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Longitudinal clinical decision support for assessing decisions over time: State-of-the-art and future directions

Tyler J Loftus[1,2], Jeremy A Balch[1,2], Jenna L Marquard[3,4], Jessica M Ray[5], Brian S Alper[6,7], Neeraj Ojha[8], Azra Bihorac[2,9], Genevieve Melton-Meaux[4,10,11], Gopal Khanna[12] and Christopher J Tignanelli[4,10,13]

Abstract

Objective: Patients and clinicians rarely experience healthcare decisions as snapshots in time, but clinical decision support (CDS) systems often represent decisions as snapshots. This scoping review systematically maps challenges and facilitators to longitudinal CDS that are applied at two or more timepoints for the same decision made by the same patient or clinician.

Methods: We searched Embase, PubMed, and Medline databases for articles describing development, validation, or implementation of patient- or clinician-facing longitudinal CDS. Validated quality assessment tools were used for article selection. Challenges and facilitators to longitudinal CDS are reported according to PRISMA-ScR guidelines.

Results: Eight articles met inclusion criteria; each article described a unique CDS. None used entirely automated data entry, none used living guidelines for updating the evidence base or knowledge engine as new evidence emerged during the longitudinal study, and one included formal readiness for change assessments. Seven of eight CDS were implemented and evaluated prospectively. Challenges were primarily related to suboptimal study design (with unique challenges for each study) or user interface. Facilitators included use of randomized trial designs for prospective enrollment, increased CDS uptake during longitudinal exposure, and machine-learning applications that are tailored to the CDS use case.

Conclusions: Despite the intuitive advantages of representing healthcare decisions longitudinally, peer-reviewed literature on longitudinal CDS is sparse. Existing reports suggest opportunities to incorporate longitudinal CDS frameworks, automated data entry, living guidelines, and user readiness assessments. Generating best practice guidelines for longitudinal CDS would require a greater depth and breadth of published work and expert opinion.

Keywords

Shared decision-making, CDS, CDSS, evolve, healthcare

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[1]Department of Surgery, University of Florida Health, Gainesville, FL, USA
[2]Intelligent Critical Care Center (IC3), University of Florida Health, Gainesville, FL, USA
[3]School of Nursing, University of Minnesota, Minneapolis, MN, USA
[4]Institute for Health Informatics, University of Minnesota, Minneapolis, MN, USA
[5]Department of Health Outcomes and Biomedical Informatics, University of Florida Health, Gainesville, FL, USA
[6]Computable Publishing LLC, Ipswich, MA, USA
[7]Scientific Knowledge Accelerator Foundation, Ipswich, MA, USA
[8]EunoChains LLC, Potomac, MD, USA
[9]Department of Medicine, University of Florida Health, Gainesville, FL, USA
[10]Department of Surgery, University of Minnesota, Minneapolis, MN, USA
[11]Center for Learning Health Systems Science, University of Minnesota, Minneapolis, MN, USA
[12]Medical Industry Leadership Institute, Carlson School of Management, University of Minnesota, Minneapolis, MN, USA
[13]Program for Clinical Artificial Intelligence, Center for Learning Health Systems Science, University of Minnesota, Minneapolis, MN, USA

Corresponding author:
Christopher J Tignanelli, Department of Surgery, University of Minnesota, 420 Delaware St. SE, Minneapolis, MN 55455, USA.
Email: ctignane@umn.edu

Introduction

Clinical decision support (CDS) efficacy continues to increase, bolstered by the widespread adoption of electronic health records and incremental adoption of interoperability frameworks.[1–3] Integration of CDS within existing digital workflows has been associated with increased patient safety,[4,5] cost containment,[6,7] and greater patient engagement in their own care.[8,9] Efforts to further optimize the development, validation, dissemination, and implementation of CDS have the potential to substantially improve healthcare quality.

