensional data are typically constructed using 1 of 2 conventions: 1) using position markers for cells based on cell value (eg. scatterplots) and 2) retain item position across columns and use markers within cells (eg. heatmaps). The highly cited TableLens retains the rows and columns convention of tabular data but represents numbers and binary variables using horizontal bar charts.(155) In addition, this work pioneered the ‘fish-eye’ technique which ‘zooms out’ on a table and enables the visualization of a larger quantity of data than is typically available. Gratzl and colleagues extended this work into the context of sorting and developed a technique that leverages barcharts to manifest the various attributes of an item in a ranked list.(156) The tool enables users to interactively refine parameters and explore the effects of changes in the item ranking, and was inspired by the author’s comprehensive analysis of requirements for the visualization of multi-attribute rankings.(156)

Chapter 3: Challenges Associated with the Clinical Management of Large Groups of HIV Patients

3.1 Background & Significance

In the United States, 42% of adults live with multiple chronic conditions and account for 71% of total healthcare spending.(157) Individuals in this high-need, high-risk population have conditions such as heart disease, diabetes, COPD, or HIV with co-occurring social and behavioral challenges that complicate disease management.(2) Innovative primary care models that deliver comprehensive care to address medical and social needs have been established as an approach to improve health and reduce healthcare costs among this vulnerable population.(2,45) Care management is one such approach that emphasizes *proactive care* and requires providers to monitor and intervene on patients with unmet care needs. This approach contrasts with traditional reactive care and has been shown to improve health outcomes and patient satisfaction among chronic disease patients. However, transitioning to such care models requires changes in clinic staffing and organization. For example, CM employs care coordinators and additional non-physician staff – often organized into *multidisciplinary care* teams – to provide intensive medical care and simultaneously address comorbid social and behavioral determinants of health (SBDH).(12,45,66)

While there is a rich body of knowledge on requirements for HIT in primary care, few studies have specifically focused on examining HIT needs in the context of CM and its focus on population monitoring. Moreover, delivering CM in primary care settings may be especially challenging, as primary care providers are typically responsible for tracking and monitoring more than 1,500 patients and may be unable to deliver all recommended care. To our knowledge, no previous studies have conducted a comprehensive assessment of clinicians' needs associated with delivering CM to large patient groups. An improved understanding of the requirements for IT systems designed to support CM could enable more effective management of large groups of chronic disease patients.

3.2 Research Questions

Research Question 1: What information is required to successfully perform activities related to complex care management delivered to HIV populations?

Research Question 2: How do information requirements vary across different staff roles in ambulatory HIV practices?

Research Question 3: What components of existing IT systems support or undermine complex care management delivered to HIV populations?

3.3 Study 1: An investigation of the informatics needs associated with delivering chronic disease care to large clinical populations

3.3.1 Background

Health information technology (IT) is an established requirement for care management and other care models that aim to coordinate the care of complex patients. The Agency for Healthcare Research and Quality (AHRQ) Care Coordination Framework outlines several activities essential for achieving coordinated care, most of which rely on health information technology (HIT).(158) For example, electronic handoff tools, continuity of care documents, and interoperability are critical for facilitating transitions (1), linking patients to community resources (2), and communication between care providers (3). Tools for electronic clinical quality measures can facilitate the assessment of needs (4) and the alignment of resources with patient and population needs (5) by providing insight into population health outcomes. Monitoring and follow-up (6) is most commonly performed using population registries, IT tools that list disease outcomes and gaps in preventative care for a defined patient panel which are widely used by alternative practice organizations such as Accountable Care Organizations. However, it is not clear whether care management, as delivered to persons with HIV, is analogous to the domains where care coordination has been previously studied.

3.3.2 Objectives

The purpose of this study was to develop an improved understanding of inefficiencies and bottlenecks associated with providing proactive care to patients with chronic disease. In this work, we focus on the delivery of CM to persons living with HIV. Because many HIV+ persons have multiple medical and psychosocial comorbidities, CM in this population is especially challenging and has traditionally been a component of HIV primary care.

3.3.3 Methods

This qualitative study employed semi-structured interviews and observations of clinical practice to better understand the information needs of stakeholders delivering proactive care to HIV patients. Interviews and observations of clinical workflows focused on the ability of IT systems to support care management activities. We used member checks with participants to ensure validity.

Participants & Settings

Interviews and observations were conducted in two established HIV care programs in New York City. The programs are hereafter referred to as clinic #1 and clinic #2 and their respective characteristics are described below.

Clinic 1

The first clinic studied is a large sexual health program at an urban academic center that provides primary care to 2500 persons living with HIV and individuals at risk of sexually transmitted infections. While the majority of patients are Medicaid or Medicare beneficiaries, some patients had private insurance. Most patients are African American or Hispanic.

The clinic is organized around 5 multidisciplinary care teams that each consist of 2 physicians, 1 RN care manager, 1 social worker, and several case managers and are responsible for 500 patients. Physicians have the most patient interaction while care managers are responsible for contacting patients in response to missed visits or abnormal lab tests. Each care team has a social worker who provides short-term behavioral health care and several grant-funded case managers, who provide services to high-need patients such as daily-observed therapy for HIV treatment.

The multidisciplinary care teams have weekly ‘case conferences’ wherein they discuss a limited number of patients requiring follow-up from clinic staff. Patient registries are the primary IT tool employed in these meetings used to identify patients with recent adverse outcomes and those at high-risk of future adverse outcomes. Team meetings are attended by all staff and are typically led by physicians and care managers who synthesize patient information and assign tasks to members of the care team.

Clinic 2

The second clinic studied is situated in an HIV primary care program at a large urban ‘safety net’ hospital that serves persons with public insurance and the uninsured. The clinic provides primary care to approximately 2800 persons living with HIV. Many patients treated in this clinic have multiple chronic conditions and/or psychosocial problems and are predominantly African American. Enrolled patients are almost exclusively Medicaid or Medicare beneficiaries.

Unlike clinic 1, clinical practice in this setting is not organized around defined multidisciplinary care teams. Physicians each manage 300-500 patients but are supported by non-physician staff. Two social workers and a cadre of community health workers (CHW) are available to support treatment of psychosocial issues and are not paired with specific physicians. Patients with uncontrolled HIV and significant medical and psychosocial issues are enrolled in the clinic’s Medical Case Management program and assigned a dedicated CHW. Another contrast with clinic 1 was that this clinic did not have additional grant funded case managers and thus had less resources to support high-risk patients.

In order to ensure that care is adequately coordinated for the most vulnerable patients, clinic staff meet biweekly to discuss patients who have repeatedly failed to achieve care goals. This meeting, referred to as the ‘Ambulatory ICU’, includes physicians, nurses, social workers, and community health workers and typically discusses 5-6 patients who physicians believe are at risk of imminent medical or social instability.

Procedures

Participants were recruited from the professional network of investigators and invited to participate in the study via email. Inclusion criteria included working within the clinics studied for at least 6 months prior to the observation period.

We conducted semi-structured interviews with study participants that lasted between 30 and 60 minutes. Participants were asked questions about their experience managing patients with complex needs; questions ranged from general (e.g. *"What is the most challenging aspect of your job?")* to specific (e.g. *"On a day-to-day basis, which types of patients are you most concerned about?*"). Interviews were conducted in person at each clinic and audio-recorded.

We also observed interdisciplinary care teams during regularly scheduled meetings wherein clinical staff discussed high-need patients and collaborated to develop action items. Study staff were passive during these sessions and recorded notes and audio with a digital recorder. Data collection continued until data saturation was reached when semi-structured interviews and observations yielded no additional information.

All procedures were reviewed and approved by the Institutional Review Boards at Columbia University and BronxCare Health System. Participating staff reviewed and signed informed consent prior to participation. Patient consent was waived due to the fact that personal health information was removed from audio recordings and patients were not directly involved in study procedures.

Analysis

All audio recordings were de-identified and transcribed verbatim for analysis. The analysis of the interview transcripts and transcripts of interdisciplinary care team meetings was combined and conducted using inductive thematic analysis.[33] Three of the authors (LM, DJF, ML) met for 4 1-hour collaborative coding sessions using the NVivo software involving the following analysis steps. First, the three authors read the transcripts and familiarized themselves with the data. Second, the authors generated initial codes by summarizing the interview data on a more abstract level. Third, the authors performed axial coding to generate higher-level themes. Fourth, the authors concluded the analysis by assessing whether the interview data aligned with the final themes. To reduce the likelihood of misinterpretation, we performed member checks with three study participants.[34] This involved presenting participants with summarized findings and select quotes that evidenced the findings. Another means of ensuring validity was the triangulation of information from administrators, physicians, care managers and social workers through both interviews and care team observations.

3.3.4 Results

We conducted 24 semi-structured interviews with 22 participants and observed 5 multidisciplinary care team meetings. This included 13 interviewees from clinic 1 (2 administrators, 4 physicians, 2 care managers, 2 social workers, 3 case managers) and 9 interviewees from clinic 2 (3 administrators, 3 physicians, 2 social workers, and 1 care manager); two participants were interviewed twice to clarify prior responses. Participants ranged in age between 30 and 60 years and 12 of 22 participants were female. Their length of experience delivering HIV care varied widely, from 6 months to 20 years. The thematic analysis identified 4 major themes presented in **Table 3.1** that were largely consistent across clinics; 1) both clinics sought to deliver proactive care by continuously monitoring patient populations, although

Table 3.1 Assessment of needs and bottlenecks associated with care management of chronic disease patients

<table>
<tr><td colspan="2">Theme 1: Delivering proactive care requires continuous monitoring of the clinic population and identification of high-risk patients</td></tr>
<tr><td>Proactive care challenging to scale</td><td>“I’m regularly scanning these spreadsheets to see whether there is someone that really needs follow-up. We don’t want people to fall through the cracks. But there is not a system that it’s really derived for me...it tends to be ‘putting out fires’ with so many patients now involved in this process” (Administrator 1 – Clinic 2)</td></tr>
<tr><td>List-making as a strategy for monitoring clinic population</td><td>“I have to develop my own spreadsheets so I have an idea of who [my patients] are... Imagine if I didn’t have this list – names wouldn’t come to mind because we encounter people every day. So, I have to keep a list.” (Care manager 1 – Clinic 1)</td></tr>
<tr><td>Providers have multiple approaches for identifying high-risk patients</td><td>“we do the best that we can with the resources that we have, but we don’t have enough resources to thoroughly address the needs of all the patients and so we triage to figure out people that we think are super high needs.” (Physician 1 – Clinic 1)</td></tr>
<tr><td>Social and behavioral determinants of health are a key component of monitoring and prioritization</td><td>“ the patients [who] are at highest risk [have] mental health and substance abuse [and] other factors such as housing instability...that would predispose someone to be readmitted or just generally have a hard time managing their disease” (Physician 2 – Clinic 1)</td></tr>
<tr><td colspan="2">Theme 2: Care management necessitates matching patient problems to appropriate interventions</td></tr>
<tr><td>Understanding ‘root cause’ of patient problems is necessary</td><td>“...even if you have a laundry list of the issues that person has, it’s still very difficult to nail down what the key levers are that would create a cascade of positive results.” (Administrator 1 – Clinic 1)</td></tr>
<tr><td>Identifying appropriate interventions for patients is challenging</td><td>"I can’t [know] what kind of a person you are from this conversation, but I can say this was the dynamic, so I think [I know] how this person might react to this intervention as opposed to this intervention. Obviously, it’s a best guess.” (Care manager 2 – Clinic 1)</td></tr>
<tr><td>Uncertainty whether patients with poor engagement will be responsive to intervention</td><td>“ [patients] just flat out are not interested in, you know, having someone follow them or having the case manager or anything like that then they will communicate that, you know, I don’t want to be called, I don’t want to have home visits.” (Case manager 1 – Clinic 2)</td></tr>
</table>

Theme 3: Frequent communication between care staff is challenging in the clinical environment	
Communication required for collaborative care of complex patients	“ for those patients who are enrolled, they often tell the medical case manager a lot of the things that they sometimes don't tell me, so I get to know things that are going on in their home” (Physician 2 – Clinic 2)
Communication between clinic staff is often burdensome	“...if I send a doctor an email, they won’t respond because the provider is probably busy or doesn’t place much importance [on my email]...the easiest way for me is to go to the clinic and speak to one of the coordinators” (Case manager 1 – Clinic 1)
Chart review supplements communication but is inefficient	“...our staff sometimes struggles with putting into words what they did with [patients]...a lot of our staff is older, so their computer savviness may not be good...finding the results of Pap smears and colonoscopies. It makes it a little difficult.” (Administrator 3 – Clinic 2)
Theme 4: Existing IT solutions are inadequate for supporting care management	
EHR is inadequate for monitoring populations	“our care managers really need a way to remember things ... [they] need a way to remember that you should be on this schedule for six months ... our [EHR] doesn’t really do that.” (Physician 2 – Clinic 1)
Registries more effective than EHR for monitoring populations but have limitations	“ [Registries] are a way to get [patients] in front of your face...I can look at my panel and see every patient that’s assigned to me and has a detectable [HIV] viral load...you’re supposed to go through that and remember...even when they’re not coming to clinic” (Physician 3 – Clinic 2)
Requirement for automated retrieval of patient’s SBDH information	“we have a lot of indicators, but I actually wish there was a mental health indicator...without dealing with that, the medical stuff is very hard to get in place. So, we don’t have an indicator for that yet” (Care manager 2 – Clinic 1)
Additional decision-support resources would help drive proactive care	“if you could predict that this patient has high risk of getting of not being virally suppressed or other poor health outcomes, that to know that upfront ... these 20 people are at high risk, then you could better use resources.... that’s important, and that’s not always easy to figure out” (Administrator 1 – Clinic 1)

the clinic with fewer resources focused less on patient outreach, 2) care management necessitates matching patient problems to appropriate interventions and was more challenging in the clinic 1 with a broader range of available interventions, 3) frequent communication within multidisciplinary care teams was difficult in both clinics, and 4) existing IT solutions are inadequate for supporting care management, particularly in regards to identifying and extracting SBDH. **Table 3.2** outlines the salient differences between the two clinics studied herein.

Theme 1: Delivering proactive care requires continuous monitoring of clinic population and identification of high-risk patients

Overall, participants stated that the provision of proactive care required changes to their work practices. Despite these strategies, providers were concerned about their ability to provide adequate care to all patients.

Proactive care is challenging to scale with limited resources and large population

In both clinics, care management entailed contacting patients in response to events including missed visits and abnormal lab tests. In addition, clinicians also sought to navigate patients towards services capable of addressing their social and behavioral needs, which if left unaddressed might prevent successful disease management.

However, study participants felt that high patient volume precluded them from providing outreach to all patients requiring contact. This was especially true in clinic 2, where physicians reported that pressing medical and psychosocial needs of patients who come to the clinic take precedent over proactive outreach.

List-making is a strategy for monitoring patients but is challenging to scale

In order to manage the complexity of providing proactive care to a large group of patients, individual staff and care teams in both clinics manually curated lists that track the patients under their care. These lists served as cognitive aids to help providers maintain awareness of their patients as well as remember to perform necessary actions.

These lists were stored in various media, including hospital-owned mobile phones, paper notebooks, and Excel spreadsheets. While all lists contain at a minimum the names of patients, most also contained a succinct summary of a patient's medical status and any relevant SBDH information. Some providers used these lists as visual aids; one care manager used color-coding to highlight patients in need of a follow-up based on patient acuity.

The maintenance of lists was perceived as labor-intensive, and several care managers and social workers reported neglecting to update or add patients to their respective spreadsheets or paper-based lists. As a result, staff reported that they were likely unaware of patients not included in their personal lists.

Providers have multiple approaches for identifying high-risk patients

In response to the limited resources available to meet all patient needs, the leadership of both clinics emphasized the importance of prioritizing high-risk, high-need patients. The identification of high-risk patients occurred during weekly multidisciplinary care team meetings and is driven by both patient registries and recall in memory, where clinicians reflect on which patients require additional care. For example, providers tended to discuss high-risk patients with whom they had a recent interaction. Other times, the team used registries during the meeting to stimulate discussion of patients requiring care.

Individual staff members used different criteria to identify high-risk patients. Physicians perceived their roles to include monitoring medical issues, while care managers focused on disease management and are most attentive to patients with poor HIV treatment and visit adherence. Social workers focused on addressing behavioral health disorders and helping patients obtain supportive services.

Interviewees from both clinics perceived that despite efforts to improve care management at scale, their approach to triage had important limitations. First, clinic staff noted that case conferences typically discuss only a relatively small number of patients (<10). Second, multiple staff asserted that additional health IT resources are necessary to alert clinicians to patients with medical and psychosocial issues who have ‘fallen off the radar’ and aren’t receiving the care they require.

Social and behavioral determinants of health a key component of monitoring and prioritization

Participants asserted that drug and alcohol abuse, low health literacy, unstable housing and homelessness, social isolation, and transportation issues all often exert a negative impact on patient’s ability to effectively managed their disease. As a result, care team meetings in both clinics often focused considerable attention on patients with unaddressed SBDH. Clinicians also reported that they often record information on patient SBDH in the spreadsheets used to monitor their respective patient panels.

Theme 2: Care management necessitates matching patient problems to appropriate interventions

Clinicians found it challenging to identify patients requiring outreach; furthermore, selecting appropriate interventions from internal & external programs presented a further difficulty. This was especially true in clinic 1, which had access to a broader range of specialty interventions.

Understanding ‘root cause’ of patient problems deemed necessary

Staff in both clinics described various hidden ‘barriers’ that precluded patients from effective chronic disease self-management. These were often related to SBDH and were hypothesized as potential targets for intervention. For example, one clinician in clinic 1 recounted a recent example where HIV treatment adherence counseling did not impact a patient's outcomes because the patient's housing and substance abuse issues remained unaddressed.

Because patients often had multiple unaddressed SBDH, stakeholders asserted that they often lacked awareness of which specific issue might preclude effective self-management and therefore were uncertain which issue be targeted first. For example, 15 minutes during a single observed team meeting was devoted to discussing possible barriers to medication adherence for a single patient in clinic 2.

Identifying appropriate interventions for patients is challenging

Furthermore, even when key barriers to HIV management are recognized, identifying appropriate interventions to address these barriers was perceived as non-trivial. Despite having a cadre of psychosocial interventions available, clinicians reported sometimes being unsure which specific intervention would best address a given patient's barriers. This difficulty was most pronounced in clinic 1, which collaborated with several community-based organizations (CBOs) and thus had a relatively large number of disease management interventions available.

Uncertainty over whether patient with poor engagement will benefit from intervention

Finally, the participants from both clinics expressed concern that some patients are unlikely to benefit from any intervention. This sentiment was typically directed towards patients who weren't receptive to past interventions and rejected increased clinic involvement in their health. This concern was especially prevalent in clinic 2, which had fewer case management staff compared to clinic 1 and thus attempted to ensure that such limited resources are used effectively. As a result, clinicians in clinic 2 expressed having more reluctance to refer patients to their medical case management program compared to clinic 1.

Theme #3: Frequent communication between care staff is critical but challenging in the clinical environment

A critical component of care management is frequent communication between clinicians on a single care team and with external organizations.

Communication required for collaborative care of complex patients

In both clinics studied herein, many stakeholders contributed to a shared understanding of individual patients. Case managers in both clinics updated primary care physicians on developments related to patients' SBDH during care team meetings, which often led to attempts to contact these patients and connect them to supportive services. In addition to the briefing of providers on their patients, care team meetings also served to distribute and coordinate labor across the care team. Outside of meetings, staff in clinic 1 often used secure health messages to communicate, while in clinic 2, because staff are collocated, face-to-face interactions were more common than secure health messages.

Communication between clinic staff is time-intensive and challenging

Staff within both clinics were unable to communicate with colleagues about all patients requiring outreach, reflecting the time-consuming nature of connecting with colleagues in-person or via secure health messages. In clinic 1, case managers reported that secure health messages regarding high-risk patients often went unnoticed by primary care physicians due to competing priorities, requiring case managers to request that care managers notify clinicians of this information in-person.

An additional challenge was the difficulty associated with identifying each patient's respective care provider to collaborate on patient outreach or care planning. The participants reported that having easier access to this information would increase the efficiency of collaborative care. In clinic 1, the population health tool stored a list of patients attributed to each provider, but these lists were often perceived as inaccurate, resulting in limited use. In clinic 2, such lists were stored in the EHR, a system which non-physician staff used infrequently.

Chart review supplements direct communication but is inefficient

A strategy employed in both clinics to supplement direct communication was chart review. Because the majority of providers document the extent of their patient interactions in free-text notes, these documents were considered to provide up-to-date patient information, though sometimes lacking the requisite detail to be reliable or useful. Further, clinic staff considered the process of reviewing patient notes to be labor-intensive and thus not practical to perform regularly.

Case managers within both clinics used a dedicated software separate from the EHR to document patient interactions; these notes were considered to be rich in detail regarding patient psychosocial issues. However, a lack of interoperability between these systems and the EHR precluded providers from accessing these notes. This was considered a major shortcoming of the tool.

Theme #4: Existing IT solutions are inadequate for supporting care management

As discussed above, clinicians developed novel strategies to manage large clinic populations. Although Health IT was often an important component of these strategies, the IT systems used by both clinics only partially supported CM.

EHR is inadequate for monitoring populations

There was a perception among participants in clinic 1 that the electronic health record (EHR) supports information retrieval for individual patients but lacks the ability to provide a population-level overview of a provider's panel. Care managers and case managers described the challenge of using the EHR to review doctor's notes and laboratory tests on a per-patient basis when managing large groups of patients. This sentiment was not observed among physicians in clinic 2, where the EHR had an embedded listing of each provider's panel that highlighted key gaps in care. In addition, a lack of interoperability between clinic 1's visit scheduling system and EHR required staff to login to an addition system when identifying patients to contact before scheduled clinic visits to prevent 'no-shows'. Participants asserted that the EHR could be improved and include reminders to perform follow-up communication with patients, as well as enable providers to schedule same-day preventative screenings and consultations for patients requiring such services.

Registries are more effective than EHR for monitoring populations but have limitations

Both clinics employed patient registries that computed care indicators from an institutional EHR system and displayed such data for each provider's respective patients. Staff asserted that registries increased their awareness of the patients for whom they are responsible, and this sentiment was shared among both physicians and non-physician staff. Registries are most frequently used to catalyze actions such as patient outreach and preventative screenings, and enable simple stratification to prioritize which patients most require care.

However, the tools do not address all needs reported by clinicians. First, registries were perceived as lacking specificity and potentially grouping together patients who have different levels of acuity. Second, clinicians reported a common desire to have additional registries added to the population health system. These included, for example, indicators for unmanaged substance abuse and mental illness. Third, despite requesting additional indicators, staff in clinic 1 reported being overwhelmed by the volume of information across their six distinct patient registries and requested functionality that could consolidate multiple registries and reduce information overload. Clinic 2 compiles multiple care indicators into a single registry, which may have ameliorated such concerns about information overload.

