

# Patient registries for substance use disorders

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**Abstract:** This commentary discusses the need for developing patient registries of substance use disorders (SUD) in general medical settings. A patient registry is a tool that documents the natural history of target diseases. Clinicians and researchers use registries to monitor patient comorbidities, care procedures and processes, and treatment effectiveness for the purpose of improving care quality. Enactments of the Affordable Care Act 2010 and the Mental Health Parity and Addiction Equity Act 2008 open opportunities for many substance users to receive treatment services in general medical settings. An increased number of patients with a wide spectrum of SUD will initially receive services with a chronic disease management approach in primary care. The establishment of computer-based SUD patient registries can be assisted by wide adoption of electronic health record systems. The linkage of SUD patient registries with electronic health record systems can facilitate the advancement of SUD treatment research efforts and improve patient care.

**Keywords:** substance use disorders, primary care, registry, electronic health records, chronic care model

## Introduction

Patient registries<sup>1</sup> have played pivotal roles in disease-focused research and as chronic care management tools to plan and evaluate disease prevention and control programs recommended by public health agencies and legislators.<sup>1-7</sup> Notable examples are national cancer registries that have monitored nearly the entire population of the United States. Researchers have analyzed over 20 years of data supported by the National Program of Cancer Registries of the Centers for Disease Control and Prevention and the Surveillance, Epidemiology, and End Results program of the National Cancer Institute. Examination of available data demonstrates notable associations between cigarette smoking and lung cancer. First, high lung cancer incidence rates parallel a high prevalence of cigarette smoking.<sup>8</sup> Second, the most rapidly declining incidence rates of lung cancer were clustered in states with the highest proportions of tobacco smokers who had quit.<sup>9-12</sup> Third, as soon as 5 years after smoking prevalence declined, lung cancer incidence rates began to decline.<sup>9</sup> Knowledge derived from studies of cancer registries has provided overwhelming evidence of the harmfulness of smoking, stimulated focused research efforts, and contributed to current smoke-free laws and tobacco tax increases in many states across the country.

Many health care organizations are now incorporating or integrating Chronic Disease Electronic Management System (CDEMS) registries within existing electronic health records (EHRs) to track chronic diseases such as diabetes, irritable bowel

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syndrome, and hypertension.<sup>13–20</sup> These CDEMS registries may ultimately serve as a main data source for state and federal chronic disease surveillance programs. Substance use disorders (SUD) are chronic illnesses that present a growing economic and public health burden due to reduced human productivity, increased costs of health care, and increased burdens on the criminal justice system.<sup>21–25</sup> SUD researchers and treatment providers have recognized that SUD can be effectively managed in chronic care models (CCMs) that combine collaborative efforts among primary care providers, behavioral health professionals, and tertiary care providers.<sup>25–28</sup> However, no SUD patient registry exists today in general medical settings. This commentary discusses the value of implementing SUD patient registries in general medical settings and offers potential solutions to overcome the challenges inherent in developing such a registry.

## Why SUD registries are needed now

Enactment of the Affordable Care Act 2010 and the Mental Health Parity and Addiction Equity Act 2008 expands SUD care into primary care settings and allows reimbursement for treating SUD using CCMs similar to other types of chronic diseases such as diabetes and hypertension. Therefore, the development of evidence-based CCMs for SUD management in general medical settings is a priority.<sup>29–34</sup> The establishment and use of patient registries in SUD, in conjunction with longitudinal study results and clinical trial results, will aid in the development of effective CCMs.<sup>34</sup>

The types of information gathered in SUD patient registries are different from those provided by longitudinal studies or clinical trials. The contemporary registry data infrastructure capitalizes on EHRs and focuses on the whole health of patients, thereby serving as an effective tool for clinicians and researchers to better document the natural history of diseases among patients with multifaceted health conditions. Registries can also monitor health status and measure the quality and effectiveness of care as a means toward quality improvement.<sup>35</sup> Large-scale longitudinal or national drug treatment evaluation follow-up studies (eg, the Drug Abuse Reporting Program [DARP] in the 1970s [N=44,000],<sup>36</sup> the Treatment Outcome Prospective Study [TOPS] in the 1980s [N=11,750],<sup>37</sup> and the Drug Abuse Treatment Outcome Studies [DATOS] project<sup>38</sup> in the 1990s [N=10,010]) have contributed to the current knowledge of drug abuse trends and treatment effectiveness. However, these studies (DARP, TOPS, and DATOS) mainly focused on recovery outcomes and predictors of

treatment effectiveness.<sup>39–44</sup> Despite years of follow-up of SUD patients within these studies, little attention was paid to the quality of life, mortality, physical health, and health care information, simply because substance use was not treated in general medical settings. Thus, researchers had no access to these patients' medical care where these important data resided.