The five "rights" of CDS includes the right information delivered to the right person in the right format through the right channel at the right *time* in workflow (e.g. if a patient were erroneously prescribed multiple anticoagulant medications, an order entry interruption should occur at order entry rather than hospital discharge).[10] We believe that "right time" should also represent the reality that for many decisions, patients and clinicians do not experience decision-making as a snapshot in time; instead, decisions evolve while supporting information accumulates and users' readiness for change moves along a continuum. These concepts do not apply for acute disease processes like myocardial infarction or traumatic injury (for acute use cases, previously described nonlongitudinal CDS are effective), but do apply for longitudinal disease processes like malignancy and congestive heart failure.[11,12] Despite the intuitive advantages of representing many healthcare decisions longitudinally and the availability of longitudinal CDS frameworks like SEIPS, peer-reviewed literature on longitudinal CDS (i.e. CDS applied at two or more timepoints for the same decision made by the same patient or clinician) is sparse.[1,13]

We performed a scoping review of articles describing longitudinal CDS to systematically map what is known and unknown on the topic, including challenges and facilitators to longitudinal CDS. We use results from this review to suggest future directions for the scientific investigation and implementation of longitudinal CDS, with a focus on operationalizing longitudinal CDS that are seamlessly integrated with existing digital workflows.

Methods

We searched Embase, PubMed, and Medline databases for articles describing longitudinal CDS published between database inception and February 25th, 2023. Article search terms, exclusion at screening, and full text review phases are illustrated in Figure 1. Obtaining informed consent was not applicable for this review article. Article search terms were as follows: ("develop*":ab,ti OR "validat*":ab,ti OR "implement*":ab,ti) AND ("decision support tool":ab,ti OR "decision support system":ab,ti OR "decision aid":ab,ti) AND ("patient":ab,ti OR "provider":ab,ti OR "clinician":ab,ti OR "physician":ab,ti OR "doctor":ab,ti) AND ("over time":ab,ti OR "longitudinal":ab,ti) AND [article]/lim AND [humans]/lim AND [english]/lim AND ([embase]/lim OR [medline]/lim OR [pubmed-not-medline]/lim). Articles were included if they (1) described development, validation, or implementation of patient- or clinician-facing CDS, (2) described CDS application (a tool, system, or aid) at two or more timepoints that both occurred after using the CDS for the same discrete decision by the same patient or clinician (i.e. not an aggregate analysis of all pre-CDS vs. all post-CDS decisions), and (3) were published in English as a peer-reviewed journal article. We excluded all articles not meeting these criteria, as well as study protocols or CDS architecture descriptions that did not report experiments or results. The search criteria identified 61 articles. After removal of two duplicates, 59 articles remained.

Abstracts were screened by two reviewers. Screening disagreements were resolved by a third reviewer. The two screening reviewers had 69.4% agreement and a Cohen's Kappa statistic for inter-rater reliability of 0.29. Forty-five articles were excluded during the screening process because they did not meet inclusion criteria. For the remaining 14 articles, quality was rated using validated quality assessment tools (e.g. the Quality Assessment of Controlled Intervention Studies and the Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies each rank 14 binary criteria).[14] Articles rated "poor" and those for which the full text did not meet inclusion criteria were excluded. Six articles were removed during full text review. Eight articles remained and were included in the final analysis. Results are reported according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines, as listed in Supplemental Table 1. Sources of funding and competing interests for each article are listed in Supplemental Table 2.

For each included article, we extracted data regarding: the study population; CDS architecture (including whether it was patient-facing, clinician-facing, or both) and performance; whether the CDS was automated (i.e. it did not require manual data entry by users); whether the CDS formally assessed user readiness for change, whether a longitudinal CDS conceptual framework (e.g. Systems Engineering Initiative for Patient Safety (SEIPS)[13]) was applied; whether the CDS was evaluated prospectively; whether the CDS used living guidelines (i.e. the CDS knowledge engine uses guidelines that are informed by a dynamic knowledge base that is automatically updated whenever new evidence becomes available, in contrast to traditional CDS knowledge engines that require manual software updates that are performed when and if developers