Requirement for automated retrieval of patient's SBDH information

Despite the fact that SBDH are perceived as critical barriers to successful HIV management, clinicians said that they were often unaware of patient's SBDH due to the inability of their EHR to effectively call attention to this information. A social worker reported that the volume of information in the EHR precluded her from effectively searching for psychosocial information because SBDH are recorded in relatively few clinical notes and physician lamented the fact that clinical notes are challenging to review for this information due to the amount of 'extraneous verbiage' unrelated to SBDH. The importance of monitoring patients with significant a burden of SBDH led one physician in clinic 1 to request that patient registries include care indicators related to substance abuse and mental health.

Additional decision-support resources would help drive proactive care

The participants explicitly requested the implementation of additional decision-support resources. Several clinicians in clinic 1 familiar with predictive modeling perceived that the prediction of adverse events would enable them to provide better care. One social worker asserted that understanding trends in depression or anxiety severity could help prevent adverse health outcomes, while multiple physicians reported that predicting outcomes related to HIV prevention and treatment would help them target resources more efficiently.

Table 3.2 Similarities and Differences Between Study Clinics

Similarities	Proactive Care o Individual staff and care teams in both clinics manually curated spreadsheets and paper-based lists that track the patients under their care o While both clinics sought to prioritize resource allocation to high-risk, high-need patients, staff asserted that their approaches to triage had important limitations o Social and behavioral determinants are perceived as a critical component of population monitoring and prioritization Identifying appropriate interventions o Staff in both clinics described the importance of addressing psychosocial factors that precluded patients from effective chronic disease self-management o Participants from both clinics expressed concern that some patients are not likely to benefit from intervention Communication o In both clinics many different stakeholders contributed to a shared understanding of individual patients o Staff within both clinics were unable to communicate about all patients requiring outreach, reflecting the time-intensiveness of such discussions o Chart review was considered an alternative to direct communication with colleagues in both clinics Existing IT o While patient registries were perceived as useful, staff asserted that they were likely unaware of all patients who might have benefitted from outreach o Administrators in both clinics sought to extract information on social and behavioral determinants from electronic records
Differences	Proactive Care o Clinic 1 had more human resources and emphasized the delivery of proactive care while clinic 2 focused on urgent patient deterioration o Clinic 1 had several established criteria for identifying high-risk patients, while clinic 2 used a more ad-hoc process Identifying appropriate interventions o Providers in clinic 1 struggled to select appropriate interventions from internal & external programs while clinic 2 had access to fewer interventions and thus did not perceived this as a problem o Providers in clinic 1 were less hesitant to refer patients with history of suboptimal adherence to costly interventions, reflecting having more human resources compared to clinic 2

	Communication o Co-located staff in clinic 2 typically communicated in person, while the dispersion and volume of colleagues forced staff in clinic 1 to use secure health messages to communicate Existing IT o Physicians in clinic 2 had a more positive view of their EHR compared to those in clinic 1, likely because of their EHRs consolidated patient list o Providers in clinic 1 reported being overwhelmed by multiple distinct patient registries, while providers in clinic 2 experienced no such problems with their consolidated EHR panel list

There was a general perception among interviewees that staff did not contact all patients who might benefit from outreach. This partly reflected their heavy workloads; care managers in clinic 1 lamented the fact that time-sensitive requests from patients for medication refills were so common that they had limited time to focus on delivering preventative services. One clinician in clinic 2 expressed interest in obtaining a web-based mental health screening platform to administer preventative screenings and increase the number of patients who received screening.

3.3.5 Discussion

This study is among the first to investigate the needs of multidisciplinary practices providing CM to a large chronic disease population. Our study outlined both new expectations for clinicians and staff presented by CM, and barriers to meeting these expectations. Specifically, our analysis suggested that the transition to CM requires monitoring clinic populations and identifying high-risk patients, the requirement to match patients to appropriate interventions, and the need to maintain frequent communication within multidisciplinary care teams. Furthermore, the study showed that existing IT solutions do not adequately support these needs, thus suggesting new opportunities for improvement. Below we discuss these findings and their implications for the design of future systems.

First, our findings indicate that proactive care requires continuous monitoring of patients and the prioritization of a limited number of high-risk, high-need individuals. This strategy was supported by patient registries, which, unlike commercial EHRs, enabled staff to conduct population-level surveillance and target care management activities to patients with unmet care needs.(71,72) However, we corroborated previous studies that have observed patient registries to be unable to satisfy all clinicians' needs, which include the need to isolate patients with multiple, overlapping chronic conditions.(4,19,25) This limitation led staff in both clinics to develop spreadsheets and paper-based lists that supported monitoring of smaller lists of patients compared to patient registries. Prior studies have also observed the creation of homegrown patient monitoring tools such as spreadsheets that enable clinic staff to consolidate information of patients who they perceive as having high-needs.(22) Despite these strategies, providers felt that when using this strategy they often lacked awareness of patients requiring care and that information on patient's SBDH was not readily available. While previous studies and clinical thought leaders have described the need for IT systems to utilize information collected in EHRs to visually reveal high-risk patients, limited research has been conducted in this area (4,7,159)

Second, study participants asserted that it was challenging to match patients to the appropriate intervention. Care providers asserted that they often struggled to ascertain the 'root cause' of a patient's failure to engage in self-management; examples of such root causes included substance abuse and unstable housing. The challenges faced by providers reflected both their inability to efficiently retrieve information on SBDH and uncertainty of which interventions might elicit the behavior change required for self-management.(41,160–164) Interactive tools that enable clinicians to identify these determinants and design evidence-based care pathways may be useful.(165–168)

Third, the study showed that communication within multidisciplinary care teams was critical for patient-centered care but was challenging. Outside of weekly or bi-weekly case conferences, staff struggled to maintain adequate communication with colleagues. This partly reflected the difficulty of identifying a patient's respective care team. Clinic staff asserted that having access to an electronic representation of each patient's providers would ameliorate some communication challenges, and evidence suggests that this information can be inferred through the secondary analysis of routinely collected EHR audit log data.(169–171) Future research should investigate the feasibility of such analyses in ambulatory settings.

In addition to suggesting opportunities to improve the design of existing solutions, this study identified several directions for novel decision support tools. First, multiple interviewees reported being unable to identify patients at risk of imminent deterioration, which was required for effective patient triage. Providers anticipated that predicting future hospitalization and failure to adhere to medication would enable a more efficient targeting of limited resources. Care management programs may also benefit from predictive models that target outreach activities to patients at high-risk.(172–174)

This study has several limitations. First, the majority of the patient population treated in the clinics studied herein are HIV+ with a high burden of SBDH and both clinics are located in large urban hospitals, which may limit generalizability to other primary care settings. However, the care models employed by these clinics is similar to those used by Accountable Care Organizations and Health Homes.(175,176) In addition, chronic disease treatment programs for diabetes and COPD and ambulatory oncology programs use multidisciplinary care teams to proactive address medical issues and thus may also benefit from our findings. Second, interviews relied on participant's memory of past events and thus may be susceptible to recall bias.

However, a strength of the methodology included triangulation of information from administrators, physicians, care managers and social workers. Third, the sample size for the study was relatively small. However, during data collection we reached saturation, suggesting that a larger sample within the clinics studied herein would not have yielded new findings. Fourth, we did not observe clinicians during clerical work; observations of clinicians contacting patients, using health IT tools, or communicating with colleagues would have provided additional insight into challenges faced by providers.

3.3.6 Conclusion

While the adoption of health IT in primary care practice is variable, systems that facilitate continuous population monitoring and collaboration between providers are increasingly recognized as important for improving the care of persons with chronic disease. The main barriers to effective CM identified in this study were monitoring multiple care indicators among a high volume of patients, communication within and between interdisciplinary care teams, and matching patients with the appropriate intervention. The development of IT tools that could overcome these barriers may positively impact the quality of care for persons with chronic disease.

3.4 Study 2: Situational Awareness in Chronic Disease Care: Requirements for Patient and Population Monitoring

3.4.1 Background

Health information technology (IT) has been posited as a means to support the delivery of care management.(7) However, limited research has been conducted on how IT can facilitate longitudinal monitoring of patient populations. Contemporary systems leverage clinical registries, which list all empaneled patients in a tabular format and present disease outcomes and health-related information in one or more columns. While the use of registries is endorsed by the American Medical Association and are used by the majority of alternative practice organizations such as Accountable Care Organizations previous studies have observed patient registries to be unable to satisfy all clinicians' population management needs.(4,11) Moreover, health IT systems do not typically represent information on SDOH in a systematic fashion.(177) This precludes monitoring of SDOH at the population level and deployment of decision support resources for addressing psychosocial issues. While these are known limitations of existing health IT, it is unclear how providers work within them and what they need to better support CM.

Conceptual frameworks have been widely used in health informatics research to explain complex problem domains and incorporate critical human and institutional characteristics into technology design. With its focus on projection and prediction, situational awareness provides a useful model for conceptualizing the information needs of healthcare providers within patient-centered medical homes.(101) For example, nurse care managers with low situation awareness might not be aware of a critical barrier to care for a patient, do not understand the implications of that barrier, or that they can't anticipate the patient's future outcomes and thus do not perform the appropriate action. In contrast, a nurse manager that has excellent situation awareness would actively survey risks across multiple domains (e.g. actively monitor patients with poor medication adherence and flag patients who recently missed clinic visits) and then subsequently respond with expected actions.

3.4.2 Objective

The purpose of this study was to develop a better understanding of how chronic disease providers monitor their respective panels by collecting data from two HIV primary care programs. Towards this end, we develop a conceptual framework of population monitoring in chronic disease care using the theory of situational awareness.

3.4.3 Methods

We performed a secondary analysis of qualitative data described in section 3.3 using the theory of situational awareness.

Data Analysis

We performed a secondary directed content analysis using the theory of situational awareness. First, low-level codes were identified by two coders using the transcripts from the previous study and the NVivo software. Second, these codes were iteratively analyzed and organized into categories representing higher level themes. These two steps were performed independently by two coders (DF, JS) and then discussed and agreed upon in an iterative fashion. Finally, themes were organized according to the theory of situational awareness. After data analysis was completed, member-checking was performed with 5 study participants to ensure validity of our findings.

3.4.5 Results

We organized our findings according to the theory of situational awareness. As portrayed in **Figure 3.1**, the framework consists of several key factors:

- SA operates at two levels of abstraction; patient- and population-level
- patient-level SA requires perception of relevant care gaps and psychosocial issues, comprehension of the urgency of a patient's status, and projection of the impact of a potential intervention on patient outcomes
- population-level SA requires perception of those patients with care gaps and psychosocial issues, comprehension of the relative priority of patients within a given population, and the ability to project which high-priority patients are likely to benefit from intervention
- the importance of goals and goal-directed attention in focusing on specific medical and psychosocial issues
- the influence of external initiatives on the goals of clinicians
- the role of expectations and mental models in directing attention to relevant information and comprehending its meaning
- the role of task and system factors that impact SA, including the effectiveness of user interfaces, the service quality of IT systems, ease of communication with colleagues, and the adverse impact of workload on SA
- the ubiquitous use of 'to-do' lists to ensure that care delivery is completed

A summary of the constructs and themes is presented in **Table 3.3** and in the following paragraphs.

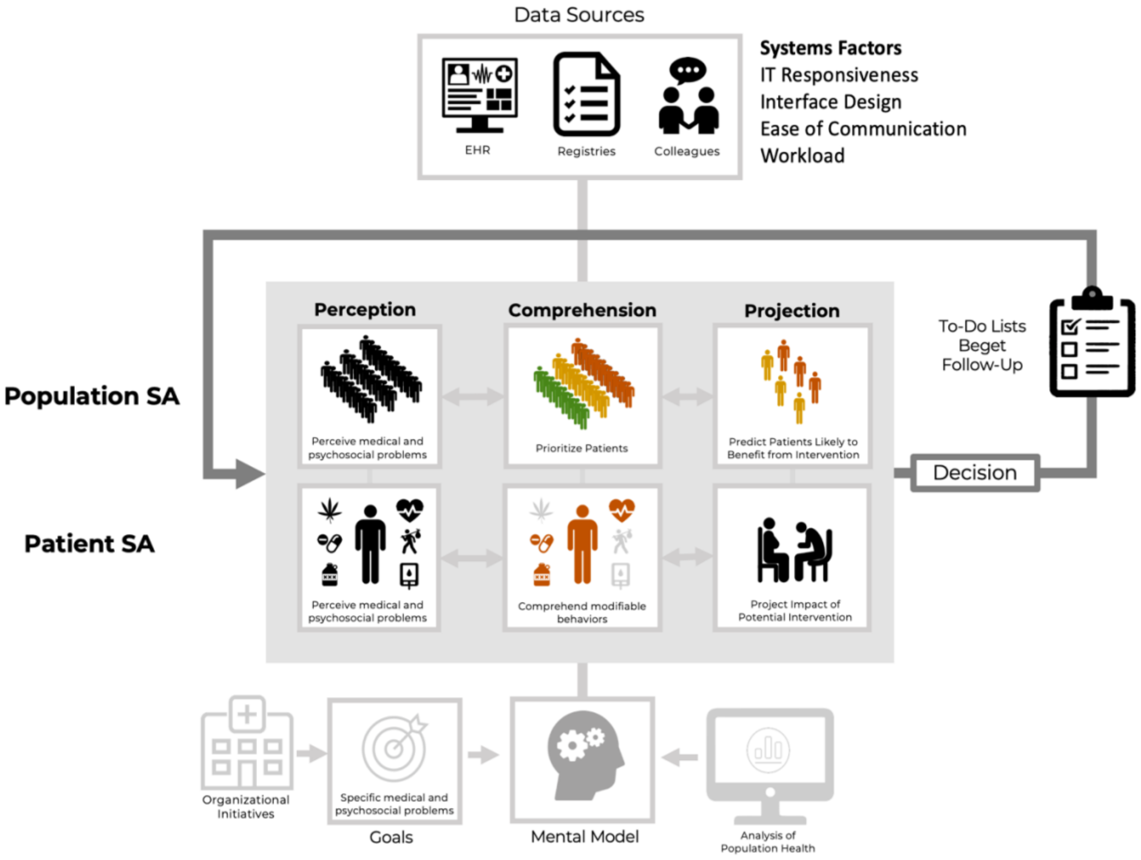


Figure 3.1 Conceptual framework of patient and population monitoring

Patient-Level Situational Awareness

The most fundamental aspect of situational awareness in chronic disease care concerns the ability of providers to maintain awareness of each patient on their respective panel. Such awareness can be conceptualized as involving the three sequential levels of SA; perception, comprehension, and projection. First, providers maintain perception of each patient's medical and psychosocial issues by communicating with colleagues and interacting with available IT systems. Second, clinicians work to comprehend the urgency of each patient's aforementioned issues, leading to a de facto triage of a patient's care gaps within the larger patient panel. Third, providers project which of several available interventions could ameliorate the identified treatment barriers and positively impact patient outcomes.

Perception: Patient Level

Clinicians asserted that they sought to be aware of all medical and psychosocial issues for their patients; however, the health status of their patients was liable to change, requiring clinicians to stay current on each patient's medical and psychosocial status. The primary means by which providers received updates on patient problems was via direct verbal and communication with colleagues:

> *"We speak daily about patients and use secure health messages...[patients] often tell the medical case manager a lot of the things that they sometimes don't tell me... I have discussions with social workers and the substance abuse counselor...so I do know what's going on with [the patients]" (Physician 2, Clinic 2)*

In addition to being alerted to emergent patient issues by colleagues, providers also reviewed patient records in EHR systems. However, the volume of information contained in the patient record was often considered overwhelming and thus not suitable for clinicians attempting to familiarize themselves with a large group of patients:

> *"we don't have enough time to take those different pieces [of information] and combine them into unified story, I mean of course a lot of those pieces are combined in a way in the EMR but not in – you'd have to sort of read this note, read that note and try to put the pieces together" (Administrator 1, Clinic 1)*

Comprehension: Patient Level

Table 3.3 Summary of Situational Awareness Constructs in Chronic Disease Care

Construct	Level	Definition	Significance
Perception	Patient	Perception of a patient's medical and psychosocial problems	Clinician may otherwise be unaware of existing patient issues or deterioration in patient status
	Panel	Awareness of all patients with medical and psychosocial problems in a provider's patient panel	Patients requiring care prevented from 'falling through the cracks'
Comprehension	Patient	Comprehension of the modifiable behaviors that prevent a patient's disease management	Providers able to address psychosocial barriers to disease self-management
	Panel	Comprehension of each patient's relative priority in a provider's patient panel	Limited resources targeted to high-risk, high-need patients
Projection	Patient	Projection of the intervention most likely to resolve a patient's medical problems	Interventions are tailored on patient characteristics
	Panel	Projection of the patients most likely to benefit from intervention in a provider's patient panel	Limited resources elicit greatest possible improvement in population outcomes

Comprehension of a patient's status transcends the mere perception of a patient's salient medical and psychosocial problems and involves the interpretation of that information is accordance with a clinician's mental model. This assessment enables clinicians to estimate the urgency of a patient's status; for example, a patient with a history of poor engagement in HIV care and substance abuse problems has an elevated risk of developing AIDS and thus is a candidate for provider outreach.

> *"the urgencies are high risk patients, the ones who are the most unstable...the ones who have serious mental health issues and substance abuse issues" (Social Worker 1, Clinic 2)*

Projection: Patient Level

Clinicians attempted to project which interventions were most likely to positively impact their patient's health outcomes. Most often, providers targeted the barriers to successful treatment that were perceived as being the 'root cause' of a patient's medical problems. Despite having a cadre of psychosocial interventions available, clinicians reported sometimes being unsure which specific intervention would be likely to address a given patient problem and often relied on a ‘best guess’:

> *"...I will usually will have met with the [patient]...I can say this is was the dynamic, so I think [I know] how this person might react to this intervention as opposed to this intervention. Obviously, it’s a best guess.” (Care Coordinator 2 – Clinic 2)*

Population-Level Situational Awareness

Providers asserted that they felt compelled to ensure that all of their patients were receiving necessary care and that it was especially important to identify and intervene on patients considered ‘high-risk’ for adverse medical events including hospitalization and mortality. These concerns were in accord with situational awareness, and the concept of *perception* can adequately represent the desire to be aware of all patients requiring care, and *comprehension* to understand the relative urgency of a patient’s status in relation to others in the population. Moreover, providers were also interested in *projecting* which patients were most likely to benefit from intervention, due to the fact that they had limited resources that prevented all patients from receiving intensive medical or psychosocial interventions.

Perception: Population Level

Secondary to being aware of less-than-optimal population outcomes, both clinics employed patient registries that identified patients requiring care. Staff asserted that registries successfully increased their awareness of the patients for whom they were responsible, especially among those patients with which they had no recent interactions.

> *“Our [patient registries] are a way to get [patients] in front of your face...I can look at my panel and see every patient that’s assigned to me and has a detectable [HIV] viral load...you’re supposed to go through that and remember and care for*

> *people who aren't in front of you...even when they're not coming to clinic" (Physician 3 – Clinic 2)*

While the aforementioned patient registries helped physicians monitor their respective patients, non-physician staff in the clinics studied lacked access to such a resource even though they were associated with dedicated patient panels. As a result, staff manually curated lists and spreadsheets that reference all patients under their care. One social worker in clinic #2 maintained an Excel spreadsheet with every patient she had interacted with, totaling more than 500 patients. These lists often served as cognitive aids to help providers maintain awareness of their patients:

> *"I have to develop my own spreadsheets so I have an idea of who [my patients] are... Imagine if I didn't have this list – names wouldn't come to mind because we encounter people every day. So, I have to keep a list." (Care Coordinator 1, Clinic 1)*

Comprehension: Population Level

The inability of clinicians to provide intensive care to all of their patients required the use of prioritization to assign resources to the highest-need patients. This process was performed in weekly and bi-weekly team meetings, which typically focused on 5 to 10 high-priority patients who were perceived as requiring immediate attention from their provider.

> *"we do the best that we can with the resources that we have, but we don't have enough resources to thoroughly address the needs of all the patients and so we triage to figure out people that we think are super high needs." (Physician 1 – Clinic 1)*

In both clinics, the characteristics that made patients more likely to be considered 'high-risk' included disease-specific biomarkers such as HbA1c or HIV viral load as well as social and behavioral determinants of health. These characteristics were adjudicated in regard to their perceived importance, with a patient's HIV outcomes being perceived as the most important indicator that a patient was prioritized for enhanced services.

> *"The patients who have been non-adherent to their antiretrovirals, persistently high HIV, RNA, and also patients who have been lost to follow up, who haven't been [to clinic] in more than six months if they are in need, those are the priorities." (Physician 2 – Clinic 2)*

Projection: Population Level

Providers were interested in projecting which patients were most likely to benefit from intervention. This reflected the fact that the clinic had limited resources, and therefore extending interventions to patients whose outcomes were unlikely to improve was thought to be inefficient.

> *"some [patient] problems are intractable and no amount of application or resources is likely to help and another group will be kind of in between...you've got to triage again because you don't have endless resources to solve every problem that every patient has" (Physician 1 – Clinic 1)*

Providers asserted that they were often reluctant to use limited resources on patients with a history of poor care engagement because they were less likely to participate fully in medical or social interventions compared to patients with more consistent engagement.

> *"[we] try to strategize who [we] can and can't see...at times you go to the patient's home and maybe you took all this time to go there and the patient is not home...they don't necessarily prioritize your coming over...if the patient is engaged it works perfectly. If they're not, then it becomes a problem"* (Administrator 2 – Clinic 2)

Goals & Goal-Directed Processing

A central tenet of Endsley's model of SA is that a decision maker's goals and plans direct which aspects of the environment are attended to in the development of SA. Goals, as described by study participants, influenced patient- and population-level perception and concerned the improvement of population-wide quality metrics such as increased rates of HIV viral load suppression. Goals were fluid and were impacted by two factors: a) external initiatives from healthcare payers and public health departments and b) continuous quality measurement within a given clinic.