Clinical trials studying SUD and their treatment are typically short, include small numbers of highly selected participants, and involve research settings that are often too restrictive to answer generalizable questions about long-term health impact in respect to effective care management models for SUD. A longitudinal SUD patient registry has the potential to provide critical information on important public health questions. For instance, an SUD patient registry could answer questions such as: 1) what factors influence the progression of a drug user from low risk and occasional use to high risk and more frequent use, and do these factors differ by type of drug of abuse?; 2) are fatal overdoses frequently preceded by nonfatal overdoses?; 3) what are the main causes of death in drug users?; 4) what is the prevalence among SUD patients of co-occurring events or diseases such as diabetes, heart attack, cigarette smoking, and cancer-associated complications?; and 5) how does substance use affect treatment, prognosis, or treatment options of other diseases? In addition to characterizing the natural history of SUD populations and the impact of SUD on ongoing medical conditions, analyses to address these types of questions are essential to provide input into developing both relevant research questions and effective CCMs for managing SUD patients.

Primary care settings are the logical place to build a registry for patients with SUD problems. Longstanding relationships between patients and their primary care providers allow for primary care providers to screen for SUD and continue monitoring them in a systematic manner and at a reasonable frequency, as is done for hypertension, depression, and diabetes patients.<sup>45–53</sup> In primary care settings, screening can serve as a starting point for substance use care with the goal to prevent substance use problems from developing into a more severe SUD. This proactive approach to bringing more people in need of treatment into primary care will offer opportunities to identify substance users across a wide spectrum, from low to high risk of an SUD. This process may offer preventive and early intervention for SUD patients. Given ready access to the electronic health records of their patients, laboratory results, medications, prescriptions, and other relevant information, primary care doctors are well

suited to provide comprehensive medical care and monitoring to patients at risk for, or with, an SUD.<sup>34</sup>

## The efficiency of establishing an SUD patient registry in health care network settings

Primary care settings are optimal for screening and enrolling substance users into a patient registry, and those participating in network care organizations with substantial EHRs systems have advantages over smaller, non-network-affiliated clinics. A cost-effective way to do this is to establish an SUD patient registry within a practice-based research and/or health care network involving health care organizations, which may include federally qualified health centers, accountable care organizations, and health maintenance organizations. Establishing an SUD patient registry within a practice-based research and/or health care network allows for better implementation of registry standards and data aggregation from disparate EHRs systems. Involving federally qualified health centers will identify a large catchment area where typically underserved SUD patients are clustered. An SUD patient registry is an ideal platform to observe chronic care modalities and potentially launch comparative effectiveness research trials to evaluate the feasibility and efficacy of CCMs for patients with various SUD and comorbid conditions.<sup>27,54,55</sup> Comparative effectiveness research can be done using experimental designs (ie, randomized controlled trials) or prospectively observational designs. Patient registries have proven to be a cost-effective platform for conducting large simple trials to answer clinically critical questions.<sup>56</sup> Lastly, SUD patient registries within primary care networks could help investigate the associations between substance use status and patient-reported outcomes in the real-world setting (eg, quality of life, social adjustment, global health, and psychosocial functioning, as well as a broad range of other comorbid health conditions and mortality rates).

## Challenges and potential solutions

Two major challenges in building SUD patient registries in primary care settings are privacy concerns and data integration from disparate EHRs. Fortunately, these challenges are surmountable.