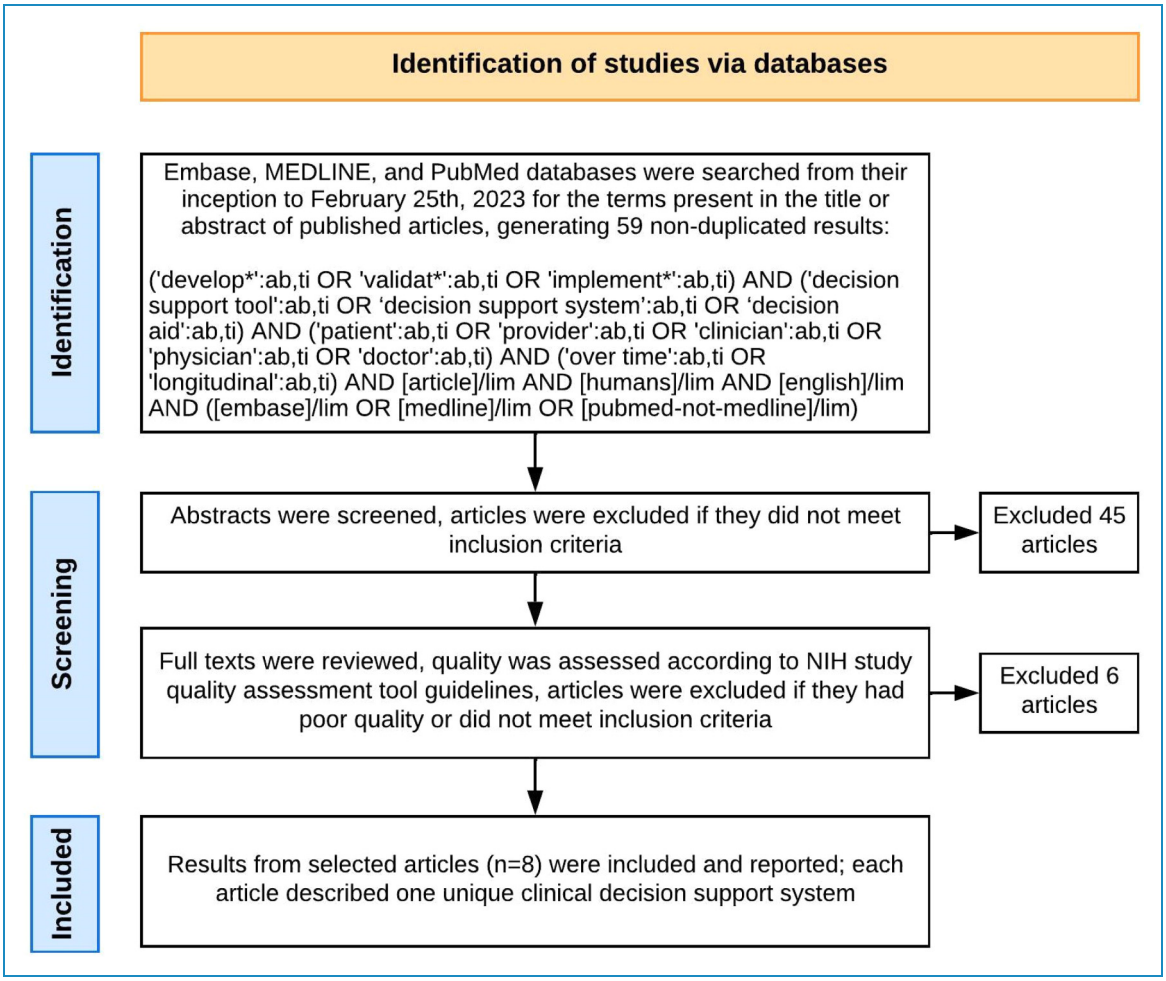

Figure 1. Article search parameters.

deem them necessary); and descriptions of challenges or facilitators to development, validation, or implementation of longitudinal CDS.

Results

No articles used a longitudinal CDS framework, automated data entry, or living guidelines

The eight included articles each described one unique CDS, which are summarized in Table 1. The number of participants ranged substantially across studies, from 15 to 1001 participants. One longitudinal CDS was clinician-facing only, 5 were patient-facing only, and 2 were both clinician- and patient-facing. Study outcomes varied, ranging from measurement of self-management behaviors ($n = 1$), clinical outcomes ($n = 2$), self-reported symptoms ($n = 4$), recommendation accuracy ($n = 1$), and system use ($n = 1$). One longitudinal CDS used a Bayesian algorithm in the CDS architecture; no other CDS used artificial intelligence modeling in generating decision support.

All CDS had several elements in common: none used a longitudinal CDS framework, none used entirely automated data entry, and none used living guidelines for updating the evidence base or knowledge engine as new evidence emerged during the longitudinal study. One commonality was positive: seven of the eight studies[15–21] performed prospective implementation and data capture.