Study participants asserted that their clinic's focus on addressing specific certain care indicators resulted both from economic incentives (i.e. pay-for-performance) sponsored by healthcare payers including the New York State Medicaid program as well as local initiatives advanced by the local public health department:

> *"[the clinic] is supporting the New York State [Medicaid] initiative around two HIV specific projects... the other driver is in New York state 'End the Epidemic' initiative...therefore the two major drivers is the changing landscape of the incentive structure to be more value-based and caring for whole populations and then the public health initiatives" (Administrator 1 – Clinic 1)*

In addition to external factors, clinicians updated their own self-declared goals by routinely assessing population-wide outcomes. One clinician noted that once the number of patients who achieved suppression was below a certain threshold, the provider would take action to ensure that this outcome improved across her panel:

> *"I use the [quality measurement dashboard] weekly to check that I'm 'green' on what I see as important. If I see I'm becoming 'red' on let say [HIV viral load] suppression, I'll click on the [patient registry] and start calling the patients or sending messages to outreach all of them...but I don't do it unless I'm in the red." (Physician 1, Clinic 2)*

Mental Models

The aforementioned goals of each clinician activate a *mental model* of clinicians that directs their attention to specific patient medical and psychosocial issues; such goal-activated mental models are hallmarks of Endsley's theory of SA. According to Endsley, mental models engender selective perception, wherein decision-makers may neglect and quickly forget stimuli that contradict prior beliefs.(102) In the context of patient and population monitoring, this manifested in providers paying close attention to patients with certain characteristics, such as a low CD4 count or a high HIV viral load:

> *" I would like to have patients that are out of care and the patients with low CD4 and very high viral load at the top [of my EHR]. That would probably be my*

> *concern. Usually when we put them in for their HIV care, if they have diabetes or high blood pressure, that responds also" (Physician 2, Clinic 2)*

Another function of provider's mental models are to explain the relationship between a patient's psychosocial factors and treatment outcomes. Once a provider had adequate perception of social determinants of health such as unstable housing or behavioral health issues, their mental models enabled them to recognize these factors as barriers to successful disease treatment and provided swift retrieval of appropriate actions and patient interventions. We observed that while most participating clinicians focused on mental health and substance abuse problems as barriers to treatment success, the degree to which other determinants such as unstable housing and socioeconomic status were considered was variable.

> *"the majority of our patients I would say have some mental health issues and that's everything. I mean without dealing with that, addressing that, the medical stuff is very hard to get in place." (Care Coordinator 2, Clinic 1)*

System Factors

Interface Design

Staff asserted that they were overwhelmed by the volume of information presented in the multiple patient registries of their population health tool and requested functionality that could consolidate multiple registries to reduce information overload. In addition, providers were eager to obtain functionality that would allow providers to interactively prioritize their patients according to multiple care indicators.

> *"There are clinical dashboards but they don't really get the full picture, housing, social stress or social isolation, whatever it might be, and all the nuances, that's a big important factor. So, I think that comprehensive story is still fragmented, there is many cases where [providers] are talking and sort of piece that together, but it's more on an ad hoc basis." (Administrator 1 – Clinic 1)*

IT Service Quality

Clinicians asserted that poor service quality of both the EHR and the population health module adversely impacted their ability to monitor and address care gaps. One clinician described how care team meetings were delayed by the unresponsiveness of the population health module:

> *"the dashboard...it's really, really slow and unresponsive and we are sitting in a meetings and staring at this" (Social Worker 1 – Clinic 1)*

Communication with Colleagues

Clinicians in both clinics asserted that they were often alerted to patients requiring care by their colleagues; this occurred both in weekly care team meetings and in-person communications throughout the workday. Case managers and RN care managers often alerted physicians to patient problems via secure health messages; such communications typically followed direct interactions with patients in the clinic or on the phone. However, there was a sentiment among clinic administrators that communication was not optimized and thus important patient issues 'fell through the cracks', thereby compromising situational awareness.

> *"there are gaps in the overall choreography of the workflows...workflows haven't been fully developed and engrained, so I think good things fall through the cracks because of it...as new developments happen, everyone [should be] aware of what those new developments are, so they can respond to it, depending on what their role is." (Administrator 1 – Clinic 1)*

Workload

Study participants asserted that having responsibility for a high volume of patients can have an adverse impact on situational awareness.

> *"It's the things that happen throughout day that sometimes making a little challenging to [monitor patients]... our responsibility has increased; we get secure health messages on patients needing refill, have to make sure [patients are] virally suppressed, make sure they've seen the doctor within the last couple of weeks or month...imagine having 20, 30 cases that you miss." (Care Manager 1 – Clinic 1)*

Table 3.4 Recommendations to Support Situational Awareness in Chronic Disease Care

Construct	Process	IT Requirements	Data Sources
Perception	Providers seek real-time updates of patient medical and psychosocial problems	IT systems that alert clinicians to critical events & required actions without disrupting workflow	Colleagues Electronic Health Records Patient Registries
	Providers develop strategies to maintain perception of patients with medical and psychosocial problems	Interactive systems which visually reveal patients requiring care	
Comprehension	Comprehending modifiable barriers to treatment	EHR summarization tools that highlight psychosocial issues	Integrate summarization tools that highlight psychosocial issues into EHRs
	Providers prioritize patients on a range of medical and non-medical needs	Interactive systems that support triage of populations	Develop interactive systems that enable clinicians to triage patient populations
Projection	Providers identify intervention most likely to impact patient outcomes	Prediction of intervention success	Support clinical decision making with evidence-based guidelines with a focus on psychosocial issues
	Interventions are targeted to patients most likely to benefit		

CDS = Clinical Decision Support. EHR = Electronic Health Record

'To Do' lists

A critical adjunct to situational awareness were 'to do' lists that ensured clinicians performed the actions that resulted from situational awareness; these lists were used by the majority of providers, stored in various media including spreadsheets and notebooks, and required due to the sheer volume of tasks existing across a large patient panel. Lists were populated with reminders to perform actions related to preventative and acute care.

> *"I do keep an excel spreadsheet...it will let me know who has missed an appointment, who I need to follow-up with, and then I'll manually put in – if they*

> *made the appointment, if they miss the appointment, if they need a social work appointment" (Social Worker 2, Clinic 1)*

Reminders included directives to contact patients after missed visits and referrals for patients to enroll in supportive services. This was perceived as ameliorating the challenge of recalling the high volume of tasks required when providing proactive care to a large patient population.

> *"whatever was the follow-up, we document whether it was followed up on...whether those steps have been completed and there is also a way to do that...[the spreadsheet] is just like a shorthand version of what we are documenting in the medical record, so that we can eyeball it very quickly and say, these patients are due for follow-up." (Administrator, Clinic 2)*

3.4.6 Discussion

We describe how situational awareness can be used as a framework to understand how clinicians manage populations of chronic disease patients. The principal contribution of this framework is a comprehensive and coherent means of understanding how providers deliver chronic disease care. Our study findings also provide a set of design goals for informatics interventions in chronic disease care. In addition, the framework gives us clear evaluation criteria for informatics interventions whose objective is to improve provider's situational awareness.

Our adaptation of situational awareness to chronic disease management provides a coherent framework for understanding a complex system and can serve to guide future qualitative studies. In addition, the framework of situational awareness also highlights cognitive processes implicated in monitoring panels of chronic disease patients. Using the theory of situational awareness to inform our data analysis led to an unexpected exploration of the influence of goals and goal-directed processing in patient monitoring. In addition, SA's consideration of the role of mental models in decision-making helped our research team elucidate the process by which clinicians interpret psychosocial information and identify barriers to successful disease treatment. Such barriers were then used by providers to prioritize patients and plan interventions including programs to address substance abuse disorders and unstable housing.(40,178,179)

An additional contribution of our framework is providing guidance for the design of IT systems whose purpose is to improve provider's situational awareness in chronic disease care. Such design guidance may be timely as longitudinal patient monitoring (*aka* 'population health') is becoming increasingly valued by health systems while existing IT systems for this purpose are perceived as inadequate.(4,159) *Perception* may be supported by IT systems that can aggregate and summarize clinical data to reduce cognitive load and improve situational awareness (159,180), while *comprehension* could be supported by systems that enable providers to dynamically arrange patients according to their health status.(4,25) Finally, *projection* could be supported by recent research related to decision support in care management; several studies have observed that it is feasible to use clinical data to predict whether a patient will respond favorably to care management interventions.(181–183) More recently, a method was developed that can estimate which care management intervention among several alternatives has the highest likelihood of success.(184)

The SA framework described herein provides a means of measuring the impact of IT tools on the ability of clinicians to adequately monitor their patients. Recent research has demonstrated the limitations of using patient outcomes as the primary criteria for evaluating data visualizations and visual analytics technologies.(28) We contribute three components of provider situational awareness that may be evaluated in future research studies; perception, comprehension, and projection. As a result, established methods of measuring situational awareness such as freeze probes, post-trial self-rating techniques, and observer-rating techniques can be used to evaluate the efficacy of informatics interventions either in contrived ‘laboratory’ settings or in actual clinical practice.

Our findings have several limitations. First, the clinics studied treated predominately HIV+ individuals with multiple, co-occurring chronic conditions and social factors. In addition, due to the intensive nature of HIV primary care, care managers were responsible for 500 patients, which is smaller than a typical primary care panel.(55,57) Results may be different in other settings. Second, we relied on participant’s memory of past events during interviews and thus our findings may be susceptible to recall bias. However, all findings were generated via triangulation of data collected from both interviews and team meeting observations. Third, a definitive link between provider situational awareness and patient outcomes has not been established in this setting; future research can be undertaken to do so.

3.4.7 Conclusion

We adapted the theory of situational awareness to advance a conceptual framework for population monitoring in chronic disease care. This framework provides a detailed and coherent representation of how population monitoring is performed and can inform the design of IT tools that support providers caring for populations of chronic disease patients. Future researchers can use the framework to evaluate the impact of informatics interventions on healthcare providers.

Chapter 4: Social and Behavioral Determinants of Sexual Health in the Patient Record

4.1 Background & Significance

Social and behavioral determinants of health (SBDH) are behavioral, environmental, and community factors that have been implicated in an array of adverse health outcomes. Because knowledge of these and other SBDH for specific patients is clinically meaningful and can lead to tailored care plans, accounting for SBDH has become increasingly recognized in healthcare delivery. This is especially critical in the management of persons living with HIV. As a result, there has been increasing momentum for incorporating social determinants into the electronic health record (EHR). In 2015, the National Academy of Medicine recommended a set of 12 SBDH indicators, part of the Meaningful Use Program. The Office of the National Coordinator for Health Information Technology (ONC) recently drafted the 2018 guidelines for collection of 8 of the 12 aforementioned indicators, all of which are mapped to standard LOINC codes. However, efforts to integrate information on SBDH into EHRs have struggled due to the fact that providers often fail to adequately document their patient’s self-reported SBDH.(17,185–189) In addition, low adoption rates for clinical screening tools for SBDH in EHRs exist as a barrier to the collection of this information in a usable format.(177,190) As a result, there has been interest in automatically inferring social and behavioral determinants from EHR data and empower healthcare providers with this information during clinical interactions with chronic disease patients.

4.2 Research Questions

Research Question 1: To what extent does EHR documentation of social and behavioral determinants change between encounters?

Hypothesis: The combination of clinical notes and structured data result in improve performance against a gold-standard compared to those sources alone

Research Question 2: How to infer from clinical data a range of social & behavioral determinants from the patient record?

Hypothesis: Not all SBDH factors have equal ability to be inferred; performance is contingent on the frequency and lexical diversity of the annotated determinant

4.3: Study 1: Towards the Inference of Social and Behavioral Determinants of Sexual Health: Development of a Gold-Standard Corpus with Semi-Supervised Learning

4.3.1 Introduction

Social and behavioral determinants of sexual health have received comparatively less attention than other SBDH. High-risk sexual activity like infrequent condom use and receptive anal intercourse is associated with increased risk for human immunodeficiency virus (HIV) and other sexually transmitted infections (STIs). Transgender persons are also at a higher risk of acquiring STIs and less likely to achieve desirable chronic-disease outcomes such as HIV viral load suppression.(188,191) Moreover, sexual orientation may play a role in STI risk. At present, sexual health SBDH are not collected in SBDH screening instruments such as the PRAPARE or the Accountable Health Communities Screening (AHCS) tool, nor routinely documented in the structured part of EHRs.(177,192) This challenges the development of clinical decision support systems and population-level interventions to reduce the prevalence of HIV and other STIs.(193,194)

Overall, there are still several research gaps when it comes to automated identification of SBDH related to sexual health: 1) only a few of the pertinent SBDHs have been examined in the literature; 2) they have diverse lexical realizations in clinical notes and for many, there might not even be good coverage in existing terminologies; and 3) documentation of SBDH are rare across patients (despite their acknowledged importance).

4.3.2 Objectives

We sought to generate a standard set of determinants related to sexual health; we describe an expert curation of 38 such SBDHs. Using this set of SBDH, we attempted to curate a sizable annotated corpus using manual review and semi-supervised learning.

4.3.3 Materials and Methods

Social and Behavioral Determinants Relevant to Sexual Health

Three physicians (JZ, PG, MY) experienced in the prevention and treatment of STIs reviewed the biomedical literature and identified six high-level domains of behavioral risk factors for STIs (gender, sexual orientation, sexual activity, drug use, alcohol use, and homelessness), along with 32 individual-level SBDH (**Table 4.1)**. These SBDH represent independent risk factors for the acquisition of STIs and have recently been the focus of targeted HIV prevention efforts.

The domain experts recommended that the six SBDH domain labels should indicate whether information related to a candidate risk domain was documented. For example, *"patient denies sexual activity"* and *"patient is sexually active"* would both result in a positive label for *the "Sexual Activity"* domain. It was hypothesized that these domain-level labels can be used to inform efforts directed at improving social and sexual history taking by clinicians.

Development of Annotation Guidelines for Sexual Health SBDH

We chose to obtain annotations at the document-level rather than mention-level because of how social and behavioral determinants are expressed in natural language. Unlike many other biomedical concepts, SBDH are infrequently expressed as named entities. For example, we observed the following examples in clinical notes at CUIMC:

> *"has continued to relapse on crack and beer since starting treatment 3 months ago"*
> *"noted that he used occasional social EtOH (scotch) at church functions"*
> *"Transmitted via heterosexual intercourse"*
> *"3-4 lifetime male unprotected sexual partners"*
> *"HIV/AIDS (Dx 1992 after unprotected sex, RF sex with both men and women"*

In addition, we also reasoned that obtaining document-level annotations would be less labor-intensive than obtaining mention-level annotations, an important consideration given how infrequently SBDH are mentioned in patient records.

We excluded from consideration relational modifiers such as amount (e.g., "*5 sexual partners"*), frequency of exposure (e.g., "*once a month"*), and status (e.g., "*current/past/none"*) because this information is not prioritized by clinical interventions addressing sexual health. However, document-level annotation does not preclude the capture of relevant modifiers such as the frequency of condom use (e.g., *"condom never"*, *"condom sometimes"*, *"condom always"*). Annotators were instructed to review the entire length of each clinical note.

Collection of Clinical Notes for Manual Annotation

A corpus of clinical notes was obtained from the clinical data warehouse at Columbia University Irving Medical Center (CUIMC), a large academic medical center in New York City. For this study, we obtained all individual notes types associated with 4,000 HIV+ individuals within the commercial EHR system at CUIMC (e.g., Admission Note, Progress Note). Additional details on this cohort are described elsewhere. The study described herein was approved by the Institutional Review Board at CUIMC.

Systematic Annotation of Clinical Notes with Curated SBDH Labels

We recruited one Infectious Disease fellow and two medical students to manually review clinical notes for the presence of the 38 SBDH labels. To train for annotation, an initial set of three longitudinal patient records were coded by all three annotators; all discrepant labels were discussed and resolved by consensus to create a shared understanding of the SBDH concepts. The annotators utilized the annotation guidelines and iteratively improved on them during that phase.

Subsequent to the initial training, annotators were instructed to systematically review all notes associated with each patient's record. After annotating >1,000 notes, we observed that many notes rarely contained SBDH mentions (e.g. "Nursing Progress Note"). The annotators then isolated their review to select note types written by healthcare providers related to hospital admission and discharge, outpatient care, and psychiatry consultations.

4.4.2 Semi-Supervised Learning for Corpus Expansion

The scarcity of clinical notes containing explicit SBDH mentions rendered the annotation process described above extremely labor-intensive. The excessive amount of human effort required to compile a sizeable annotated corpus exists as a barrier to the use of deep neural networks, which achieve state-of-the-art performance on a range of NLP tasks. As a result, we employed a technique leveraging modern distributional semantic techniques to accelerate the manual annotation process by identifying clinical documents likely to mention SBDH.

Training Word Embeddings for SBDH

We used the popular GloVe software package to train vectors representations of words. We isolated the social history section of 343,322 randomly selected notes from within our overall clinical data warehouse (343,322 patients). We extracted Admission, Nursing Adult Admission History, and Ambulatory Aim Primary Provider notes because these notes often contained relevant SBDH information and had a Social History section. Prior to training, clinical notes were preprocessed by removing non-alphanumeric characters, replacing numbers with a special token, and converting all tokens to lowercase.

We evaluated several different configurations of GloVe by using word vectors of 50, 150, and 300 dimensions while using a window size of 8 words and 50 iterations of training. 50-dimensional vectors were chosen because they had similar performance compared to 150 and 300-dimensional vectors with lower complexity; performance was assessed by evaluation precision at 10 on a held-out testing set of 20% of the notes with 0 patients overlapping between the testing and training sets. The isolated corpus yielded 33,206,266 tokens and 2,37,072 unique words.

Removal of words with fewer than 5 mentions in the corpus were excluded to generate a vocabulary size of 47,479.

Creation of Centroid Document for each SBDH Label

We then sought to retrieve and rank unannotated clinical notes with regard to similarity to annotated notes with explicit mentions of our target SBDH. This required the generation of a single centroid document for each SBDH label. For each SBDH label, we isolated the social history sections of all notes with valid mentions of the specific SBDH and represented each document itself as a 50-dimensional vector by averaging the word embeddings associated with the document. The singular centroid for each SBDH was generated by again averaging the document vectors associated with the SBDH. We did not construct a centroid for gender-related documentation.

Identification of Unannotated Notes Likely to Contain SBDH Documentation

We then isolated 144,432 clinical notes associated with HIV+ individuals obtained from the enterprise data warehouse at Columbia University Irving Medical Center. Each note was represented as a 50-dimensional vector by averaging the individual word embeddings of each note as described above. For each SBDH label, cosine similarity was used to rank unannotated notes in order of descending cosine distance to the corresponding SBDH centroid document. This resulted in a ranking of notes in regards to cosine distance from one or more document centroids. Notes identified using this methodology are hereafter referred to as candidate SBDH notes.

Annotation of Candidate Clinical Notes

Following the annotation guidelines, two annotators subsequently annotated candidate SBDH notes corresponding to 5 domain-level SBDH and observed high interrater reliability; a Kappa statistic of 0.598 was observed across all SBDH labels.

4.3.4 Results

Three physicians experienced in the prevention and treatment of STIs reviewed the biomedical literature and identified six high-level domains of behavioral risk factors for STIs (gender, sexual orientation, sexual activity, drug use, alcohol use, and homelessness), along with 32 individual-level SBDH (**Table 4.1)**. These SBDH represent independent risk factors for the acquisition of STIs and have recently been the focus of targeted HIV prevention efforts.

The domain experts recommended that the six SBDH domain labels should indicate whether information related to a candidate risk domain was documented. For example, *"patient denies sexual activity"* and *"patient is sexually active"* would both result in a positive label for *the "Sexual Activity"* domain. It was hypothesized that these domain-level labels can be used to inform efforts directed at improving social and sexual history taking by clinicians.

Three annotators reviewed every clinical note associated with 32 randomly selected HIV+ individuals to detect the presence of all SBDH labels. 76 notes were double annotated (Kappa 0.736 across all SBDH). 3883 clinical notes were manually annotated and 17.9% (695) had one or more SBDH label. On average, there were 0.83 SBDH mentions per annotated note. In addition, we observed a high frequency of redundant text, reflecting the widespread usage of copy-and-paste at CUIMC.

While our annotation process is underway, we thus far have amassed a corpus of 4,045 annotated clinical notes, overall associated with 105 HIV+ individuals. 19.0% of notes (770) contained documentation of 1 or more of the six SBDH domains. Among domains, alcohol use

Table 4.1 Summary of annotation guideline for 6 domain-level and 32 individual-level SBDH indicators.

SBDH Indicator	Example	SBDH Indicator	Example
Gender Documented *56 yr. old male*		Transgender Male	*trans male, trans FtoM*
Male	*male, man, boy*	Transgender Female	*trans female, trans MtoF*
Female	*female, woman, girl*	Non-Conforming	*non-conforming*
Sexual Orientation Documented *pt. is heterosexual*		Bisexual	*male and female partners*
MSW	*has a wife*	WSM	*heterosexual female*
MSM	*gay male, LGBT male*	WSW	*LGBT female*
Sexual History Documented *pt. not sexually active*			
History of STIs	*history of GC/CT*	Condom Always	*consistent condom use*
Oral Sex	*reports oral sex*	Condom Sometimes	*infrequent, occasional*
Vaginal Sex	reports vaginal sex	Condom Never	*pt. doesn't use condoms*
Insertive Anal Intercourse	*insertive anal intercourse*	Receptive Anal Intercourse	*receptive anal intercourse*
Alcohol Use Documented *pt. denies alcohol use*		Social alcohol use	*pt. drinks occasionally*
Active alcohol use	*currently uses alcohol*	Alcoholism	*pt. drinks frequently*
Substance Use Documented *pt. denies substance use*		Cocaine	*pt. reports cocaine use*
History of Drug Use	*used cocaine in the past*	Methamphetamine	*reports meth use*
Active Drug Use	*pt. reports cocaine use*	Intravenous Drug Use	*uses intravenous drugs*
Marijuana	*pt. uses cannabis*	Cocaine	*pt. reports cocaine use*
Housing Status Documented *pt. lives alone*			
Homeless	*pt. lives on the street*	Stable housing	*lives in apartment*
Living with family/friends	*lives on friend's couch*	Unstable housing	*reports unstable housing*

was documented most frequently (439 notes), followed by substance use (422), housing status (335), sexual activity (326), and sexual orientation (259). No mention of patients who were transgender or gender non-conforming was observed.

In the annotated corpus, we observed 2,466 mentions of individual SBDH. *"Marijuana use"* was the most frequent (188 notes), followed by "living with friends" (171 notes), and "alcohol abuse" (143 notes). 99 notes documented patients as LGBT, with 73, 22, and 9 "MSM", "Bisexual", and "WSW", respectively. 12 SBDH labels were each documented in fewer than 25 notes.