## Patient privacy protection

Multiple laws and regulations (eg, the Health Insurance Portability and Accountability Act and 42 Code of Federal Regulations Part 2 regarding confidentiality of alcohol and drug abuse patient records and state laws) exist to protect

SUD patients' drug use-related information. The illegality of using controlled substances or illicit drug(s) makes privacy concerns related to SUD more complicated than other chronic diseases. SUD patient registry planners must be able to accurately interpret and adhere to these privacy laws and regulations. Patients included in a registry must provide informed consents, and the consents must clearly delineate the collection and future use of protected health information (PHI). For example, registry implementers must ensure that PHI in SUD patient registries will be shared only among designated care providers and public health researchers. In states where clinical information is collected, there must be state-wide privacy and security regulations and measures in place to specify how PHI data may be accessed, extracted, queried, analyzed, and published. Additionally, when registry data are reused, they should be in an aggregated format, and PHI should be excluded to minimize risks of disclosing identities of SUD patients.<sup>34,57</sup> Many privacy concern issues can be solved technically through increasingly improved modern health information technologies (eg, data segmentation of informed consent<sup>58</sup>).

## Abstraction, transmission, and merging of registry data from disparate EHRs systems

Major data infrastructure development has been funded through American Recovery Act awards by the Agency for Healthcare Research and Quality.<sup>20,59-63</sup> This effort has led to the establishment or enhancement of EHRs-linked multicenter patient registries to track health outcomes and measure the quality and performance of health care. Successful transmission of data from disparate EHRs systems into a centralized registry system with interpretable data by end users is crucial to the success of developing a modern patient registry.<sup>59,64</sup> However, current commercially available EHRs systems often do not have uniform standards in either data elements or data domains. This is particularly true for SUD-relevant EHRs data, as illegal drug use data collection standards have yet to be incorporated into "meaningful use" criteria for EHRs systems. Thus, an initial essential step is to generate and implement SUD patient registry data standards among the participating health care settings. These standards should be consistent with the clinical information systems (ie, EHRs systems), in that the data in EHRs systems are transferrable and interpretable by the central registry repository. Therefore, common data standards, vocabularies, and common data elements (CDEs) are needed across SUD patient registries and clinical information systems to provide

a standardized terminology for the uniform collection and exchange of health information across multiple data sources. Two key steps toward these goals are 1) integration of SUD-related CDEs into EHRs systems and patient registries, and 2) routine collection of SUD with other behavioral health and medical data as part of usual clinical care in general medical settings.

Two federal initiatives are underway to enhance EHRs data standards useful for the development of patient registries. First, the National Institutes of Health, through its National Library of Medicine, is promoting a CDE initiative (<http://www.nlm.nih.gov/cde/>). The goals for this initiative are to improve data sharing to facilitate in-depth data analysis across different research disciplines and to expedite the merger of research data with patient care medical records. Second, the Office of the National Coordinator for Health Information Technology under the United States Department of Health and Human Services recently started a “structured data capture” standards development initiative, which focuses on generating common data standards specifically for EHRs systems to interface with research data systems and patient safety reporting (<http://www.healthit.gov/buzz-blog/electronic-health-and-medical-records/ehr-interoperability-structured-data-capture-initiative/>). These efforts provide a vision for greater health information exchange and data sharing. Likewise, the National Institute on Drug Abuse Center for the Clinical Trials Network is developing CDEs related to substance use and addiction intended for researchers and EHRs system developers to adopt.<sup>65</sup> These developments, in turn, will help guide the development of SUD patient registry data standards. Discussion has been published elsewhere of matters related to registry data entry and integrity, quality assurance issues and registry infrastructure maintenance, use of steering committees and oversight boards, as well as access to, and use of, registry data for research.<sup>35</sup>

## Summary

Disease and patient registries have played pivotal roles in understanding the natural courses of chronic diseases, disease management, and population health research. Along with the widespread adoption and meaningful use of EHRs, incorporating a CDEMS registry within existing EHRs systems to monitor patients’ long-term progress has become an important trend in managing chronic diseases and has shown positive results in improving health care quality and performance. SUD are preventable chronic relapsing diseases/disorders. Establishing SUD patient registries is a critical priority for monitoring and implementing chronic

care management of SUD and their comorbidities, which also provides an essential tool for responding to the national call for an innovative clinical trial enterprise.<sup>66</sup> The Affordable Care Act 2010 has greatly expanded access to SUD treatment in general medical settings, and many promising health information technologies are emerging. Thus, the initiation of an SUD registry is timely. Major challenges for establishing SUD registries are privacy concerns and health information exchange issues related to disparate EHRs systems. These challenges are surmountable through both policy and technology advances. Although substantial costs and resources may be required for developing and maintaining an SUD registry capable of interfacing with EHRs and effectively used for monitoring and implementing chronic care management of SUD, the value of the data generated from such a registry is immeasurable.

## Disclosure

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