Readiness for change assessments were sparse

Of the eight CDS, one—reported by Horwood et al.[20]—included formal readiness for change assessments. Nurses in rural Africa who would be entering information about children's conditions in a computer based-CDS were assessed for their capabilities, opportunities, and motivation according to a behavior change framework developed by Michie et al.[22] In a rural African setting where computer-based care was not routine, this assessment demonstrated that 40% of the nurses were "not very confident" (indicating the least possible confidence) about using a computer, and 60% had not used a computer within the last month.

Table 1. Summary of included studies.

Reference	Study population	CDS architecture	CDS performance summary	Challenges to longitudinal CDS	Facilitators to longitudinal CDS
Begley[14]	21 adult patients with epilepsy at 3 clinics in Houston, TX	Patient-facing CDS displays a list of "at-risk" self-management behaviors derived by comparing patient survey responses to evidence and guides the patient in developing medication management goals	The average frequency of at-risk lifestyle self-management behavior decreased over time; the frequency of medication and seizure management behaviors remained constant	The patient interface showing the longitudinal comparisons with prior timepoints was not intuitive and required additional attention	Use of a tablet PC platform for manual data entry by patients
Chiang[15]	4 synthetic and 4 real patient seizure diaries, 24 epilepsy clinicians	Patient-facing CDS uses a Bayesian algorithm and captures temporal dependencies using a Markov process, predicts risk for outpatient seizure, and generates recommendations accordingly	Compared with clinicians, the algorithm had greater accuracy (87.5% vs. 74.7%, P = 0.002) in generating recommendations according to seizure risk	Inter-rater reliability of clinicians was low-moderate, which challenged the use of clinician data as a longitudinal comparison group to assess efficacy of the CDS	Longitudinal assessment of seizure based on raw seizure frequency is confounded by natural variability; the algorithm allowed formal assessment of seizure control rather than raw frequency
Hooker[1]	214 adult women with BRCA1/2 mutations	Patient-facing interactive decision aid mailed by CD-ROM which uses user-entered information to tailor informational content; compared with usual care in a randomized trial	Women randomized to the CDS group had lower cancer-specific distress and genetic testing-specific distress but similar overall distress over 12 months	Actual use of the CDS could not be tracked because it was administered as a CD-ROM mailed to participants; an unexpectedly small number of women chose to undergo prophylactic mastectomy, so assessments of decision-making outcomes were underpowered	Prospective enrollment and active follow-up were successful, resulting in enrollment of 91% of eligible participants with minimal dropout over time
Horwood[12]	15 nurses specializing in managing childhood illness	Provider-facing CDS in which nurses enter information about children's conditions in a computer-based CDS which then generated patient-specific classifications and treatment recommendations	Overall uptake across 15 clinics was low, never greater than 40% in 12/15 clinics, never reached 70% in any clinic	Technical support required computer skills to access and nurses lacked computer skills, the CDS disrupted workflows, increasing administrative workload	At several clinics, uptake increased over time as nurses gained additional exposure to the CDS

(continued)

Table 1. Continued.

Reference	Study population	CDS architecture	CDS performance summary	Challenges to longitudinal CDS	Facilitators to longitudinal CDS
Kunzler[16]	246 chronically ill patients expected to lose decision-making capacity within 18–24 months, plus their caregiver	Patient-facing CDS in which patients and caregivers together complete advance care planning documentation, post-hoc analysis of randomized trial data	Use of the CDS was not associated with less caregiver strain, burden, or anxiety longitudinally	The study was performed in an exploratory fashion due to lack of prior longitudinal data on the topic and so study design may have been suboptimal	Used existing randomized trial data that was collected longitudinally
Leighl[13]	207 patients who were considering chemotherapy for metastatic colorectal cancer	Patient-facing take-home decision aid booklet with audio recording sharing information about chemotherapy for metastatic colorectal cancer compared with standard care in a randomized trial	The decision aid increased understanding of prognosis, options, and benefits compared with standard care ($P < 0.001$) and did not affect anxiety, decisional conflict, or treatment decisions	Most patients felt confident in their decision at the time of initial consultation, so the longitudinal effects of the CDS were difficult to assess; using a booklet (rather than living guideline) hindered incorporation of new evidence-based information in the decision aid	Prospective patient enrollment with active follow up facilitated longitudinal information capture
Wang[17]	1001 patients with atrial fibrillation and moderate-high risk for stroke	Patient- and provider-facing CDS toolkit. Included a brief video, interactive questions, quiz evaluating understanding, patient worksheet, and an online guide for clinicians compared with standard care in a randomized trial	The CDS decreased decisional conflict (primary endpoint) at 1 month ($P = 0.007$)	The intervention was delivered only once, so it could not be assessed whether repeated exposure to the intervention would prolong its effects	Prospective enrollment with active follow up and a digital interface allowed for an adequate sample size and low dropout rate (5.8%) despite the COVID-19 pandemic
Zhang[18]	126 type 2 diabetes patients whose PCPs ($N = 43$) participated in a QI project to improve glucose control, 147 control patients	Patient- and provider-facing CDS in which patients complete a survey about blood glucose control, the CDS recommended personalized treatment regimens based on society guidelines	Patients in the intervention group had a 1.7% (SD 2.8) decrease in hemoglobin A1c (measure of long-term glucose control) over time); controls decreased A1c by 1.3% (SD 2.3)	Use of locked society guidelines (rather than a living guideline) did not allow for incorporation of new evidence in the CDS longitudinally	Feedback from providers allowed CDS developers to redesign the user interface over time and move frequently used fields to the top of the screen