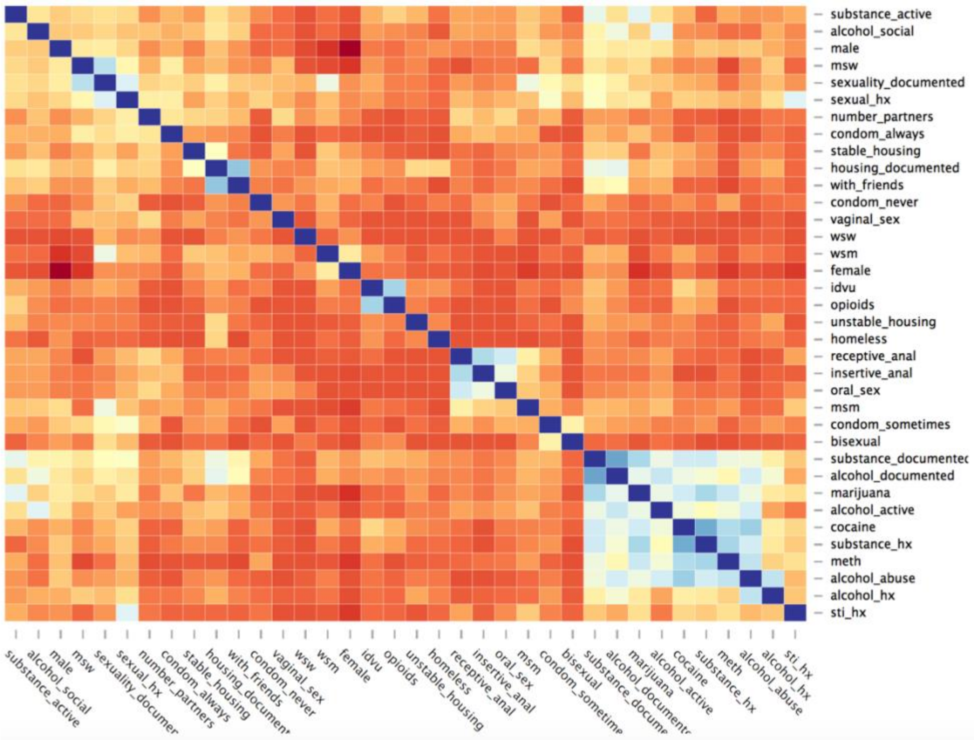


Figure 4.1 Label Dependence among SBDH indicators

We observed a significant among of dependence among individual SBDH labels, displayed in **Figure 4.1**. SBDH related to active substance use such as methamphetamine and cocaine use (correlation coefficient = 0.63) often displayed a strong correlation, as did active alcohol use and a history of substance abuse (0.39). MSM and receptive anal intercourse (0.35) also displayed a correlation. However, the correlation matrix suggests that a considerable number of SBDH exhibit little association with other labels.

Semi-Supervised Learning

We isolated 10 clinical notes within the lowest cosine distance compared to 5 'domain-level' centroids and computed precision-at-10. Our approached yielded the following precision-at-10 results: "*housing status documented" (100%), "alcohol documented" (90%), "substance use documented" (90%), "sexuality activity documented" (60%),* and *"sexual orientation documented" (60%).* Averaged across these, we observed a precision-at-10 of 80%.

118 notes with high similarity to 1 or more SBDH centroids were annotated and 113 notes (95.7%) contained 1 or more SBDH mentions. On average, there were 8.26 SBDH mentions per note. This represents an astounding 10-fold increase in the yield of positive SBDH mentions compared to the systematic review (0.83 vs. 8.26 SBDH per note). In addition, the 118 notes were associated with 80 HIV+ patients, achieving our goal of diversifying the annotated corpus and reducing the frequency of redundant text.

4.3.5 Discussion

We posit that our schema of SBDH related to sexual health can serve as a common foundation on which to build data collection and analysis efforts. Our set of 32 individual-level SBDH constitute an array of behaviors that have been associated with an increased likelihood of acquiring syphilis, HIV, and other STIs.(195) In addition, our six domain-level SBDH indicators may be used to assess the quality of clinical documentation. The annotation guidelines can inform future efforts in corpus curation and computational methods to infer determinants of sexual health from EHRs (available at github.com/danieljfeller/SBDSH).

We advance a standard for the annotation of clinical notes for social and behavioral determinants of sexual health. Overall, the SBDH domains were observed infrequently in clinical notes; alcohol and substance use were the most prevalent individual-level SBDH in our corpus but were observed in only 4% of annotated notes. Sexual orientation was documented in less than 1% of notes. SBDH documentation occurred mostly in outpatient notes, admission notes, and discharge summaries. We are also the first to observe inter-SBDH correlation; several individual-level SBDH displayed moderate associations with other labels (e.g., *"cocaine use"* and *"alcohol use"*). This label dependence could potentially be leveraged to improve their automated extraction.

Because SBDH documentation is so rare and the requirement of a large gold-standard corpus to learn from, our approach necessitated the use of computational methods to identify clinical notes likely to contain SBDH content. Our semi-supervised approach using similarity based on section-embeddings successfully increased the yield of manual annotation. Annotators observed 8.26 distinct SBDH mentions per note for the 60 notes closest to the 6 SBDH domain centroids, compared to 0.83 mentions per note randomly sampled from a cohort of HIV+ individuals. The utility of distributional semantics techniques for modeling the diverse lexical realizations of SBDH in notes has been established.(196) Our approach allowed our research team to increase the size and diversity of our annotated corpus. Further, this approach may also enable the diversity of our corpus in patients and types of lexical realizations of SBDH, thereby ensuring the extensibility of future SBDH models to various patients and healthcare settings.

The manual annotation confirmed our hypothesis that there is a wide variation in lexical realizations of SBDH, ranging from word to multi-word expressions to whole sentences. As such our approach to treating annotation as document-level labeling circumvented this phenomenon. We experimented with using supervised learning to infer SBDH labels for given clinical notes. The inability to infer the presence of individual-level SBDH likely reflects the limited size of our annotated corpus, as compared to the training size typical of other document classification systems for medical concept recognition.(197,198) Moreover, the poor classifier performance may reflect the UMLS's lack of coverage for SBDH; 62% of annotated notes with explicit mentions of SBDH were tagged with no relevant UMLS concepts by our in-house named-entity recognition system. Only 38% of annotated notes with explicit mentions of SBDH were tagged with 1 or more relevant UMLS concepts. There are a number of ways to improve on our experiments: (1) multi-label classification may be improved by accounting for the observed structure of SBDH labels. Hierarchically structured sets of SVM have demonstrated improved performance compared to binary relevance for multi-label classification of clinical documents.(199–202) In addition, it may be possible to leverage the SBDH label dependence exhibited in **Figure 1**;(203) (2) document-level SBDH labeling may benefit from document zoning.(204) Long documents like clinical notes typically contain many words unrelated to the modeling task; in clinical documentation this is manifested by sections (ie. 'Review of Systems') potentially irrelevant to SBDH; (3) structured elements of the EHR such as laboratory tests and diagnosis codes can improve the inference of social determinants compared to using notes alone. Future studies should examine whether laboratory tests for STIs hold prognostic value; and (4) with a larger annotated corpus, a neural network with attention layer that could provide transparency for classification decisions, may improve results.

Our study has several limitations. First, document-level annotations lack the granularity of mention-level annotations and thus systems trained on such data may be inappropriate for some informatics interventions.(205) Second, our semi-supervised learning approach relied on notes which contained a social history section; not all notes do so. Third, a relatively small sample size was used for evaluation of the semi-supervised learning approach.

4.3.6 Conclusion

We describe a set of social and behavioral determinants related to sexual health and report on the curation of a gold-standard corpus of clinical notes documenting such determinants. Our findings demonstrate that while these SBDH are infrequently documented in clinical notes, semi-supervised learning can reduce the burden of manual annotation. In addition, our experiments with supervised learning suggest that existing lexical resources may be inadequate for extracting SBDH.

4.4 Study 2: Longitudinal analysis of social and behavioral determinants of health in the EHR: exploring the impact of patient trajectories and documentation practices

4.4.1 Introduction

Despite the fact that many previous studies have attempted to automatically infer patient SBDH status from clinical data, it is unclear how SBDH related to sexual health are expressed in longitudinal patient records. Walsh and Elhadad used topic modeling to characterize the content of social history sections and observed more language relevant to sexual history in outpatient notes compared to inpatient notes.(206) Chen and colleagues reviewed clinical notes across 3 health systems and found that sexual activity and sexual orientation were infrequently documented; combined these topics were mentioned with less frequency than caffeine use.(207) Simple textual searches for sexual orientation (e.g., ‘LGBT’, ‘gay’, ‘lesbian’) identified several thousand records at Vanderbilt University Medical Center.(208) While these studies suggest that information related to sexual health is sparsely documented in EHR data, they reported neither the prevalence nor lexical characteristics of specific SBDH related to sexual health in clinical notes.

Other characteristics of SBDH as expressed in the patient record are unclear, including 1) to what extent does EHR documentation of social and behavioral determinants change between encounters, and 2) how do indicators of SBDH manifest in both structured and unstructured data within the EHR. These questions should be addressed in service of perhaps the most widespread research question, which is 3) how to infer from clinical data a range of SBDH from the patient record?

It is unlikely that a patient’s documented SBDH status is invariably consistent with the patient’s true state. Patients are often hesitant to disclose sensitive information such as sexual orientation and substance use to healthcare providers and may be less likely to share sensitive information with non-physician providers.(162,209) In addition, the quality of social history taking by clinicians is variable, and providers are liable to make incorrect assumptions about their patient's health.(210,211) As a result, a patient's SBDH status recorded in the patient record may reflect inaccuracies attributable to phenomena inherent to clinical docu38–43mentation of sensitive information. There is little knowledge of how social and behavioral determinants of health as expressed in patient records change through time. To our knowledge, the only relevant study was conducted by Bejan et. al. in 2017, which observed cyclic transitions between the at-risk and homeless categories among homeless patients, and less frequent transitions among individuals with stable housing.(212)

4.4.2 Objectives

This study sought to advance the understanding of how SBDH are manifest in the patient record; we performed a longitudinal analysis of how such determinants are manifested across time in the EHR. We also assessed the degree to which such changes reflected data quality issues.

4.4.3 Methods

The analysis described herein focused on 4 SBDH; sexual orientation, housing status, alcohol use and drug use. Encounters with confirmed documentation of SBDH were isolated and analyzed to examine changes in a patient's SBDH status. and potential data quality issues. We then manually reviewed pairs of notes authored on the same-day with conflicting documentation to identify possible sources of data quality issues related to SBDH.

SBDH Preprocessing

A distinct dataset was created for each SBDH of interest and included only notes where the respective high-level SBDH was documented. For example, to be included in the analysis of ‘drug use’ status, it was necessary that a note discuss drug use (even if drug use was a negative label, as in *“no history of substance use”*). This way, all notes in that SBDH dataset had explicit discussion of that SBDH and either positive or negative findings for that SBDH. Notes that did not discuss the SBDH were not included; absence of a certain SBDH in a clinical note most often reflects the fact that this domain was not discussed by patient and provider, rather than evidence that the patient is a negative case.[28]

Survival Analysis

To assess the rate of change in SBDH status, we simply parameterized each annotated document using sequence time (e.g., visit_time$_1$, visit_time$_2$, etc. where visit_time$_i$ represents the time between the first and i_{th} visit in the longitudinal record of a patient) and estimated the likelihood that a patient at visit$_t$ would transition to a different state (e.g., ‘never used alcohol’ to ‘actively using alcohol’), as documented within the documentation at the next visit. This analysis was conducted using the corpus generated by a comprehensive annotation of the entire longitudinal record of the 32 HIV+ individuals in our cohort.

We used survival analysis to analyze the expected duration of time associated with changes in patient SBDH status. Observation periods were established between adjacent notes in a patient’s longitudinal history and time was measured in days. An event was defined as any change in SBDH status observed in the subsequent note. Observations were (right) censored when the subsequent note was observed with the same SBDH status as observed in the preceding (index) note. A survival function was estimated for each SBDH using the Kaplan-Meier estimate and can be interpreted as the fraction of clinical notes observed at time *T* with an observed change in SBDH status documented in the subsequent note:

$$\widehat{S}(t) = \prod_{i:\ t_i \leq t} \left(1 - \frac{d_i}{n_i}\right)$$

where d is the number of notes with subsequent SBDH changes at time *t* and *n* is the number notes not associated with any subsequent SBDH change (and who have not yet been censored) at time *t.*

Quantitative Analysis of Data Quality

In order to assess data quality in SBDH documentation, we used a larger cohort of patients who were required only to have multiple notes manually annotated. Using the parameterization of sequence time described above, we considered *illegitimate transitions* to be those that were chronologically impossible; for example, a patient could be documented as having ‘never used alcohol’ *subsequent* to being documented as ‘actively using alcohol’.

In addition, we identified same-day conflicts in SBDH documentation by isolating clinical notes that were written on the same day by distinct providers. Similar to previous analyses, we required that all notes under consideration have confirmed documentation of the relevant high-level SBDH domain. Same-day conflicts were defined as observed discrepancies in SBDH status (e.g., documentation of *“no active alcohol use”* and *“active alcohol use”*).

Qualitative Analysis of Data Quality

We manually reviewed 20 note pairs that exhibited same-day conflicts in patient SBDH status with the goal of developing an understanding of the sources of data quality problems. 5 note pairs were gathered from each of the four SBDH analyzed herein. The sources of data quality issues were identified using a set of annotation guidelines we created for this analysis. Data quality issues reflected 1) *inappropriate use of copy & paste* if content was duplicated across notes of the same type, 2) an *inaccurate problem list* if outdated information contained in structured clinical data was automatically inserted into narrative free-text, 3) *variable history taking* wherein the note with positive documentation contained significantly more information regarding SBDH compared to the note with negative documentation, 4) a *patient hesitant to disclose sensitive information* when it was clear that both notes contained a detailed social history but that the patient gave conflicting answers across the notes, and 5) the use of a *standard note template* which automatically inserted negative and formulaic documentation of SBDH status.

Among the 20 manually reviewed note pairs with same-day conflicts in SBDH, 14 (70%) conflicts reflected variable quality of social history taking by clinicians, wherein the note with positive documentation contained significantly more detailed information regarding SBDH compared to the note with negative documentation. 2 note pairs exhibited evidence of an inaccurate problem list, wherein note content automatically generated from the patient's EHR problem list conflicted with information contained in narrative free-text. 2 note pairs exhibited evidence that a patient was hesitant to disclose SBDH, as it was clear that both notes contained a detailed social history but that the patient gave conflicting answers across the notes.

4.4.4 Results

Cohort Characteristics

3273 clinical documents associated with 32 HIV+ individuals were manually annotated and included in the longitudinal corpus. All available clinical notes associated with these patients was annotated with a range of 11 to 473 notes per patients (median 50, mean 102). The longitudinal histories of patients in this analysis were of variable lengths and ranged from 196 days to 3146 days; the mean longitudinal history was 997 days and the median was 772 days.

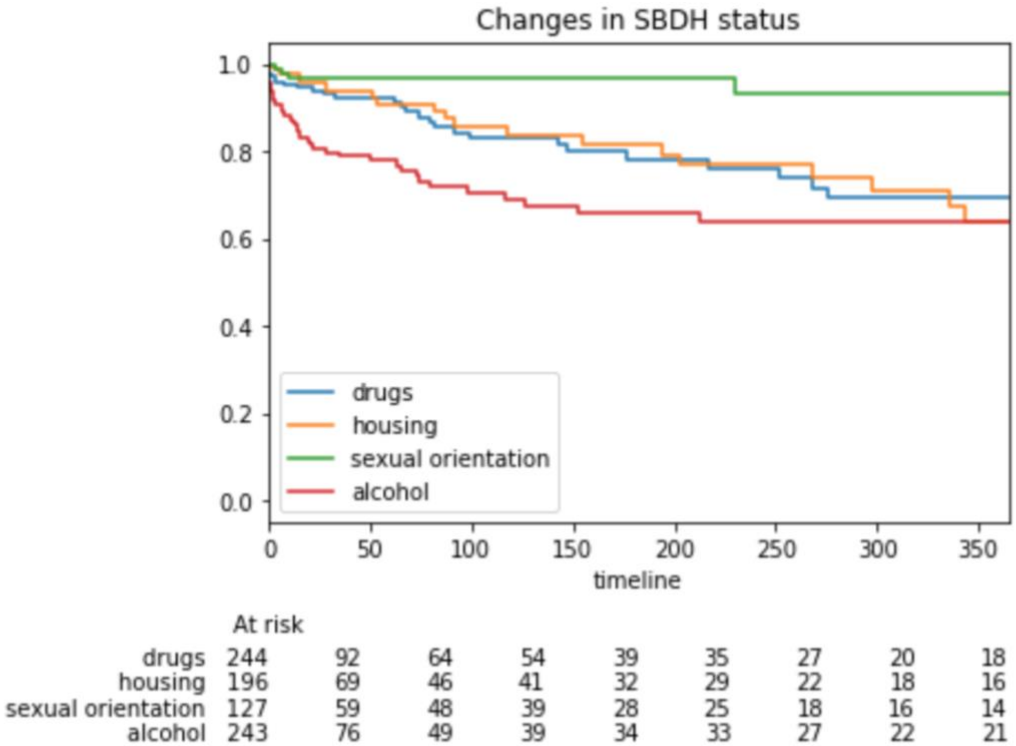
75% of individuals were male (24) and the average age was 46 years with a standard deviation of 13.5 years. Race and ethnicity information was missing for a majority of the cohort, but 8 patients were documented as African American, 7 as Caucasian Hispanic, 2 as Caucasian non-Hispanic, and 1 as Asian.

The larger cohort used in the data quality analysis included 366 individuals with multiple annotated notes (4294 notes total). All available clinical notes associated with these patients was annotated with a range of 2 to 473 notes per patients (median 2, mean 11). The longitudinal histories of patients in this analysis were of variable lengths and ranged from 0 days to 3146 days; the mean longitudinal history was 469 days and the median was 174 days. 60.3% of individuals were male (221) and the average age was 53 years with a standard deviation of 12.2 years. Race and ethnicity information was missing for a majority of the cohort, but 71 patients were documented as African American, 58 as Caucasian Hispanic, 30 as Caucasian non-Hispanic, and 1 as Asian.

Longitudinal Changes in SBDH

A state diagram illustrating changes of documentation status for alcohol use computed across the cohort of 366 individuals is presented in **Figure 4.3**, across 1077 pairs of consecutive notes.

Many patients in the longitudinal cohort of 32 individuals were observed to have temporal changes among all SBDH analyzed. Alcohol status was most likely to change across subsequent notes (23.3%), followed by drug use (10.4%), drug use (8.7%), and sexual orientation (1.1%). A



drugs	244	92	64	54	39	35	27	20	18
housing	196	69	46	41	32	29	22	18	16
sexual orientation	127	59	48	39	28	25	18	16	14
alcohol	243	76	49	39	34	33	27	22	21

Figure 4.2 Survival function of SBDH changes for drug use, housing, sexual orientation, and alcohol use.

chi-square goodness of fit test found a significant difference in these proportions (2: 29.2, *p* < 0.001).

A Kaplan-Meier plot that presents the 365-day survival function of the 4 SBDH analyzed in this study in presented in **Figure 4.2**. The y-axis represents the proportion of notes without changes in SBDH documentation, and the x-axis represents the number of days between each subsequent note. 365-day transition rates for housing status, drug use, and alcohol use were 39.6%, 30.6%, and 36.3%, respectively. The 365-day transition rate for sexual orientation was 6.9%.

Data Quality in SBDH Documentation

While most of the transitions in SBDH status looked sensible, we observed illegitimate transitions in SBDH status as shown in **Figure 4.3**. Among 353 notes documenting patient SBDH status as ‘active alcohol use, 43 were followed by documentation of ‘never used alcohol’ (12.2%). Moreover, among 165 notes documented that the patient had ‘historical alcohol use’, 26 were followed by documentation of ‘never used alcohol’ (15.7%).

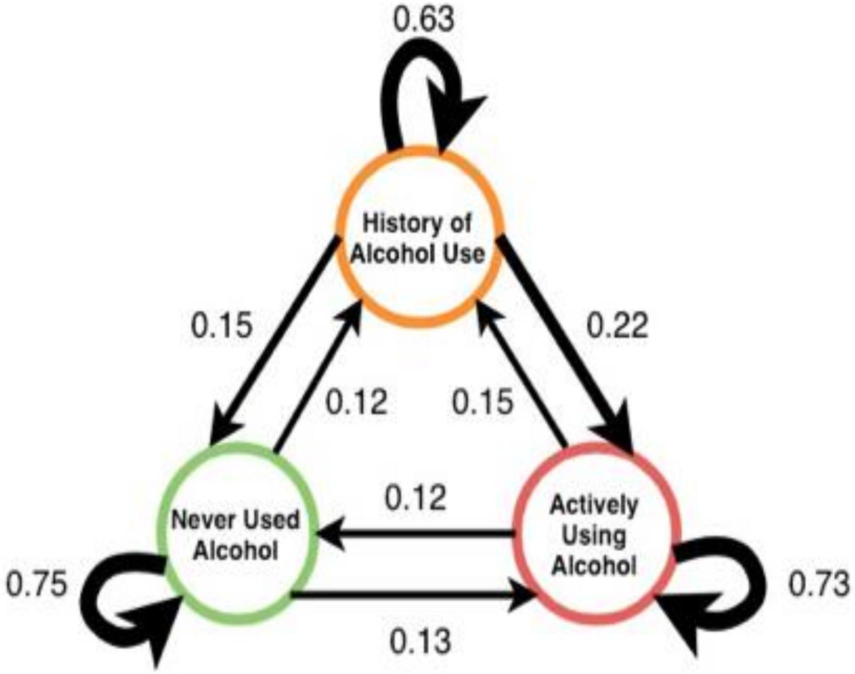


Figure 4.3. State diagram of changes in documentation of alcohol use across all patients in the cohort.

We also observed same-day conflicts in patient SBDH status. For instance, 23.2% of 56 same-day note pairs with alcohol status documented had conflicting indications of alcohol use, 21.2% of 52 same-day note pairs had conflicting indications of substance use, 6.8% of 44 same-day note pairs had conflicting indications of patient housing status, and 8.0% of 25 same-day note pairs had conflicting of sexual orientation. We also observed conflicts in SBDH documentation within a 7-day period. 12.6% of annotated notes associated with the same patient had conflicting indications of alcohol use (N = 230). In addition, 14.3% of notes describing drug use exhibited the same changes (N = 265), as did 7.6% of notes describing housing status (N=198). 1.6% of notes with sexual orientation documentation exhibited same-week conflicts (N = 127).

Manual review of 20 same-day conflicts in SBDH revealed multiple sources of poor data quality with incomplete social history taking by clinicians being most common. Among the 20 manually reviewed note pairs with same-day conflicts in SBDH, 14 (70%) conflicts reflected variable quality of social history taking by clinicians, wherein the note with positive documentation contained significantly more detailed information regarding SBDH compared to the note with negative documentation. 2 note pairs exhibited evidence of an inaccurate problem list, wherein note content automatically generated from the patient's EHR problem list conflicted with information contained in narrative free-text. 2 note pairs exhibited evidence that a patient was hesitant to disclose SBDH, as it was clear that both notes contained a detailed social history but that the patient gave conflicting answers across the notes. 1 note pair conflict reflected the use of a standard note template, which automatically declared negative SBDH status.

4.4.5 Discussion

The findings of this study provide evidence that social and behavioral determinant of health as expressed in the patient record exhibit changes over time. Our longitudinal analysis of 4 distinct risk-factors suggests that a patient's SBDH status should be treated as a shifting, mutable variable in electronic systems. We provide additional evidence that some changes in SBDH documentation may reflect data quality issues and not actual changes in the patient state.

We present a longitudinal analysis of multiple SBDH as expressed in patient records. Four distinct SBDH were examined throughout the course of 32 patient records and exhibited varying rates of change. A patient's recorded alcohol status was most likely to change, as 23.3% of adjacent encounters with documentation of alcohol use contained conflicting information.

This may reflect the high prevalence of heavy episodic drinking among persons living with HIV, which has resulted in calls for repeated assessments of alcohol consumption in this population.(213,214) While documentation of substance abuse and housing status were less likely to change compared to alcohol use, these SBDH exhibited changes across as much as 10% of adjacent encounters. Epidemiological studies suggest that these SBDH are likely to change; most individuals who are considered with unstable housing experience only transient periods of homelessness (215), and many HIV+ persons with substance abuse disorder engage in episodic rather than sustained use.(216,217) These findings suggest that automated approaches to inferring SBDH should not treat these variables as fixed patient characteristics and thus should reevaluate a patient's SBDH status on a regular basis.

In contrast to alcohol use, substance abuse, and housing status, a patient's recorded sexual orientation was unlikely to change, as 1.1% of adjacent encounters with documentation of sexual orientation contained conflicting information. This rate reflects the infrequent changes in sexual orientation observed among persons experiencing stigma and discrimination.(218) This findings demonstrate that distinct SBDH may be likely to change at different rates and thus may be reevaluated on different time scales.

Multiple findings indicated that some changes in patient SBDH status reflected data quality issues and not legitimate changes in the patient state. We observed a high frequency of implausible longitudinal changes in patient SBDH status, wherein a patient transitioned from an active status (e.g. active alcohol use) to having no history of active status (e.g. no history of alcohol use). In addition, we observed same-day conflicts in patient's documented SBDH status. Our manual review of these discrepancies observed that most conflicts reflected the variable nature of social history taking. It has been established that some healthcare providers are reluctant to discuss sensitive issues with their patients, thereby limiting their ability to take a comprehensive social history.(219) While our study methodology does not allow us to hypothesize the cause of the observed data quality issues, the implication of our findings is that any attempt to characterize a patient's SBDH status should likely not reflect only the patient's most recent documentation. Decision support systems that aggregate multiple instances of SBDH documentation may provide a more faithful representation of a patient's SBDH status compared to data collected during a single encounter. Information retrieval and classification methods should utilize observation windows that leverage only recent EHR data (220,221), or weight decay techniques that model the decreasing relevance of data elements to computational phenotypes.(222,223)

Future research should conduct a more comprehensive analysis by annotating all notes associated with a large corpus and use techniques such as mutual information to assess how the predictability of future SBDH status relative to existing documentation changes with time.(224) Such an analysis would open the possibility for techniques that could accurately model the relevance of social and behavioral determinants of health documentation.(225,226)

Limitations

First, our findings were generated by analyzing data from a specific patient cohort treated at a single institution. The high prevalence of SBDH within the study cohort may have resulted in a higher frequency of SBDH changes. Second, while our annotators achieved a relatively high inter-rater reliability, there were likely some erroneous annotations and thus some temporal changes in SBDH status may reflect annotation errors and rather than changes in documented SBDH status. Third, our methods did not enable us to quantify the proportion of SBDH changes that reflected true changes in the patient state and the proportion that reflected documentation errors.

4.4.6 Conclusion

We provide evidence that social and behavioral determinant of health as expressed in the patient record exhibit changes over time. Our longitudinal analysis of 4 distinct risk-factors suggests that a patient’s SBDH status should be treated as a shifting, mutable variable in electronic systems. We also provide evidence that some changes in SBDH documentation likely reflect data quality issues and not actual changes in the patient state.

4.5 Study 3: Automated identification of social and behavioral determinants of health with structured and free-text clinical data

4.5.1 Introduction

Previous work on extracting social determinants of health from clinical data have typically employed Natural Language Processing (NLP) techniques, hypothesizing that this information is most reliably documented in clinical notes. NLP approaches, and in particular information extraction techniques, have been applied to different types of SBDH including smoking status(227–229), substance abuse(230–232), and homelessness.(14,212) Smoking status was the focus of the first i2b2 NLP shared task in 2008 and many NLP systems were subsequently developed to recognize the labels "past smoker", "current smoker", "non-smoker" in clinical text.(227–229) Several recent studies have focused on drug and alcohol abuse and have extracted status ("current", "past", "none") and relational modifiers including amount, type, and frequency.(230–232) In addition, the increasing recognition of homelessness as an important social determinant has catalyzed the development of systems capable of extracting this information from EHRs.(14,212) Extraction techniques that have been used include regular expressions, named entity recognition, and more contemporary distributional semantic techniques. Efforts aimed at using NLP to infer SBDH have generally achieved modest performance, reflecting the inherent challenges associated with processing clinical notes (e.g., lexical and semantic ambiguity) and challenges specific to inferring SBDH.(233,234) Most significantly, the language used to express SBDH is often institution-specific, limiting the usefulness of lexicons contained in clinical terminologies like the Unified Medical Language System (UMLS).(196)

While the majority of documentation related to SBDH exists in free-text notes (16), information on SBDH is also manifest in the structured data elements such as diagnosis codes and laboratory tests.(207,206,212) Multiple studies have observed that diagnosis codes have high specificity but poor sensitivity for SBDH including alcohol and drug abuse. Vest and colleagues recently observed that structured EHR data alone could be used to estimate a patient's need for social services. In addition, recent research suggests that there is correlation between SBDH (e.g. drug abusers more likely to lack stable housing) that could potentially be exploited to improve classification.(174) Pettey and colleauges used network projects of ICD codes to reveal patterns prior to documentation of homelessness; alcohol related diagnoses along with economic circumstances such as unemployment and legal circumstances frequently coincided with homelessness.(235) Two studies have observed healthcare utilization, behavioral health, substance abuse, and educational achievement to be important predictors of homelessness in clinical text.(196,236) Despite the potential utility of structured EHR data in systems for extracting social and behavioral determinants, no previous study has leveraged such data to improve the performance of supervised learning models.

4.5.2 Objectives

Our objective was to explore the automated inference of both the presence of SBDH documentation and individual SBDH risk factors in patient records. In addition, we sought to compare the relative ability of clinical notes and structured EHR data, such as laboratory measurements and diagnoses, to support inference.

4.5.3 Methods

For each of the 5 SBDH topics and 11 SBDH risk factors a discrete classifier was trained. To avoid any potential data leakage between training, validation and testing stages, each patient's data was included only once in the entire dataset. Their respective status was obtained from a single annotated clinical note, and the text contained within this note was the only unstructured input to classification models. A 30-day observation window prior to the annotated note was used to capture structured EHR data associated with each patient (see **Figure 4.4**).

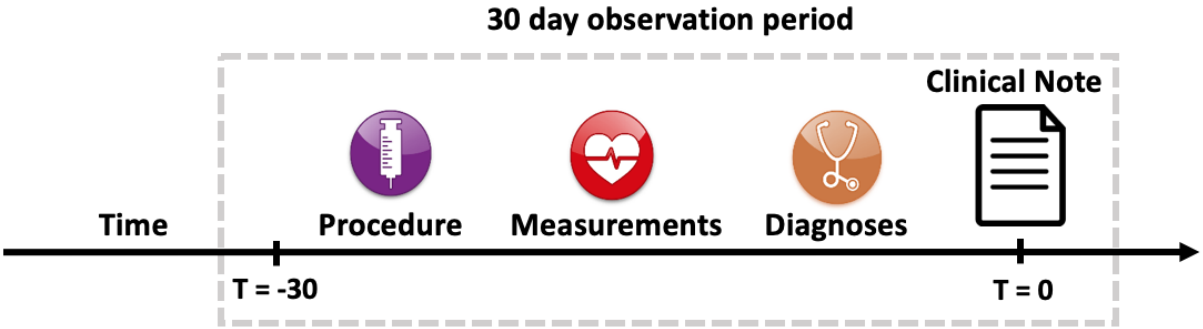


Figure 4.4 Prediction Task for SBDH labels

Unstructured Input

Clinical documents were represented as a bag-of-words using term frequency-inverse document frequency (tf-idf) weights. Preprocessing of documents comprised the following steps: (i) tokenize all documents, (ii) remove all non-alphabetical characters, (iii) remove general-domain stop words, and (iv) remove words that were observed fewer than 3 times. These steps yielded a vocabulary size of approximately 14,000 words.

Structured Input

For each patient, structured EHR data was aggregated from the 30-day period preceding the date of the patient's recorded SBDH status. We hypothesized such an extended observation period was necessary to collect enough structured EHR data to impact model performance. However, a longer observation period was not used due to the fact that a patient's SBDH status is liable to change overtime.

Diagnoses, procedures, laboratory tests, and demographics were collected from the institutional data warehouse, which has been mapped to the OMOP Common Data Model, a standard for storing healthcare data. We reduced each data table to contain only those observations that were collected between 0 and 30 days prior to the date the patient's SBDH status was observed (see **Figure 4.4**). Structured features were represented as a vector of counts for each vocabulary item (e.g. 2 occurrences of ICD9 code V08) associated with the patient in the 30 days prior to the index date. When structured and unstructured data was combined, we simply concatenated the features obtained from the notes and the structured EHR data described above.

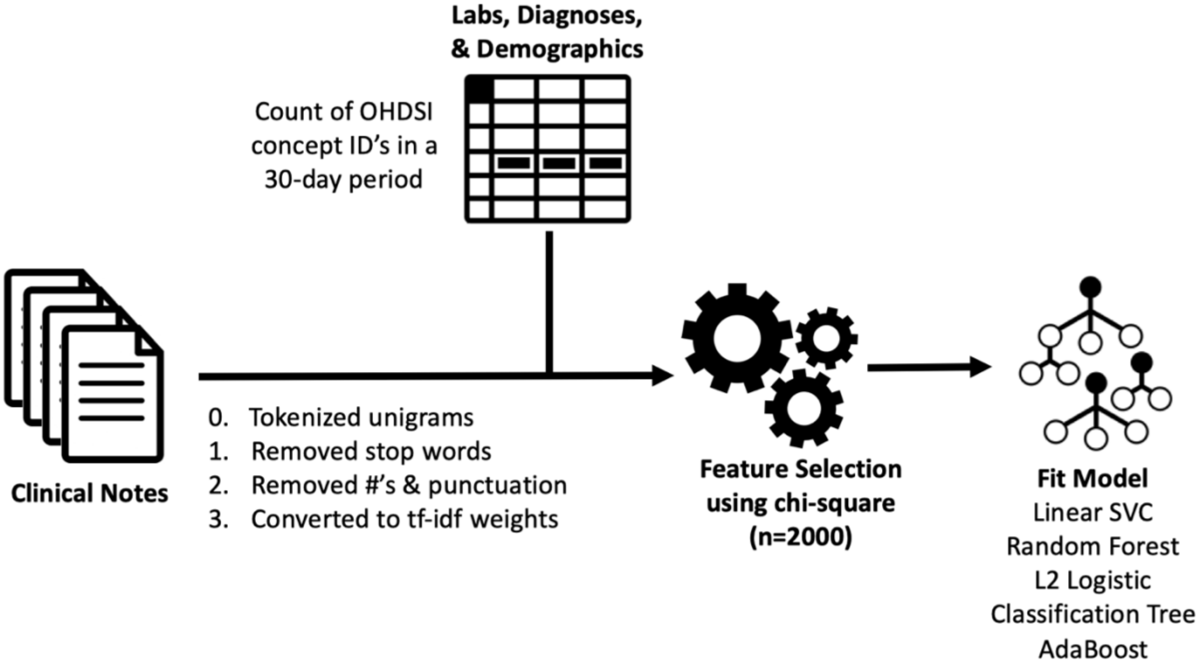


Figure 4.5 Overview of methods for machine learning

Training Classifiers

We used Scikit Learn to train a classifier for each of the 5 SBDH topics and 11 SBDH labels under three conditions (clinical notes alone, clinical notes + structured data, structured data alone). We experimented with a variety of classifiers including L2-penalized logistic regression, support vector machines, Random Forests, CaRT, and AdaBoost. Each model training leveraged chi-square feature selection, using 2000 features with the strongest univariate association with the classification target; this step improved performance and reduced model training time.

We found that in all cases either AdaBoost or CaRT yielded the best performance. In order to optimize performance of the AdaBoost classifiers, we empirically identified the optimal number of weak learners (AdaBoost's primary hyperparameter) and number of features retained using chi-square feature selection. We evaluated 30, 50, and 100 weak learners with 2000 and 4000 features selected using chi-square on a development set.

We also experimented with several deep learning models that have been previously shown to successfully leverage both structured and unstructured clinical data for classification tasks. We fit both feedforward and convolutional neural networks and performed hyperparameter search over learning rate, number of layers, and batch size. However, all neural networks yielded worse performance compared to the machine learning approach described above due to the small size of our training dataset.

Evaluation

Precision, recall, and F1 scores were computed across the SBDH models using 5-fold cross validation. We estimated the standard deviation associated with each metric by bootstrapping 200 classifiers for each SBDH on different samples and calculating the standard deviation of resultant scores. We also estimated feature importance by using the total decrease in node impurity attributed to a single feature, averaged over all trees in an AdaBoost ensemble classifier. The effect of label frequency on classification performance was estimated using

Spearman rank correlation between a classifier's F1 score and the number of positive labels available for model training.

In addition, we conducted an error analysis to gain insight into model performance for SBDH risk factors. This was performed by reviewing a random sample of 100 incorrectly labeled patients. First, incorrectly classified patients were labeled as either a true or false error, the latter being attributable to incorrect annotation. Second, we associated each true error with 1 or more of the following characteristics: 1) idiosyncratic language used to express SBDH, 2) unrecognized negation, 3) attribution (e.g. *"her mother is homeless"*), 4) historical phrases (*"he stopped drinking heavily in 2007 and now drinks approximately 1/month"*), 5) syntactic dependencies, 6) conflicting information, and 7) misspelling.

4.5.4 Results

4,663 notes associated with 1,501 patients treated at a large urban academic medical center were manually reviewed for mentions of SBDH. 76 notes were double annotated and a Kappa statistic of 0.736 was observed across all SBDH risk factors. The average age of persons in this cohort was 52.2 years old (sd. 12.9 years) with 916 males and 585 females. The number of patients with explicit mentions of specific SBDH ranged from 274 for cocaine abuse (most prevalent) to 36 for amphetamine abuse (least prevalent, **Table 4.3)**.

Classifier Performance

Classification results inferring the presence of topic-specific SBDH documentation ranged from F1: 92.7 for substance use to F1: 78.7 for sexual history. While in 3 of 5 cases, models with text and structured data yielded the best results, these differences were not statistically significant.

Table 4.2 Performance of models inferring presence of SBDH documentation among 1,501 patients using 5-fold cross validation

	Documented (Missing)	Structured EHR Features			Text Only			Structured EHR + Text		
		F1	P	R	F1	P	R	F1	P	R
Sexual History	807 (694)	64.6 ±1.7	60.4 ±2.1	71.6 ±2.2	78.6 ±1.4	80.3 ±1.9	77.1 ±2.0	78.7 ±1.8	80.0 ±2.3	77.4 ±1.9
Sexual Orientation	1059 (442)	65.3 ±1.9	74.8 ±2.7	73.4 ±2.8	85.3 ±1.7	86.0 ±2.6	84.9 ±2.9	86.1 ±1.8	86.0 ±2.6	86.4 ±2.5
Alcohol Use	1192 (309)	88.0 ±1.4	80.5 ±2.2	96.7 ±2.0	91.3 ±1.2	88.7 ±1.9	94.1 ±1.7	90.7 ±1.3	89.0 ±2.0	92.5 ±1.8
Substance Use	1262 (239)	90.8 ±1.3	90.5 ±2.0	94.6 ±1.7	92.5 ±1.0	90.5 ±1.7	94.6 ±1.5	92.7 ±1.1	90.7 ±1.8	94.8 ±1.6
Housing Status	1240 (261)	88.7 ±1.3	83.0 ±2.0	95.5 ±2.1	92.6 ±1.1	90.0 ±1.8	95.5 ±1.6	92.2 ±1.1	90.0 ±1.8	94.5 ±1.6
P = precision, R = recall, ± standard deviation estimated using bootstrap method										

The highest performing SBDH risk factor model was the classifier of LGBT status trained using heterogenous data (F1: 82.7), while the lowest performing model was the classifier for ‘intravenous drug abuse’ using structured data (F1: 28.5). In 10 of 11 cases, training models with both text and structured data yielded better results than models trained with either of those data sources alone. In contrast to other models, the classifier for ‘unsafe sex’ achieved best results when trained using only text data.

Features Used for SBDH Risk Factor Classification

Table 4.3 Performance of models inferring SBDH labels using 5-fold cross validation

	+/-	**Structured EHR Features**			**Text Only**			**Structured EHR + Text**		
		F1	P	R	F1	P	R	F1	P	R
Sexual History										
LGBT status	263/796	54.4 ±5.1	55.9 ±4.9	58.1 ±5.7	79.2 ±4.3	84.8 ±5.3	74.7 ±5.7	82.7 ±4.0	86.1 ±4.9	80.0 ±5.7
History of STIs	204/603	32.3 ±6.4	30.1 ±7.5	48.2 ±8.0	48.9 ±6.3	50.1 ±7.7	56.7 ±7.7	54.0 ±6.7	54.2 ±7.9	53.7 ±8.0
Unsafe Sex	160/647	21.1 ±6.4	21.3 ±7.5	35.0 ±7.4	43.8 ±6.3	52.1 ±7.7	38.9 ±7.7	38.5 ±6.5	46.0 ±7.5	35.8 ±8.0
Alcohol Use										
Social Alcohol Use	252/940	27.9 ±5.6	35.0 ±7.3	23.8 ±5.3	39.2 ±6.7	49.4 ±8.8	32.7 ±6.7	40.1 ±6.5	51.6 ±8.6	33.2 ±6.7
Alcoholism	165/1027	33.4 ±8.6	49.9 ±11.5	42.4 ±8.3	50.0 ±7.9	61.2 ±10.3	42.4 ±8.3	52.0 ±7.9	62.8 ±10.3	44.8 ±8.5
Substance Use										
Marijuana Use	210/1052	29.0 ±7.4	52.5 ±11.1	21.4 ±6.4	49.8 ±6.8	51.7 ±7.8	49.0 ±8.3	56.4 ±6.8	57.8 ±7.8	55.7 ±8.6
Cocaine Abuse	274/988	56.2 ±5.6	70.2 ±7.3	47.0 ±6.3	62.1 ±5.5	67.2 ±7.3	58.4 ±6.3	65.1 ±5.1	66.0 ±6.2	64.6 ±7.0
Opioid Abuse	99/1163	30.9 ±9.9	48.8 ±16.6	23.2 ±8.5	37.9 ±10.7	48.7 ±15.1	23.2 ±10.3	40.0 ±11.8	48.3 ±14.7	34.4 ±12.0
Intravenous Drug Abuse	65/1197	13.8 ±9.6	19.9 ±14.2	10.8 ±10.0	27.3 ±11.5	43.4 ±19.6	21.5 ±10.2	28.5 ±12.3	38.3 ±22.0	23.1 ±10.1
Amphetamine Abuse	36/1226	33.6 ±16.3	55.4 ±36.7	27.5 ±17.8	47.0 ±19.5	68.4 ±31.1	42.5 ±18.4	51.1 ±17.1	51.4 ±19.7	53.5 ±21.9
Housing Status										
Unstable Housing	262/978	27.4 ±5.6	35.0 ±6.0	23.6 ±6.4	49.3 ±6.4	59.4 ±7.8	42.3 ±7.5	53.1 ±6.4	62.2 ±5.8	46.9 ±7.2
P = precision, R = recall, ± standard deviation estimated using bootstrap method										

Textual features used by the classifiers included explicit indicators of SBDH as well as co-occurring determinants. For example, top features for the cocaine abuse classifiers included ‘cocaine’, ‘psa’ (for *polysubstance abuse*) and ‘heroin’.

While the majority of top features utilized by the heterogenous models were derived from text, models also included structured features. The top feature for the alcohol abuse classifier was SNOMED code 191811004 (‘continuous chronic alcoholism’), while codes 191918009 (‘nondependent cocaine abuse’) and 78267003 (‘cocaine abuse’) were among the top 10 features used by the cocaine abuse classifier. LOINC code 5393-4 (‘treponema pallidum Antibody test’) is a test for syphilis infection and was a leading indicator for having a ‘history of STIs’.

Several textual features were institution-specific or regional in nature. For example, the word ‘nicholas’ used in the homelessness classifier likely refers to a homeless shelter in New York City. In addition, ‘hasa’ represents the HIV/AIDS Services Administration, a governmental organization in New York that provides housing for persons with HIV.

Label Frequency

We also tested the impact of the prevalence of each SBDH on the performance of the classification models (see **Figure 4.6**). A comparison between the number of positive cases used to train each classifier and the resulting performance of that classifier yielded a correlation coefficient of 0.762 (p = 0.0059). Amphetamine abuse seemingly invalidated the trend, as the classifier only had 36 positive cases available but achieved a modest F1 score of 51.1.

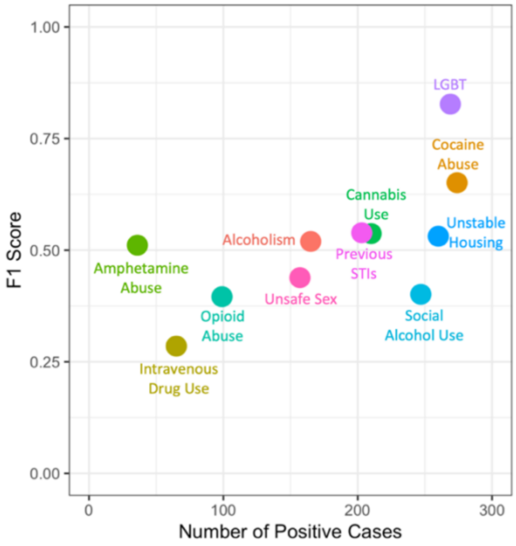


Figure 4.6 Relationship between SBDH prevalence and classifier performance

Error Analysis

Among 100 randomly sampled incorrect classifications, 18 errors were attributed to historical phrases, such as *"hx of cocaine snorting quit 18 years ago"*. 17 were attributed to short- and long-term syntactic dependencies such as *"reports very large amounts of alcohol consumption, iv heroin, and cocaine use"*. Unrecognized negation was associated with 15 errors (e.g., *"has not had etoh intake in over twenty years"*), and lexical diversity accounted for 13 errors (e.g., *"actively smokes crack"*) that reflected use of idiosyncratic language by clinicians. Three errors reflected misspellings (e.g., *"former iv cocaine and heroine use"*), and two errors reflected conflicting information in the note (e.g. *"his wife was present during the interview...in private [patient] reported sex with men"*). Four errors were in fact correct and attributed to inaccurate annotations.