CD-ROM: compact disc read-only memory, PCP: primary care provider, and QI: quality improvement.

Qualitative analyses of in-depth interviews revealed that the CDS was poorly aligned with other priority clinic programs, which may have affected nurses' motivation to use the CDS. Throughout the study period, CDS uptake—calculated as the proportion of all consultations with children aged less than 5 years in which the CDS was used—was never greater than 40% in 12 of 15 clinics, never reaching 70% in any clinic. Among four of the other seven

CDS,[16,18,19,23] there was no evidence of a statistically significant change in behavior, decisions, or perceptions, and it remains unknown whether results would have been positively affected by selection of participants who were ready for change, or by implementation of methods intended to increase readiness.

Challenges to longitudinal CDS

Four CDS encountered study design challenges. Kunzler et al.[19] performed an exploratory longitudinal CDS study, presumably because longitudinal data on the topic were unavailable when their study began. In the absence of a power analysis or sample size determination, it was difficult to ascertain the false negative rate, i.e. finding no observed association between the CDS and decreased caregiver strain, burden, or anxiety when one actually existed. For the CDS proposed by Chiang et al.,[18] focused on predicting outpatient seizures among patients with epilepsy, the authors used clinician assessments alone (i.e. unaided by CDS) as a comparison for the CDS. Inter-rater reliability of clinicians was low–moderate, which compromised the statistical validity of the comparison. Wang et al.[21] delivered the CDS intervention, focused on anticoagulation decisions for patients with atrial fibrillation and at risk for stroke, only once and then assessed outcomes (primarily, decisional conflict) over time, so it could not be assessed whether repeated exposure to the intervention would prolong its effects. Finally, Leighl et al.,[16] whose CDS focused on chemotherapy decisions by patients with metastatic colorectal cancer, found that most patients already felt confident in their decision at the beginning of the study, hampering assessment the longitudinal effects of the CDS. Two CDS faced user interface challenges. Begley et al.[17] noted that their patient interface which showed longitudinal comparisons with prior timepoints was difficult for users to interpret. The clinician-facing CDS proposed by Horwood et al.,[20] whose CDS focused on medication management by patients with epilepsy, was hindered by a lack of user computer skills. Technical support was made available by the investigator team, but technical support was accessible only by computer. Finally, Hooker et al.[15] provided their CDS to patients by mailing them a CD-ROM, which meant that they could not track its use.

Facilitators to longitudinal CDS

Four CDS[15,16,19,21] optimized enrollment and follow-up via randomized trial or post-hoc analysis of randomized trial designs. Two CDS may have benefitted from the longitudinal design itself. Zhang et al.[23] used feedback from clinicians to redesign and optimize the CDS user interface over time by moving frequently used fields to accessible, highly visible areas. Horwood et al.[20] noted that clinical uptake increased over time as users gained additional exposure to the CDS. One CDS demonstrated the potential advantages of machine learning approaches that are tailored to the CDS use case. Chiang et al.,[18] in developing a CDS built on seizure prediction, recognized that longitudinal assessment of seizure based on raw seizure frequency is confounded by natural variability in the disease process. Therefore, they used a Bayesian algorithm and captured temporal dependencies using a Markov process to allow formal assessment of seizure control rather than raw frequency, with good results: the algorithm had significantly greater accuracy than clinicians in predicting seizure. Although no CDS used living guidelines to incorporate emerging evidence, doing so would represent another advantage of the longitudinal design model.