4.5.5 Discussion

Our findings suggest that the identification of topic-specific SBDH documentation and individual SBDH risk factors can be improved by leveraging both structured EHR data and clinical notes. We also provide evidence that model performance is correlated with the lexical diversity used by clinicians to document a given SBDH and the prevalence of a given SBDH within a patient population.

The presence of topic-specific SBDH documentation in the patient record was inferred using classification models. A 2014 report published by the Institute of Medicine brought attention to the importance of collecting SBDH information in electronic health records, as well as the fact that such information is sporadically collected in patient records.(237,238) The acceptable performance of classification models trained to infer presence of SBDH documentation suggests that IT systems could alert providers when certain SBDH topics are undocumented in the patient record, thereby supporting the development of quality initiatives to improve provider's documentation of SBDH. Such an approach could increase the specificity of EHR prompts alerting clinicians to collect SBDH information, which have been previously deployed in clinic settings.(239,240)

The combination of free-text and structured data yielded better performance than either data source alone when inferring SBDH risk factors. These findings are corroborated by recent studies that combined textual features with diagnoses and laboratory data and observed improved phenotyping and prediction compared to using those sources alone. Several of these techniques have found improved performance by preprocessing textual data with topic modeling(241,242) and structured data with autoencoders.(243) More recently, deep neural networks have been used to leverage heterogenous clinical data for prediction, although our findings demonstrate that these methods require much larger datasets then are currently available in the SBDH domain.(244,245)

We observed a positive correlation between model performance and the prevalence of each specific SBDH. This suggests that similar modeling approaches should generate gold-standard corpora of an adequate size, especially for infrequently documented SBDH such as those related to sexual activity.(13) However, the 'amphetamine use' and 'LGBT' classifiers outperformed SBDH models for labels with similar prevalence, likely reflecting the limited lexical diversity used to express these SBDH. For example, amphetamine use was often referenced by 'meth' or 'methamphetamine' and most LGBT patients in our cohort were gay men who were characterized as 'msm' or 'men who have sex with men'.

The results of our error analysis suggest several areas for improvement in automated SBDH inference. The inability of the SBDH classifiers to detect syntactic dependencies and historical phrases is unsurprising given our use of a simple bag-of-words approach to extracting information from clinical text. In addition, several of the SBDH were associated with high lexical diversity, suggesting that clinicians lack a standardized way for expressing those SBDH. While contemporary methods that leverage distributional semantics and use neural networks to model temporal sequences can overcome such challenges, these methods require very large datasets that are difficult to curate in the medical domain.(13,246) Transfer learning – which entails pre-training a neural network on a large, related dataset and subsequently 'fine-tuning' the network on a smaller dataset – has the potential to overcome the aforementioned barriers posed by the challenge of collecting large annotated corpora.(247,248)

4.5.6 Limitations

First, our SBDH classifiers were trained using data from a single institution. However, our use of the OMOP Common Data Model enables generalizability of our trained models to other institutions. Second, our overall modest results may have resulted from data quality issues in the documentation of SBDH and/or inaccurate annotation. Third, most approaches cast this problem as a named-entity recognition task but because we approach the problem as a document labeling task, our experimental setup does not allow for direct comparison to previous work. Fourth, our model performance may have been improved by considering negation or by correcting misspellings in text. Fifth, a considerable number of the patients whose records were used to train the classification models were HIV+ and receive regular healthcare from infectious disease specialists. The records of these patients likely differ from patients who have not been tested or HIV or are currently HIV negative, potentially compromising the generalizability of the classification models. Sixth, we did not use a 'holdout' dataset that was never used in model training; we simply did not have the requisite volume of data to create training, validation, and test sets and thus the observed model performance may be inflated.

4.5.6 Conclusion

We observed that the presence of SBDH documentation can be automatically inferred from the patient record, motivating the development of EHR prompts to improve the quality of provider documentation of SBDH. In addition, our findings suggest that while automated inference of patient SBDH status is challenging, the combination of text and structured EHR data improves performance compared to either data source alone. The study findings suggest that SBDH prevalence and the lexical diversity used to express a given determinant have an impact on the performance of classification algorithms for this purpose. Future studies should explore computational methods that can effectively learn models using datasets of limited size.

Chapter 5: Using Visualization to Improve the Situational Awareness of Clinicians in Chronic Disease Care

5.1 Background & Significance

A fundamental shift in medical care in the 21st century is the increased responsibility of healthcare providers for the health outcomes of the patients for whom they are responsible. Initiatives and incentives from governmental agencies and healthcare payers termed ‘pay-for-performance’ or ‘value-based care’ have resulted in efforts by providers and health systems to more actively participate in their patient’s care.(90) As a result, the adoption of innovative care models wherein clinical staff longitudinally monitor patients has been growing. For example, contemporary oncology care involves nurses who remotely monitor patients for adverse reactions to chemotherapy.(249,250) Primary care providers contact patients when they lack basic preventative care like cancer screening or immunizations. Chronic disease programs employ legions of case managers who contact patients whenever incomplete medication adherence endangers their health.(19,23) In an attempt to prevent readmissions, hospitals employ ‘discharge nurses’ to systematically follow-up with patients post-discharge.(251) The aforementioned care models all require that clinicians maintain continuous awareness of their patients and their respective health statuses.

The population monitoring process discussed above is most commonly performed using patient registries, IT tools that list disease outcomes and gaps in preventative care for a defined patient panel.(11,21) Studies have found that registries do not satisfy all needs related to population monitoring(25) and that clinicians often invent ‘homegrown’ tools such as paper-based lists and Excel spreadsheets to supplement patient registries.(4,22–24) As a result, there is a need for the development of tools that can satisfy clinician's needs related to population monitoring. The research associated with Aim 3 attempts to design an interactive system capable of supporting HIV care management, an example of a clinical domain where healthcare providers must monitor patients to ensure that they are adherent to HIV antiretroviral therapy to prevent AIDS-related morbidity and mortality.(252)

5.2 Research Questions

Research Question: How can provider awareness of patients within chronic disease populations be improved?

Hypothesis: Provider awareness of patients within chronic disease populations can be improved with data visualization and user-controlled prioritization

5.3 Study 1: Using interactive visualization to improve population monitoring in chronic disease care

5.3.1 Introduction

Increasingly, information visualization is being considered as a means to support healthcare providers who utilize large volumes of clinical data.(26–28) The healthcare settings that have been shown to from data visualization are quite diverse; examples include Intensive Care Units, where dashboards which aggregate and visualize data from physiologic monitoring systems and can ameliorate cognitive load and prevent medical errors.(139,180,253) Alternatively, hospitals and emergency departments have deployed visual dashboards that identify hospitalized patients at high-risk of adverse drug events (137,140,254) and disease exacerbations (138,141), as well as “electronic whiteboards”(133) that visualize all admitted ED patients and their dispositions but have had limited adoption due to limitations in information timeliness, quality of data and lack of customization for different user groups.(134,135)

We hypothesize that information visualization applied to a provider’s patient panel can improve the ability of clinicians to successfully perform tasks related to population monitoring. Using the theory of situational awareness to illustrate the process of population monitoring, we design and evaluate an interactive tool that uses visualization to support the identification of population-wide needs and patients requiring care. Our specific focus is on the management of persons living with HIV – a clinical setting where providers manage large patient panels and are required to intervene on patients with complex needs.

5.3.2 Methods

First, we conducted an exploratory study by interviewing and observing more than 22 clinicians (including doctors, nurses, and social workers) to better understand IT needs related to caring for large populations of HIV patients. The data collection process is described in detail in section 3.3 of this dissertation. Second, we adapted the theory of situational awareness to develop a conceptual framework of population monitoring that informed user needs, design requirements, and evaluation criteria. The development of this framework is detailed in section 3.4 of this dissertation. Third, we conducted user-centered design to develop PanelViz. Fourth, we evaluated the impact of the visualization tool on provider's situational awareness in a controlled laboratory experiment.

Participatory Design & Tool Development

The design of PanelViz was informed by the design requirements identified through the exploratory research and conceptual framework described in sections 3.3 and 3.4, respectively. Seven physicians with experience in HIV primary care took part in design sessions. During these sessions, physicians were presented with functioning prototypes that contained synthetic patient data and were asked to navigate the tool and identify patients they considered to be high-risk. These sessions continued until the design of the tool was finalized. The development of the tool, called PanelViz, was achieved using the *shiny* and *DT* libraries in R version 3.5.3.

Controlled Experimental Evaluation

We employed a within-subjects study design in a laboratory setting to compare the ability of PanelViz and patient registries to support the user needs enumerated in **Table 5.4**. For the controlled experimental evaluation, the primary evaluation criteria was whether participants could successfully complete a series of tasks that corresponded to the aforementioned user needs. Each task was developed by reviewing qualitative data generated through the exploratory interviews and observations (section 3.3) to identify the clinician's stated information needs.

The secondary evaluation criteria was perceived utility of each interface as assessed by the Health Information Technology Usability Evaluation Scale (Health-ITUES). Health-ITUES is a validated survey instrument that assesses whether a user expects that a health IT system will provide adequate support for performing a given task. Because the survey instrument is customizable, it was adapted to reflect the specific user needs explored in this study while still enabling harmonization of findings across studies in disparate application settings. Qualitative data was also collected to provide a rich description of clinician's experience with both PanelViz and the patient registry used in the study. 5-minute semi-structured interviewers were performed after the conclusion of the study to assess participant's tool preference and receive feedback on the perceived utility of tool features.

Participants

All participants were employed by the HIV ambulatory care program at Columbia University Irving Medical Center (CUIMC) and recruited via the professional network of the study team. The inclusion criteria for study participants required that participants had at least 1 year experience managing HIV+ patients in a primary care setting. Participating clinicians received $20 in compensation for the 60 minutes required to complete the study. All participants provided written consent and study procedures were approved by the Institutional Review Board of CUIMC.

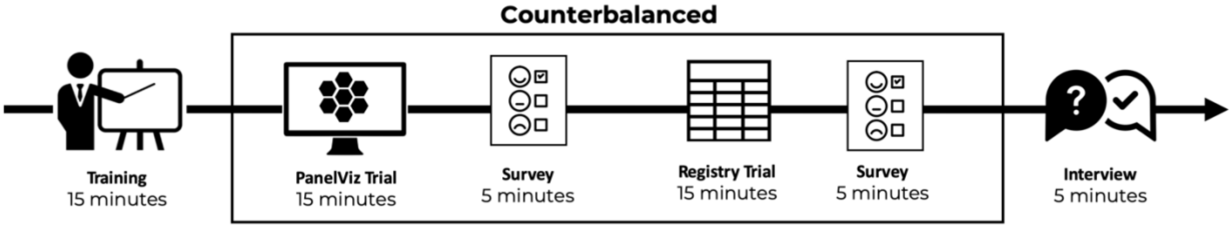


Figure 1. Study Procedures

Procedures

An outline of study procedures is presented in **Figure 5.1.** All participants first received a 15-minute training in the usage of PanelViz and the baseline system. The training period consisted of a 5-minute video tutorial on using the interfaces and a subsequent 10-minute period available for interacting with both tools using a synthetic dataset of randomly generated patient data. Study staff were available to answer any questions about tool functionality posed by participants during the training period.

During each of the two study trials, participants had 15 minutes to examine a dataset with a simulated patient panel containing 500 patients and complete 7 tasks, each of which are listed in **Table 5.1.** Each task is reflective of information needs identified in exploratory user research. The tasks were reviewed by 2 HIV Medical Directors to ensure the ecological validity of the tasks and remove any unanticipated ambiguities. Participant's responses varied according to each task; some tasks required participants to identify one or more patients that met some criteria, while others asked about the status of a specific care gap or properties of the dataset such as the proportion of patients who met some criteria. While participants explored different datasets when using each interface, the tasks performed were identical across the trials.

The order of in which the tools were presented was *counter-balanced*, which ensured that exactly half of study participants used the registry interface in their 1st trial, and that the other half used PanelViz in their 1st trial. Participants were provided with pen and paper and instructed to record their responses the tasks. Audio and the participant's screens were recorded for the duration of each study trial using Quicktime.

Table 5.1 Situational awareness constructs and corresponding study tasks

	Construct	Definition	Task
Patient-Level Situational Awareness	Perception	Perception of a patient’s medical and psychosocial problems	Identify all medical and psychosocial problems for [randomly selected patient].
	Comprehension	Comprehension of the modifiable behaviors that prevent a patient’s disease management	Identify a patient who exhibits lack of viral load suppression together with alcoholism and drug abuse.
	Projection	Projection of the intervention most likely to resolve a patient’s medical problems	N/A
Population-Level Situational Awareness	Perception	Awareness of all patients with medical and psychosocial problems in a provider’s patient panel	Which of the following medical problems is more common: cardiovascular disease or chronic kidney disease? Which of the following is more common among patients who are virally unsuppressed: drug use or alcoholism?
	Comprehension	Comprehension of each patient’s relative priority in a provider’s patient panel	Select 5 or more medical or psychosocial problems to identify high priority patients and estimate the proportion of patients with 3 or more selected problems.
	Projection	Projection of the patients most likely to benefit from intervention in a provider’s patient panel	N/A

Following each of the two 15-minute trials, a member of the research team administered the Health Information Technology Usability Evaluation Scale (Health-ITUES). The adapted Health-ITUES used for this study is presented in **Table 5.3**. The survey consisted of 20 items on a Likert scale with five levels from strongly disagree (1) to strongly agree (5); a higher scale indicates higher perceived usability. We administered all component subscales of the Health-

ITUES, which include (1) quality of work life, (2) perceived usefulness, (3) perceived ease of use, and (4) user control.

At the conclusion of the second study trial, a member of the study staff conducted a 5-minute semi-structured interview with each participant. Participant's verbal statements were audio recorded and transcribed verbatim. Each participant was asked the following three questions:

1. Do you feel that in your clinical practice you can adequately perform the 5 study tasks?
2. Which of the two software tools did you prefer? Please explain your reasoning.
3. What were the strengths of the visualization tool? What were the weaknesses?
4. What were the strengths of the patient registry tool? What were the weaknesses?

Dataset

We created two datasets that each contained 500 HIV+ patients and 18 care indicators identified as critical for HIV care management. We first identified a population of 500 actual HIV+ patients within CUIMC's electronic health record (EHR) system using the criteria of 2 HIV diagnosis codes accompanying a routine ambulatory visit between 2016 and 2019.(255) Second, we obtained demographic, diagnosis, laboratory, and procedure data from the EHR to ascertain each patient's status of the 18 care indicators listed in **Table 5.2** below, which was distributed to study participants. A unique set of 500 synthetic patient names was created for each dataset to protect confidentiality.

Table 5.2 Data dictionary provided to study participants

Data Dictionary

Behavioral Health (past 12 months)
Alcohol Abuse: diagnosis code for dependent abuse of alcohol
Drug Abuse: diagnosis code for dependent or nondependent abuse of cocaine, opiates, or amphetamines
Depression: diagnosis code for ‘major depression’
Anxiety: diagnosis code for ‘anxiety disorder’

Social Determinants
Unstable Housing: diagnosis code for ‘unstable housing’ or ‘homelessness’

Medical Conditions (past 12 months)
New HIV Diagnosis: lab tests & diagnosis codes indicative of recent HIV diagnosis
Schizophrenia: diagnosis code for schizophrenia or related psychoses
Hypertension: diagnosis code for ‘essential hypertension’
Chronic HCV: diagnosis code for chronic hepatitis C
Cardiovascular Disease: diagnosis codes with congestive heart failure or coronary artery disease
Chronic Kidney Disease: diagnosis code of chronic kidney disease
Diabetes: diagnosis code of diabetes mellitus

Laboratory Tests (most recent result)
Virally Suppressed
Most recent HbA1c value
Most recent CD4 count

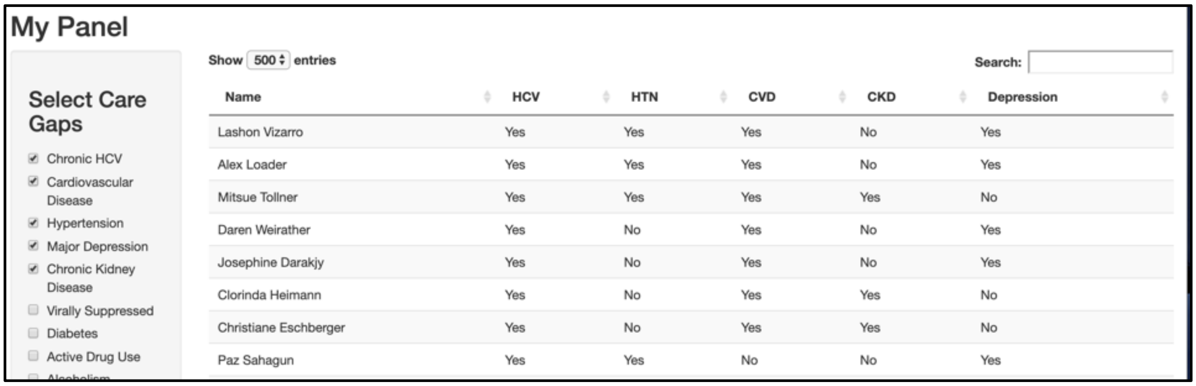
Healthcare Utilization (past 12 months)
 # Office visits: number of outpatient ‘evaluation & monitoring’ visits
 # Emergency Room visits: number of emergency department visits
 # Inpatient admissions: number of inpatient admissions

The study design required that each dataset have different characteristics so that the answers to each study task outlined in **Table 5.1** were different across the two study conditions. As a result, the care indicators extracted from the EHR were manipulated so that the prevalence of each indicator diverged at least 20% across datasets (e.g. 40% drug abuse in dataset 1 vs. 20% drug abuse in dataset 2). This two-part process; wherein we first obtained authentic EHR data and then modified each care indicator, was important to ensure that the joint distribution of care gaps was realistic; for example, study participants would have been disoriented if the proportion of patients achieving HIV viral load suppression was similar in patients with positive and negative ‘drug abuse’ care indicators, as persons with substance abuse disorders are much less likely to achieve viral load suppression.(41,160)

In the dataset used for the trials involving PanelViz, the following indicators were modified: alcohol abuse, depression, unstable housing, schizophrenia, chronic HCV, chronic kidney disease, viral load suppression, most recent CD4 count, office visits, and inpatient admissions. Drug abuse, anxiety, new HIV diagnosis, hypertension, cardiovascular disease, diabetes, HbA1c value, and emergency room visits were modified in the dataset used for the patient registry trials.

Baseline System

This baseline system simulated a typical patient registry and is presented in **Figure 5.2**. This tool is analogous to the patient registries currently used across disease management programs and displays patients with unmet care needs in a tabular format. Users were able to select care gaps using the toolbar on the left to add or remove care indicators from the tabular visualization. Users could also sort the order in which patients are listed by reordering the care indicators; this was a ‘deterministic sorting’ which sorted the entire table on the first selected



☑ Chronic HCV
☑ Cardiovascular Disease
☑ Hypertension
☑ Major Depression
☑ Chronic Kidney Disease
☐ Virally Suppressed
☐ Diabetes
☐ Active Drug Use
☐ Alcoholism

Name	HCV	HTN	CVD	CKD	Depression
Lashon Vizarro	Yes	Yes	Yes	No	Yes
Alex Loader	Yes	Yes	Yes	No	Yes
Mitsue Tollner	Yes	Yes	Yes	Yes	No
Daren Weirather	Yes	No	Yes	No	Yes
Josephine Darakjy	Yes	No	Yes	No	Yes
Clorinda Heimann	Yes	No	Yes	Yes	No
Christiane Eschberger	Yes	No	Yes	Yes	No
Paz Sahagun	Yes	Yes	No	No	Yes

Figure 5.2 Patient Registry ('Baseline')

indicator and then used subsequent indicators to further sort while retaining the order imposed by the first indicator. An example of this sorting can be seen in **Figure 5.2**. A functioning version of this interface can be found at https://djf2150.shinyapps.io/consolidated_registry/.

Evaluation

We evaluated the impact of PanelViz on a) the accuracy of participant's responses, and b) perceived utility of each interface for population monitoring.

Participant's responses were considered accurate when the response accurately described the dataset used by the interface being tested. For task 1, an accurate response consisted of a complete list of the correct care gaps for the randomly selected patient, while for task 2 an accurate response was the name of any single patient who was virally unsuppressed and abusing both drugs and alcohol. For task 3, the correct response was the medical problem with the highest prevalence among patients in the dataset. For task 4, the correct response was the whichever substance abuse problem (drug abuse or alcoholism) had the highest prevalence among patients with unsuppressed viral load in the dataset. An accurate response for task 5, an accurate response was any estimate within 10% of the correct proportion of patients associated with 3 or more of the care gaps chosen by the participant. The subject matter experts asserted that 10% was a reasonable margin of error when estimating the population prevalence of high-

Table 5.3 Adapted Health-ITUES survey

Item		**Concept**
Quality of Work Life		
1	I think PanelViz* will be a positive addition to the delivery of HIV care.	System impact-career mission
2	I think PanelViz would improve the quality of care for persons living with HIV.	System impact-organizational level
3	PanelViz will become an important part of my clinical practice related to population monitoring.	System impact-personal level
Perceived Usefulness		
4	Using PanelViz makes it easier to identify high-risk patients under my care.	Productiveness
5	Using PanelViz enables me to identify high-risk patients under my care more quickly.	Productiveness
6	Using PanelViz makes it more likely that I will not lack awareness of high-risk patients under my care.	Productiveness
7	PanelViz is useful for identifying identify high-risk patients under my care.	General usefulness
8	I think PanelViz presents a more equitable process that will allow all providers to identify high-risk patients under their care.	General usefulness
9	I am satisfied with PanelViz for identifying high-risk patients under my care.	General satisfaction
10	I can identify and address high-risk patients under my care in a timely manner because of PanelViz.	Performance speed
11	Using PanelViz increases the number high-risk patients under my care I was aware of.	Productiveness
12	I think that I will be able to identify high-risk patients under my care whenever I use PanelViz.	Information needs
Perceived Ease of Use (Cronbach α= .95)		
13	I am comfortable with my ability to use PanelViz.	Competency
14	Learning to operate PanelViz is easy for me.	Learnability
15	It is easy for me to become skillful at using PanelViz.	Competency
16	I find PanelViz easy to use.	Ease of use
17	I can always remember how to log on to and use PanelViz.	Memorability
PanelViz was modified to 'registry' when administering survey are patient registry trials		

priority patients.

The perceived utility of each interface was assessed by each study participant using the validated Health-ITUES survey instrument. The adapted survey is presented in **Table 5.3** and was adapted to the application of HIV care management using the theoretical framework described in section 4.3 and user needs described in section 5.3. The overall Health-ITUES score for each survey was the mean of all survey items with each item weighted equally. Hypothesis testing was performed using paired t-tests.

The analysis of the interview transcripts was conducting using inductive thematic analysis using the NVivo software. First, the authors generated initial codes by summarizing the interview data on a more abstract level. Second, the authors performed axial coding to generate higher-level themes. Thirds, the authors concluded the analysis by assessing whether the interview data aligned with the final themes. Study staff were blinded to metadata associated with each statement.

5.3.3 Results

IT Needs Related to Population Monitoring

22 interviews in 2 HIV primary care programs revealed that monitoring and tracking patient populations required the development of novel strategies that could only be partially supported by existing health IT. First, critical patient problems were at times unbeknownst to clinicians and interviewees, leading multiple staff to conclude that additional health IT could potentially help surface undetected patient problems. In particular, patient information on mental health and social behavioral determinants such as unstable housing were perceived as being important for care delivery but challenging to extract from the patient record. Second, staff reported being overwhelmed by the volume of information across their six distinct patient registries and requested functionality that could consolidate multiple registries would reduce information overload. Third, participants explicitly requested the implementation of additional decision-support resources. Several clinicians in clinic 1 familiar with predictive modeling perceived that the prediction of adverse events would enable them to provide better care. One social worker asserted that understanding trends in depression or anxiety severity could help

prevent adverse health outcomes, while multiple physicians reported that predicting outcomes related to HIV prevention and treatment would help them target resources more efficiently

Participating clinicians disclosed that they attempted to overcome the limitations of existing health IT by creating homegrown tools that enabled them to monitor large group of patients. These tools constituted simple patient lists that served as cognitive aids to help providers maintain awareness of their patients and were stored in various media, including hospital-owned mobile phones, paper notebooks, and Excel spreadsheets. While all lists contained at a minimum the names of patients, most also contained a succinct summary of key medical and psychosocial issues. Some providers used these lists as visual aids; one care coordinator used color-coding to highlight patients in need of a follow-up based on patient acuity.

Theoretical Framework

We developed a conceptual framework to inform the design and evaluation of a tool for monitoring patient populations. Our adaptation of the theory of situational awareness delineates two levels of abstraction; patient- and population-level situational awareness and is presented in **Figure 3.1**. Patient-level SA requires perception of relevant care gaps and psychosocial issues, comprehension of the urgency of a patient’s status, and projection of the impact of a potential intervention on patient outcomes. Population-level SA requires perception of those patients with care gaps and psychosocial issues, comprehension of the relative priority of patients within a given population, and the ability to project which high-priority patients are likely to benefit from intervention. Finally, a critical part of the framework is the role of the role of expectations and mental models in directing attention to relevant information and comprehending its meaning. User needs as conceptualized using SA are presented in **Table 5.4**.

Table 5.4 Situational awareness constructs, user needs, and design requirements

	Construct	Definition	User Need	Design Requirement
Patient-Level Situational Awareness	Perception	Perception of a patient’s medical and psychosocial problems	Maintain awareness of each patient’s medical and psychosocial problems	Display each patient’s medical and psychosocial problems
	Comprehension	Comprehension of the modifiable behaviors that prevent a patient’s disease management	Identify the modifiable behaviors that prevent a patient’s disease management	
	Projection	Projection of the intervention most likely to resolve a patient’s medical problems	Identify the intervention most likely to resolve a patient’s medical problems	Recommend interventions that will resolve a patient’s medical problems
Population-Level Situational Awareness	Perception	Awareness of all patients with medical and psychosocial problems in a provider’s patient panel	Identify all patients with medical and psychosocial problems under a user’s care	Present all patients with medical and psychosocial problems under a user’s care
	Comprehension	Comprehension of each patient’s relative priority in a provider’s patient panel	Identify the patients with highest priority under a user’s care	Sort patients according to their priority as assessed by the user
	Projection	Projection of the patients most likely to benefit from intervention in a provider’s patient panel	Identify the patients most likely to benefit from intervention under a user’s care	Recommend patients likely to benefit from intervention

Using situational awareness in the design process is helpful also because there is a precedent for using it effectively to inform the development of software interfaces.(105,110,111)

Design Requirements

We enumerate six design requirements that were generated using the conceptual framework described above and are presented in **Table 5.4**. We also discuss potential approaches to satisfying these requirements.

1. Display each patient's medical and psychosocial problems

Providers monitoring their patients require information on the care required by each patient. This informs their understanding of the care gaps that must be resolved for a given patient and their interpretation of the impact of SBDH, which can be perilous for patients with chronic disease. There are several paradigms for presenting a collection of patient data to clinicians including extractive summaries[56,57] (expert selected variables organized in tables) and abstractive summaries(258–260) (patient problems inferred from structured & unstructured data).

2. Recommend interventions that will resolve a patient's medical problems

The clinicians interviewed reported that it was difficult to match patients to the appropriate intervention; this often reflected a failure to ascertain the 'root cause' of a patient's poor disease management. IT tools should support efficient retrieval of information on common barriers to treatment such as SBDH including substance abuse and unstable housing.(41,160–164) Interactive tools that enable clinicians to design care pathways based on established interventions for SBDH may be useful.(165–168)

3. Present all patients with medical and psychosocial problems under a user's care

Healthcare providers have recency biases that may prevent them considering patients with whom they have had no recent interactions (261), and many providers we interviewed reported being concerned that patients often 'fell-off-the-radar'. This may be ameliorated by providing a visualization of all patients on a clinician's panel. Zhou et. al.'s Panel Support Tool used tables to present a provider's panel and but required users to scroll through many pages to view all patients.(89,262) Although they present data on much fewer individuals, learning analytics systems use visualizations wherein each student is represented by a marker on a plot, thereby enabling all students to be presented on a single page.(103,104) Any visual solution in healthcare would have to be respectful of the graph literacy of healthcare providers, potentially limiting the possibilities for patient visualization.(142)

4. Recommend patients likely to benefit from intervention

Prioritization of patients who require enhanced attention is a growing need among clinicians in primary care settings who have 500 or more patients on their panel. In a tabular visualization, prioritization could be operationalized by enabling users to filter out data to focus only on high-priority patients or sort the data such that high-priority patients occupy the most immediate visual space. In other visualization modalities such as heatmaps, users could adjust their field-of-view to either a detail view (only presenting high-priority patients) or a fisheye view, which provides both a detail view and overview without obscuring any single patient.

Users must have control over the mechanism by which patients are sorted. This reflects the fact that clinic staff with distinct patient care responsibilities are required to identify ‘high-priority’ patients who likely have different characteristics based on whether the user is a behavioral health provider or an internal medicine physician, for example.(262) In addition, studies have observed that clinicians are mistrustful of automated stratification and that human review is a critical aspect of risk stratification.(82,263) By using a ‘doctor-in-the-loop’ approach to patient prioritization, tools can satisfy both the diverging needs of clinic staff with distinct patient care responsibilities and clinician’s requirement for controllable risk-stratification. In addition, the importance of goal-directed processing in situational awareness means that a user’s prioritization criteria may change in response to events such as a clinical quality initiative that places transient emphasis on specific care indicators.

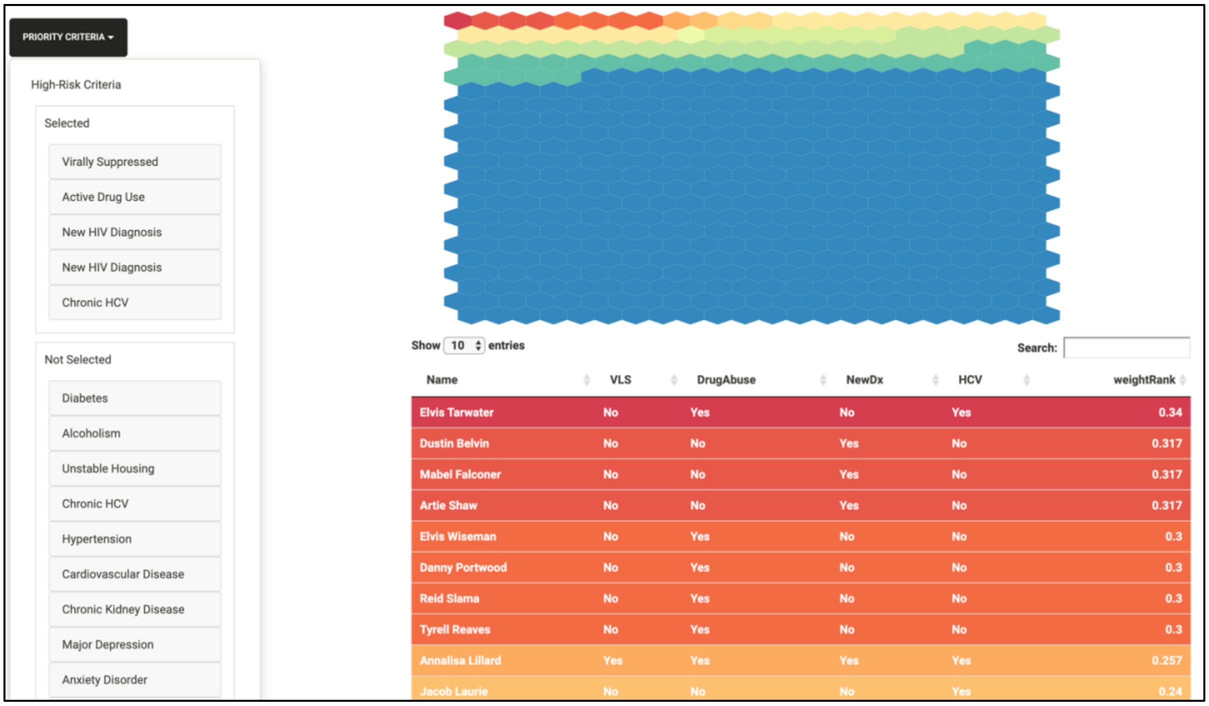
In the conceptual framework presented in **Figure 3.1**, providers must understand the relative proportion of patients considered ‘high-risk’. In the case that a large proportion of patients are high-risk, the prioritization criteria might be refined so that staff have a manageable workload for patient outreach, while if too few patients are considered high-risk then the prioritization criteria will be expanded so that more patients can receive much needed supportive services.

5. Highlight the patients most likely to benefit from intervention

In resource limited settings, providers attempt to target interventions to patients who are most likely to benefit. Clinicians we spoke with primarily used evidence of suboptimal past engagement in care as indicators that a patient was unlikely to be receptive or engage fully with a care management intervention. Tools to support such targeting could provide a succinct summary of a patient’s past engagement in care. Alternatively, recent studies have demonstrated the ability of machine learning models to successfully identify a patient’s ‘propensity to succeed’ in a care management intervention.(172–174) As a result, future IT tools could integrate such predictions.

Architecture of PanelViz

10 design sessions were conducted with 7 clinicians with more than 100 years combined experience managing patients with HIV. The earliest iterations of the PanelViz tool consisted of a tabular visualization similar to patient registries that used color-coding to draw user's attention to care gaps and high-risk patients. However, presenting 500 patients in a tabular visualization required users to scroll through many pages to view all patients and would require additional charts to satisfy design requirement #6. When showed a mockup of a colored hexagon, users found it easy to both identify high-risk patients and quickly estimate the number of high-risk patients on their panel. Below we describe the architecture of the final prototype.



Name	VLS	DrugAbuse	NewDx	HCV	weightRank
Elvis Tarwater	No	Yes	No	Yes	0.34
Dustin Belvin	No	No	Yes	No	0.317
Mabel Falconer	No	No	Yes	No	0.317
Artie Shaw	No	No	Yes	No	0.317
Elvis Wiseman	No	Yes	No	No	0.3
Danny Portwood	No	Yes	No	No	0.3
Reid Slama	No	Yes	No	No	0.3
Tyrell Reaves	No	Yes	No	No	0.3
Annalisa Lillard	Yes	Yes	Yes	Yes	0.257
Jacob Laurie	No	No	No	Yes	0.24

Figure 5.3 PanelViz Interface

The PanelViz tool was designed to support visualization of a provider's entire patient panel and yields awareness of absolute panel size and the relative number of high-risk patients (**Figure 5.3**). A functioning prototype of the tool can be found here: https://djf2150.shinyapps.io/panelViz/. Each hexagon in the heatmap represents 1 patient and the color of each hexagon denotes each patient's priority score; red indicates 'high risk' and green/blue indicates ‘low risk’. The spatial configuration of the hexagons are arranged in order of decreasing priority. Users can retrieve patient-level information by hovering the mouse over a given hexagon; patient-level information on selected care gaps will then appear inside the information box on the righthand side of the interface.

Users can manipulate the patient prioritization criteria by toggling the dropdown menu which enables selection and sorting of prioritization criteria. The priority score of each patient changes dynamically as users manipulate the prioritization criteria. PanelViz uses a linear equation to incorporate all selected care gaps into a single priority score for each patient. This is accomplished using the multi-attribute global inference of quality (MAGIQ) technique, which only requires decision makers to rank their selected decision criteria (care gaps) according to their perceived importance. These selected rank order of the care gaps are automatically converted into attribute weights using rank order centroids, a value representing the distance between adjacent ranks on a normalized scale between 0 and 1.(85) All care gap variables are then normalized to values between 0 and 1 and multiplied by their corresponding attribute weight.

The interactive visualization satisfies four of the six aforementioned design requirements. Requirement #1 is achieved by enabling users to highlight each patient’s medical and psychosocial status either by searching for the patient in the data table or by moving their mouse over a hexagon. The hexagon plot satisfies requirement #4 because of its ability to present a large amount of data in a small visual space; the plot in **Figure 5.3** contains approximately 500 patients, which is a typical panel size in HIV primary care. Requirement #5 is achieved by using color-coding to indicate a patient’s relative priority and interactive prioritization controlled by users. Users can select and sort prioritization criteria using the dropdown at the left of the hexagon plot; this triggers an immediate change in patient prioritization across the panel. Because of the breadth of its field of view, the hexagon plot enables providers to make a rapid assessment of the proportion of patients who are considered high-risk and thus satisfies requirement #7. The ability of PanelViz to satisfy the aforementioned design requirements as compared to patient registries is summarized in **Table 5.5**.

Table 5.5 Ability of baseline and panelViz tools to support design requirements

Design Requirement	Patient Registry	panelViz
1. Display each patient's medical and psychosocial problems	+ Select medical and psychosocial problems presented within each row	+ Users can move their mouse over a hexagon to reveal the associated patient's problems in tabular form
4. Present all patients with medical and psychosocial problems under a user's care	- Users must scroll through multiple pages to review all patients with medical and psychosocial problems	+ Hexagon plot visualizes an entire patient panel in a small visual space
5. Sort patients according to their priority as assessed by the user	- Deterministic sorting prevents the consideration of diverse criteria - Tabular representation doesn't confer awareness of the prevalence of high-priority patients	+ Hexagon plot uses color-coding to indicate a patient's relative priority while data table uses sorting + Using a linear equation to compute priority enables considerable of diverse criteria + The hexagon plot enables providers to rapidly estimate the prevalence of high-priority patients
(+) feature supports design requirement (-) feature that doesn't support design requirement		

Table 5.6 Accuracy of participant responses to study tasks

Task	**Registry**	**PanelViz**
1. Identify all medical and psychosocial problems for [randomly selected patient].	92.8%	78.5%
2. Identify a patient who exhibits lack of viral load suppression together with alcoholism and drug abuse.	71.4%	100%
3. Which of the following problems is more common: cardiovascular disease or chronic kidney disease?	100%	92.8%
4. Which of the following is more common among patients who are virally unsuppressed: drug use or alcoholism?	71.4%	85.7%
5. Select 5 medical or psychosocial problems and estimate the proportion of patients with 3 or more problems.	21.4%	64.2%
Overall	**71.4%**	**84.2%**

5.5 Controlled Experimental Evaluation

Interface Evaluation

14 clinicians with experience in HIV primary care were recruited to participate in a formal evaluation of PanelViz; 9 participants were physicians (64%) and 5 were nurse practitioners (36%). Participants completed the 5 study tasks in 9.12 minutes on average while using PanelViz, and 10.16 minutes while using the patient registry tool. ($p = .17$)

As reported in **Table 5.6**, overall task accuracy was slightly higher with PanelViz (84.2%) compared to the patient registry (71.4%), although these differences were not significant ($p = .08$). The tools were similar in their ability to support tasks #1-4, where no significant differences were observed in the accuracy of responses generated using the patient registry and PanelViz. However, participants were more likely to provide accurate responses to task #5 using PanelViz (64.2%) compared to the patient registry (21.4%, $p < 0.05$).

Table 5.7 Health-ITUES scale scores across study conditions

Scale	Patient Registry	PanelViz	*p-value*
Impact	3.88	4.26	$p < .05$
Perceived Usefulness	3.75	4.49	$p < .005$
Perceived ease of use	3.50	4.04	$p < .05$
Overall Score	**3.70**	**4.32**	$\boldsymbol{p < .005}$

Compared to the patient registry, PanelViz was associated with higher overall Health-ITUES scores (3.70 vs. 4.32, $p < .005$). Among all three subscales tested, PanelViz was associated with more favorable responses from participants. The 'perceived usefulness' subscale exhibited the largest difference between the patient registry and PanelViz tool (3.75 vs. 4.49, $p < .005$) The mean of the overall Health-ITUES score and each component subscale associated with each interface is presented in **Table 5.7**.

At the conclusion of the study, participants were asked several questions regarding their overall impression of the patient registry tool and PanelViz, including significant benefits or limitations of each interface. We identified the following two themes related to the interfaces used by study participants:

Theme 1: PanelViz preferred by participants because of user-controlled prioritization and visualization features

13 out of 14 asserted that they preferred the PanelViz interface compared to the patient registry. This partly reflected participant's favorable assessment of the population visualization, wherein all of the 500 patients on their panel was presented on a single screen and represented by a color related to their assigned 'priority score':

> *"I liked the [visualization], I think because it was easy the way it was laid out. It was able to condense a lot of information into a very small physical space...and so you could use that to visualize 500 patients worth of data in just a very small compact space"* (MD 1)

For the study tasks requiring estimation of population-level characteristics, clinicians felt that the visualization enabled them to quickly estimate the proportion of patients with a specific set of characteristics:

> *"I preferred the visualization tool...helped reduce the complexity of complex data and allowed me to more efficiently group variables of interest in a way that was easy to...the visualization tool was much, much easier and more intuitive, and [the patient registry] straining my eyes"* (MD 6)

The patient prioritization module of PanelViz was mentioned by seven clinicians as being a useful feature. These participants appreciated the ability to use a multiplicity of priority criteria in identifying high-priority patients and felt that the ability to sort selected criteria according to their perceived importance was intuitive. Clinicains felt that a flexible, user-controlled patient prioritization module would enable them to focus on medical and psychosocial problems that were especially prevalent on their panels:

> *"the visualization in particular, let's me prioritize [variables] however I want...I think viral load suppression is always the first thing we prioritize...but then you can then prioritize [other indicators] in a variety of different ways. It also depending on who you're talking to...when I talk to the psychiatrist, I might want to prioritize people with mental health s that I can have her help me with those patients. If I'm talking about just patients that I'm prescribing medications for, I might then be focused more on the patients with physical illness like cardiovascular disease, kidney disease, etc." (MD 3)*

Theme 2: Patient registry useful for simple tasks but does not facilitate understanding of population characteristics

Study participants asserted that the retrieval of patient information was more straightforward using the patient registry tool, due to the simplicity of the tool's tabular format:

> *"...maybe not easier, but it was maybe a little bit faster to answer the first couple of questions on the registry tool. Just because you're literally just displaying data...I felt like it was just a little bit faster to be able to like rank order and in group things, but I don't know, they kind of seem like they're all rolled into one with the tool." (MD 4)*

Despite facilitating easy retrieval of patient-level information, the patient registry did not support clinicians in estimating population-level characteristics. Participants often resorted to counting individual cells to accomplish tasks such as estimating the prevalence of specific medical and psychosocial problems and one participant reported that using this tool causes significant ‘eye strain’.

> *“I think it was hard to do things like estimation, because again, it's a lot of information. Not in a compact space. So it's hard to estimate like a proportion of patients, you know, with selected problems or, for example, kind of quantifying what's more common cardiovascular disease or chronic kidney disease. I found it more difficult to estimate...”* (MD 1)

In addition, study participants felt that the patient registry did not enable them to adequately prioritize complex patients and constrained their selection of priority criteria to only one or two variables:

> *“If you were just looking at one or two variables, I think [the registry] was okay. But the sorting I did not find it terribly easy. So, if it was just like one or two variables, and if you just wanted to know who was using drugs or who was virally suppressed...but if you wanted multiple variables, the other tool is much, much better and easier to use.”* (NP 4)

5.3.4 Discussion

In this study, we developed and evaluated an interactive visualization tool designed to help clinicians maintain awareness of patients for whom they are responsible. While most tasks related to population monitoring could be achieved using either PanelViz or a simulated patient registry, only by using PanelViz were clinicians able to accurately estimate the proportion of complex patients on their panels. Moreover, clinicians asserted that the visualization tool had higher perceived ease of use and perceived usefulness compared to patient registries; this reflects participant’s favorable assessment of the tool’s user-controlled prioritization module and population visualization.

Previous studies have observed that large volumes of clinical data can overwhelm clinicians and lead to worse quality of care (264,265) but our findings suggest that interactive visualizations like PanelViz may better enable clinicians to draw insight from voluminous data. Only with PanelViz were clinicians able to accurately estimate the proportion of complex patients – defined as those with 3 or more medical or psychosocial problems. When using the patient registry to accomplish this task, many participants attempted to review each row and count complex patients one-by-one, inevitably becoming so frustrated that some participants simply asserted that they 'could not perform' the task. In contrast, PanelViz highlighted complex patients in red and orange, enabling users to quickly estimate of the proportion of complex patients. Participants asserted that with the visualization, proportions could be estimated by comparing the relative size of groups of patients as defined by their respective colors. Color-coding has been used in visualizations designed for clinicians (88,89) and can effectively focus a decision-makers attention on important and/or extraordinary aspects of the data. (108,110) Our findings suggest that future studies should evaluate whether data visualization can help providers maintain awareness patient populations in other clinical settings and assess how such IT tools can be integrated into clinical workflows.