Discussion

This review highlights the lack of peer-reviewed reports of longitudinal CDS, and that CDS in existing reports lack longitudinal CDS frameworks, automated data entry, living guidelines, and readiness assessments. These findings suggest major opportunities to improve the volume and quality of longitudinal CDS in efficiently and effectively representing decision evolution while simultaneously demonstrating the how information and users' readiness for change evolves over time. To this end, several common themes emerged regarding challenges and facilitators to longitudinal CDS.

Concerns regarding study design were apparent in half of the included articles, consistent with the pioneering nature of longitudinal CDS scientific investigation; as peer-reviewed literature accumulates, investigators designing studies will access a greater repository of salient knowledge. Similarly, challenges in designing optimal user interfaces and CDS delivery mode may be attributable to a lack of guidance on best practices. These would require a greater depth and breadth of published work alongside expert opinion on longitudinal CDS. The most common facilitator to longitudinal CDS was performing a randomized trial for optimizing enrollment and follow-up. Unfortunately, performing randomized trials is resource intensive; other, more accessible facilitators are needed. One investigator group[18] demonstrated the potential utility of integrating machine-learning algorithms into CDS to escape the constraints of linear and rule-based knowledge engines when representing complex, nonlinear processes like longitudinal seizure activity.

We are unaware of any prior reviews regarding longitudinal CDS. Although CDS gained prominence in the 1980s and have evolved substantially, longitudinal CDS are relatively novel.[1] We hope that this review will highlight the sparsity of peer-reviewed literature regarding longitudinal CDS and encourage the scientific community to increase the volume and quality of longitudinal CDS development, implementation, and investigation.

Although published literature contains too few examples for making evidence-based recommendations of best practices in longitudinal CDS, several opportunities emerge from this review. First, for purposes of standardization and reproducibility, it seems prudent to use a longitudinal CDS framework like SEIPS.[13] Second, to improve efficiency and decrease user activation energy, longitudinal CDS should use automated data entry techniques. All CDS may benefit from automation, but it may be especially important for longitudinal CDS that depend on the same users opting to maintain engagement with the CDS over time. There may be opportunities to integrate automation steps with artificial intelligence algorithms that enable and augment the CDS, as previously described for nonlongitudinal CDS.[24–26] Third, to maintain up-to-date evidence and knowledge, longitudinal CDS should abandon static rules and knowledge engines and instead use living guidelines that are updated in real time as evidence emerges. Fourth, readiness assessments should be performed to ensure that the right person is receiving the intervention at the right time and to aid in interpretation of negative results by determining whether a lack of change in behavior, decisions, or perceptions was inevitable, rather than a failure of the CDS itself.

Limitations

This scoping review was limited by the small number of included studies, although highlighting the small number of relevant studies is an important outcome. Although the small number of included studies could indicate that more time must pass before it would be ideal to review longitudinal CDS, we see value in an early description of published work that identifies barriers and facilitators that may aid future endeavors. Also, because it is difficult to replicate the article search parameters when surveying nonclinical bibliographic databases, and because our focus was on clinical aspects of CDS, this review does not include articles from more technical, nonclinical peer-reviewed journals.

Conclusions

There are few peer-reviewed reports of longitudinal CDS. Existing reports suggest opportunities for improvement by incorporating longitudinal CDS frameworks, automated data entry, living guidelines, and user readiness assessments. These opportunities are observed in the absence of guidance on best practices for longitudinal CDS; generating best practice guidelines would require a greater depth and breadth of published work and expert opinion. We hope that this review will encourage the scientific community to embark on a course of increasing the volume and quality of longitudinal CDS that accurately represent the evolving nature of many healthcare decisions.

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ORCID iDs: Tyler J Loftus https://orcid.org/0000-0001-5354-443X
Jeremy A Balch https://orcid.org/0000-0002-1826-7884
Christopher J Tignanelli https://orcid.org/0000-0002-8079-5565

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