The physicians and nurse practitioners who participated in the study overwhelming preferred PanelViz to the patient registry interface. Our findings that clinicians considered the registry interface to exhibit only modest usefulness is corroborated by previous studies that have observed patient registries to be unable to satisfy all clinicians' needs.(4,19,25) The ability to identify high-priority patients according to a diverse set of multiple priority criteria is an established need(85,86) that was also observed in our exploratory studies. In contrast to patient registries, PanelViz enabled providers to derive a 'priority score' for all patients on their panel by selecting and ranking up to 20 prioritization criteria. Clinicians responded favorably to this flexible prioritization feature and asserted that it would enable them to focus on medical and psychosocial problems that were especially prevalent on their panels. Because several studies have observed that physicians reject patient stratification approaches such as predictive models that are unable to incorporate clinical intuition and had limited interpretability(83,84), user-controlled prioritization modules similar to PanelViz may engender transparency while also allowing providers to account for multiple disparate outcomes in patient stratification. Allowing clinicians to have more control over which patients are prioritized could further the ‘doctor-in-the-loop’ paradigm wherein intuition is paired with machine supported stratification.(87) PanelViz was informed by the guidelines for the design of tools for visual analysis. We leveraged 4 of the 12 principles outlined by Heer and Schneiderman’s taxonomy of interactive dynamics for visual analysis.(266) Specifically, *visualization* enabled clinicians to more easily interact with data that reflects the state of their respective panels; multiple participants reported difficulty reading the information contained within the patient registry but reported no such challenges when using the visualization. *Sorting* enabled clinicians to quickly identify patients with the highest priority on their respective panels. This was especially useful when providers attempted to estimate the proportion of specific medical and psychosocial problems, as all patients with a given problem were isolated at the top of the visualization. Priority scores were *derived* by each clinician when they selected a set of priority criteria. Heer and Schneiderman assert that when users find data to be insufficient, the data can be transformed into new attributes that satisfy the user’s end goals.(266) Because prioritization is an important goal aspect of care management and clinicians value different priority criteria, users should have the ability to derive prioritization scores that align with their assessment of patient priority. Users were able to *navigate* the visualization by using their cursors to inspect individual patients and this was often used to ascertain the groups of patients with the same color (and thus priority score). Novel tools that support population monitoring should include features that facilitate these four task types.

This study has several limitations that should be considered. First, the limited sample size of our study may have not been sufficient to demonstrate statistical significance. Second, we used datasets containing 500 patients in study trials, but the actual caseload of providers may vary given different clinical settings. Third, our visualization tool was a prototype, and we expect that usability would improve with further refinement. Fourth, the user-centered design and experimental evaluation was conducted in a simulated HIV primary care setting and thus results may not be generalizable to other healthcare settings. The components of the interactive solution may support the management of HIV but not be relevant to the management of other chronic diseases. Fifth, the experimental evaluation was conducted with dataset of synthetic patients. In actual practice, clinicians would be familiar with most or all of the patients on their panels and thus some of the study tasks are more challenging to accomplish in a laboratory setting. Sixth, users were unable to investigate the EHR data that was aggregated to create the 18 variables presented in the registry and PanelViz systems. Future systems should feature an aspect of *data provenance*, where users can generate confidence in derived data elements by examining raw data.(267,268)

5.3.5 Conclusion

As care models that require healthcare providers to continuously monitor large patient groups become more widespread, there is an unmet need for health IT systems that can help clinicians identify patients with complex care needs. Using a novel visualization tool, physicians and nurse practitioners were able to accurately identify patient- and population characteristics across a simulated panel of 500 HIV patients. These findings suggest that data visualizations may ameliorate the challenge of simultaneously monitoring many complex patients. Future research should identify opportunities to leverage data visualizations in other areas of care delivery.

Chapter 6: Conclusions

6.1 Summary of Work

This dissertation consisted on six distinct studies that used both qualitative and quantitative methods to explore how computational methods can better support clinicians in care management settings. I will now provide an overview of these studies and their principal research findings.

6.1.1 Aim 1

The research conducted in Aim 1 examined the IT needs of healthcare providers managing large panels of patients living with HIV. Specific lines of inquiry included an enumeration of the challenges to the delivery of care management and assessment of whether existing health IT systems satisfy provider's needs. The first study of Aim 1 consisted of semi-structured interviews and direct observations conducted in two HIV primary care clinics situated within large urban hospitals. Inductive thematic analysis was used to generate findings from qualitative data and compare and contrast the use of health IT in the two clinics. The second study of Aim 1 leveraged the data generated in the first study to develop a conceptual framework of population monitoring in chronic disease care by adapting the theory of situational awareness.

The first study of Aim 1 found that the delivery of care management requires the development of novel strategies to support population monitoring. The strategies included prioritizing 'high-priority' patients and the creation of homegrown tools such as spreadsheets to help clinicians monitor these patients. We also observed that providers in both clinics struggled to retrieve information related to social and behavioral determinants and use that information to target psychosocial interventions to appropriate patients. Finally, despite the fact that team-based care is a hallmark of care management and similar care models, clinicians had difficulty communicating with colleagues, thereby hindering their ability to maintain awareness high-priority patients and deliver multidisciplinary interventions. Together these findings suggest that improvements in health IT may ameliorate many of the challenges currently faced by clinicians delivering care management to chronic disease populations.

The second study of Aim 1 adapted the theory of situational awareness to conceptualize the process of population monitoring in chronic disease care. The conceptual framework that resulted from this adaptation posits several key elements. First, the framework asserts that situational awareness operates at two levels of abstraction in population monitoring; patient- and population-levels. Patient-level SA requires perception of each patient's medical and psychosocial problems, comprehension of modifiable behaviors, and projection of the impact of potential intervention on patient outcomes. Population-level SA requires perception of those patients with medical and psychosocial issues, comprehension of the relative priority of patients within a given population, and the ability to project which high-priority patients are likely to benefit from intervention. Second, the framework acknowledges the importance of a clinician's goals in directing their attention to specific medical and psychosocial issues among patients on their panels. The framework also acknowledges the impact of a clinician's workload on their ability to maintain awareness of patients on their panel.

6.1.2 Aim 2

The research conducted in Aim 2 examined how information related to social and behavioral determinants of health is documented in EHRs and was motivated by the fact that this information is critical for care management. Three studies were conducted in support of Aim 2 and advanced the knowledge required to build a system that can automatically infer patient

SBDH status from the patient record. The first study of Aim 2 focused on creating a corpus of clinical notes to serve as a dataset for analysis in subsequent studies. This involved collaborating with domain experts to curate a comprehensive list of SBDH relevant to HIV primary care and subsequently manually annotating a large volume of notes with those SBDH. Because SBDH is infrequently documented and the annotation process was time-intensive, we were able to use semi-supervised learning to significantly accelerate the process of creating a gold-standard corpus. The second study of Aim 2 used the aforementioned dataset to analyze the longitudinal characteristics of 4 common SBDH as expressed in the patient record and compared the rates of change among distinct SBDH. In addition, manual review of patient notes was undertaken to establish whether changes in patient SBDH status reflected legitimate changes in patient status or rather potential data quality issues. The third study of Aim 2 attempted to 1) automatically infer the presence of SBDH documentation to support initiatives designed to improve social history taking by clinicians, and 2) evaluate methods for inferring a patient's respective SBDH from electronic health record data. We hypothesized that modeling approaches that leverage both structured and unstructured data for this task will yield better performance than attempts based on either data source alone.

The first study of Aim 2 initially involved three clinicians who identified an array of more than thirty distinct SBDH associated with adverse health outcomes such as hospital readmission and the acquisition of sexually-transmitted infections. The clinicians classified each SBDH as belonging to one of five SBDH topics: *alcohol use* (social alcohol use, alcoholism), *substance abuse* (amphetamine, opiates, cannabis, cocaine, intravenous drugs), *sexual orientation* (men who have sex with men, men who have sex with women, women who have sex with men, women who have sex with women, bisexual), *sexual activity* (history of sexually transmitted infections, condom usage, oral sex, vaginal sex, receptive and insertive anal intercourse), and *housing status* (homeless, unstable housing, living with friends). Three annotators then manually reviewed the entire patient records of 33 HIV+ individuals for documentation of the 6 SBDH topics and 30 risk factors listed above. Because the scarcity of clinical notes containing explicit SBDH mentions rendered the annotation process described above extremely labor-intensive, we employed a technique leveraging modern distributional semantic techniques to accelerate the manual annotation process by identifying clinical documents likely to mention SBDH. Our semi-supervised approach using similarity based on word-embeddings successfully increased the yield of manual annotation. Annotators observed 8.26 distinct SBDH mentions per note for the 60 notes closest to the 6 SBDH domain centroids, compared to 0.83 mentions per note randomly sampled from a cohort of HIV+ individuals.

The second study of Aim 2 focused on 4 SBDH risk factors; sexual orientation, housing status, alcohol use and drug use. Encounters with confirmed documentation of SBDH were isolated and analyzed to examine changes in a patient's SBDH status. and potential data quality issues. We then manually reviewed pairs of notes authored on the same-day with conflicting documentation to identify possible sources of data quality issues related to SBDH. The findings of the study suggested that social and behavioral determinants of health as expressed in the patient record exhibit change over time. While some of these changes likely reflect true changes in the patient state, multiple findings indicated that some changes in patient SBDH status may reflect data quality issues. We observed a high frequency of implausible longitudinal changes in patient SBDH status, wherein a patient transitioned from an active status (e.g. active alcohol use) to having no history of active status (e.g. no history of alcohol use). In addition, we observed same-day conflicts in patient's documented SBDH status.

The third study of Aim 2 attempted to use supervised learning to infer the presence of SBDH documentation and individual SBDH risk factors in patient records. Our experimental results indicate that combining clinical free-text notes and structured data may provide the best approach to classifying both the presence of SBDH documentation and patient SBDH status. While the majority of top features utilized by the heterogenous models were derived from text, models also included structured features. Several textual features were institution-specific or regional in nature. The performance of the classification models suggested that it is likely feasible to infer presence of SBDH documentation, but that challenges remain for inferring patient SBDH status. Inferring patient SBDH status is most challenging among SBDH with low prevalence and high lexical diversity.

6.1.3 Aim 3

The research of Aim 3 explored whether an interactive visualization can improve provider's ability to perform tasks related to population monitoring. User-centered design was employed to develop a tool featured user-controlled prioritization, which enabled clinicians to identify high-priority patients according to whichever criteria they considered important. This interface, named PanelViz, was evaluated using a within-subjects experimental study that recruited physicians and nurse practitioners to perform several tasks with both the interactive visualization and a simulated patient registry. This experimental study measured the accuracy of participant's task responses and measured perceived usefulness using a validated survey.

The design process demonstrated that clinicians found it difficult to navigate the tabular data representation typically associated with patient registries, instead preferring a data visualization that presented the entirety of their patient panels in a compact visual space. The experimental evaluation demonstrated that the data visualization made it easier to identify patients with complex care needs compared to the patient registry. Only with PanelViz were clinicians able to accurately estimate the proportion of complex patients – defined as those with 3 or more medical or psychosocial problems. In addition, the prioritization module within PanelViz, which enabled providers to derive a 'priority score' for all patients on their panel by selecting and ranking up to 20 prioritization criteria, was received favorably. Providers asserted that systems with user-controlled prioritization would enable them to focus on medical and psychosocial problems that were especially prevalent on their panels and create distinct groups of high-priority patients for different intervention types.

6.1.4 Implications for the treatment of COVID-19

The studies associated with this dissertation were completed prior to the emergence of Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) in the United States. However, the research findings described herein may have implications for the treatment of coronavirus disease 2019 (COVID-19), which is the condition associated with SARS-CoV-2 infection. First, our development of a conceptual framework and a prototype tool to support patient monitoring could inform IT solutions designed around the clinical management of multiple COVID-19 patients. Situational awareness at both the patient- and population-level is likely required by clinicians managing many patients on overwhelmed inpatient wards. Moreover, the framework's focus on the process by which clinicians prioritize patients to receive limited resources may be indicative of the process by which clinicians adjudicate whether patients should be admitted or rather discharged from emergency departments. The framework's assertion that clinician's may have distinct prioritization criteria – and the ability of our PanelViz tool to support user-controlled prioritization – supports the type of decision making that may be required when minimal evidence about a condition exists and there are few available treatment guidelines.

Second, our work advancing the science of inferring social and behavioral determinants of health may inform the development of systems that can target social services to patients adversely impacted by the severe economic consequences of the SARS-CoV-2 pandemic. A sharp increase in unemployment has raised concerns about whether social services can meet the growing need for food, rent, and utility assistance.(269) IT systems that attempt to identify patients with housing difficulties can leverage our findings to develop more accurate models to infer this information. In addition, our insights into the expression and inference of information related to alcohol and drug abuse may also serve health systems that attempt to identify unmet social needs and prevent subsequent population health issues.(270,271) The link between unemployment and greater rates of drug and alcohol abuse has been established.(272,273)

6.2 Contributions

The research presented in this dissertation contributed to biomedical informatics community in the following three ways; 1) revealed the limitations of existing health IT for care management, 2) demonstrated how computational methods can be leveraged to infer social and behavioral determinants of health , and 3) introduced data visualization and user-controlled prioritization as a means of improving the process of population monitoring.

Our qualitative inquiry conducted in two HIV primary care programs provided evidence that existing IT systems including EHRs and patient registries may not adequately support care management. Challenges experienced by providers included the difficulty of monitoring a high volume of patients, lack of awareness of patient social and behavioral determinants of health, labor-intensive communication within interdisciplinary care teams, and the inability to match patients with appropriate intervention. Our findings may motivate the informatics community to design novel IT solutions that enable clinicians to more easily identify a patient’s social and behavioral determinants of health and recommend evidence-based interventions that may ameliorate the psychosocial factors that preclude disease management. The conceptual framework advanced in Aim 1 exists as another contribution that may facilitate specifically the development of solutions that support monitoring a high volume of patients. The framework will enable the research community to operate with a more comprehensive understanding of the population monitoring process, design tools that satisfy provider's needs, and provide a set of evaluation criteria for novel IT systems.

The research findings described herein describe previously unknown characteristics of clinical documentation related to social and behavioral determinants of health and describe computational approaches that may improve the automated inference of SBDH from patient records. First, we contribute a set of social and behavioral determinants related to sexual health that the research community may employ for both content analyses and modeling experiments. Second, the success of the semi-supervised learning approach described herein can lower the annotation burden experienced by research teams as they seek to develop their own gold-standard corpora. Third, the second study of Aim 2 demonstrated that patient SBDH statuses are subject to change over time, and that data quality issues may be common in SBDH documentation. These findings have implications for future approaches to automated inference of SBDH information from clinical data; computational models may benefit from aggregating only recent historical data when inferring patient SBDH status and performing inference on multiple data points to minimize the likelihood of misclassification resulting from data quality issues. Fourth, the experimental results from the third study of Aim 3 suggest that both unstructured and structured data can be leveraged for automated inference of patient SBDH status, which may reorient the research community's singular focus on using natural language processing to infer SBDH.

The conceptual framework of population monitoring and the experimental study we conducted can inform the development of novel health IT solutions designed to support population monitoring in chronic disease settings. The framework adapted the theory of situational awareness to enumerate several design requirements for novel systems that include the ability to identify all patients requiring care and prioritize patients with complex care needs. This framework influenced the design of a prototype tool, called PanelViz, which featured an interactive visualization and was received more favorably by physicians and nurse practitioners compared to a simulated patient registry. Clinician's favorable reception of PanelViz' population visualization and the interfaces' ability to support identification of patients with complex care needs suggests that data visualization may enable providers to better interact with clinical data and maintain awareness of their patient panels. In addition, the research community can build on our efforts to empower clinicians with a flexible, user-controlled prioritization module. Similar approaches could replace automated stratification methods such as predictive models, which clinicians may be mistrustful of due to their inability to incorporate human review and clinical intuition.(82–84)

6.3 Limitations

The studies described herein have several limitations which must be considered.

The two clinics selected for the two studies in Aim 1 are both HIV primary care programs in New York City; the majority of the patient population treated in the clinics studied herein were HIV+ with a high burden of SBDH and both clinics are located in large urban hospitals, which may limit generalizability to other primary care settings. Although both clinics are focused on HIV patients, the care models employed by these clinics is similar to those used by Accountable Care Organizations and Health Homes. Second, interviews relied on participant's memory of past events and thus may be susceptible to recall bias. However, a strength of the methodology included triangulation of information from administrators, physicians, care coordinators and social workers. Third, the sample size for the study was relatively small. However, during data collection we reached saturation, suggesting that a larger sample within the clinics studied herein would not have yielded new findings. Fourth, we did not observe clinicians during clerical work; observations of clinicians contacting patients, using health IT tools, or communicating with colleagues would have provided additional insight into challenges faced by providers.

Several limitations of the 3 studies in Aim 2 are related to our creation of a gold-standard corpus for analysis and experimentation. Document-level annotations lack the granularity of mention-level annotations and thus systems trained on such data may be inappropriate for some informatics interventions. Second, our semi-supervised learning approach relied on notes which contained a social history section; not all notes do so. Third, a relatively small sample size was used for evaluation of the semi-supervised learning approach.

Our approach to analyzing the longitudinal characteristics of SBDH documentation has several limitations. First, our findings were generated by analyzing data from a specific patient cohort treated at a single institution. The high prevalence of SBDH within the study cohort may have resulted in a higher frequency of SBDH changes. Second, while our annotators achieved a relatively high inter-rater reliability, there were likely some erroneous annotations and thus some temporal changes in SBDH status may reflect annotation errors and rather than changes in documented SBDH status. Third, our methods did not enable us to quantify the proportion of

SBDH changes that reflected true changes in the patient state and the proportion that reflected documentation errors.

Lastly, our approach to performing automated inference of patient SBDH status has addition limitations. First our SBDH classifiers were trained using data from a single institution and performance may degrade when applied to distinct healthcare institutions. Second, our overall modest results may have resulted from data quality issues in the documentation of SBDH and/or inaccurate annotation. Third, while there has been work in extracting social determinants of health from clinical notes, most approaches cast this problem as a named-entity recognition task (i.e., extract particular passages in the notes). Because we approach the problem as a document labeling task, our experimental setup does not allow for direct comparison to previous work. Fourth our model performance may have been improved by preprocessing the text by considering negation and correcting misspellings. In addition, reducing the dimensionality of the structured EHR features using deep auto-encoders or an algorithm such as Independent Components Analysis may have also improved performance.

The user-centered design and prototype evaluation described in Aim 3 has several limitations that should be considered. First, the limited sample size of our study may have not been sufficient to demonstrate statistical significance. Second, we used datasets containing 500 patients in study trials, but the actual caseload of providers may vary given different clinical settings. Third, our visualization tool was a prototype, and we expect that usability would improve with further refinement. Fourth, the user-centered design and experimental evaluation was conducted in a simulated HIV primary care setting and thus results may not be generalizable to other healthcare settings. The components of the interactive solution may support the management of HIV but not be relevant to the management of other chronic diseases. Fifth, the experimental evaluation was conducted with dataset of synthetic patients. In actual practice, clinicians would be familiar with most or all of the patients on their panels and thus some of the study tasks are likely more challenging to accomplish in a laboratory setting.

6.4 Future Work

In the first study of Aim 1, we identified several barriers to effective CM that could be addressed by the development of IT tools that improve on existing systems. Clinic staff also asserted that having access to an electronic representation of each patient’s providers would ameliorate some communication challenges, and evidence suggests that this information can be inferred through the secondary analysis of routinely collected EHR audit log data. Future research should investigate the feasibility of such analyses in ambulatory settings.

The second study of Aim 1 advanced a conceptual framework of population monitoring that adapts the theory of situational awareness. Although we hypothesize that a healthcare provider’s awareness of patients requiring care on their respective panels is likely to impact patient outcomes, no definitive link between provider situational awareness and patient outcomes has been established in this setting. Future research should attempt to establish such a link, thereby enabling the use of the framework as an evaluation metric for future informatics interventions.

The first study of Aim 2 observed correlations between individual SBDH documented in patient records; for example, alcoholism and history of substance abuse displayed a strong correlation, as did sexual orientation and high-risk sexual activity and cocaine use showed a strong correlation. Future research aimed at automatically inferring SBDH from patient records should attempt to leverage this dependence using multi-label classification methods.(203) In addition, future research efforts that rely on gold-standard annotated corpora can leverage our semi-supervised learning approach to significantly decrease the labor required to identify clinical notes with relevant SBDH mentions.

The second study of Aim 2 analyzed documentation related to SBDH among a sample of persons with HIV and observed longitudinal changes in patient SBDH status. Future research should conduct a more comprehensive analysis by annotating all notes associated with a large corpus and use techniques such as mutual information to assess how the predictability of future SBDH status relative to existing documentation changes with time.(224) Such an analysis would open the possibility for techniques that could accurately model the relevance of social and behavioral determinants of health documentation.(225,226)

The third study of Aim 2 demonstrated that incorporating both structured and unstructured EHR can improve the ability of classification models to infer patient SBDH status. Future studies can likely improve on our results by using more sophisticated modeling approaches: 1) model performance is likely to be improved by considering negation or by correcting misspellings in text, 2) multi-label classification may be improved by accounting for the observed structure of SBDH labels. Hierarchically structured sets of SVM have demonstrated improved performance compared to binary relevance for multi-label classification of clinical documents (199–202), 3) document-level SBDH labeling may benefit from document zoning.(204) Long documents like clinical notes typically contain many words unrelated to the modeling task; in clinical documentation this is manifested by sections (ie. ‘Review of Systems’) potentially irrelevant to SBDH, and 4) with a larger annotated corpus, a neural network with attention layer may improve results while providing transparency for classification decisions.(274)

In Aim 3, physicians and nurse practitioners asserted that an interactive visualization of their patient panel had higher perceived usefulness and ease of use compared to a patient registry. This finding suggests that future research should evaluate whether interactive tools that visualize a provider's entire patient panel can support provider awareness of patients in diverse clinical settings including other chronic disease treatment programs, family practice settings, or even ambulatory oncology care. In addition, research is needed to understand how these tools would be integrated into clinical workflows and whether user-controlled prioritization is perceived as beneficial by providers in other clinical domains.

6.5 Conclusions

As care models that require healthcare providers to take responsibility for the health outcomes of their patients become more widespread, there is a need for novel systems that help clinicians monitor their respective patient panels. This dissertation provides insight into how computational methods can be used to support this goal. We posit a set of requirements for such systems through a conceptual framework that adapts the theory of situational awareness. One such requirement – the availability of patient information related to social and behavioral determinants of health – can be supported by information retrieval approaches that are informed by our research findings, which enumerate several important considerations related to the expression of SBDH in clinical data. This dissertation also suggests that novel systems can leverage data visualization to satisfy the requirement for providers to maintain awareness of all patients requiring care. As healthcare providers struggle to deliver all required care to the increasing number of patients that they are responsible for, future research should identify opportunities to leverage data visualizations in other areas of care delivery.

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