

Enabling Patient-Centered and Interoperable Patient-facing Clinical Decision Support: Recommendations from the PCCDS Learning Network

Laura Haak Marcial, PhD¹, Beth Lasater, MSPH¹, Joshua E. Richardson, PhD, MS, MLIS¹, Barry Blumenfeld, MD, MS¹, Danny van Leeuwen, Opa, RN, MPH², Shafa Al>Showk, MPH³, Brian S. Alper, MD, MSPH, FAAFP, FAMIA⁴, Noam H. Arzt, MSEd, PhD, FHIMS, FAMIA⁵, Amy Baxter, MD⁶, Steve Bernstein³, Aziz Boxwala, MD, PhD, FACMI⁷, James Breen, PharmD⁸, David A. Dorr, MD, MS⁹, Roland Gamache, MBA, PhD³, Bryan Gibson, DPT, PhD¹⁰, Camilla A. Hayden, RN, BSN, MS¹¹, Melinda L. Jenkins, PhD, FNP¹², Caterina E.M. Lasome, PhD, MSN/MBA, MHA, RN, CPHIMS¹³, Zhen Lin, PhD, MS, RN¹⁴, David F. Lobach, MD, PhD, MS¹⁵, Edwin Lomotan, MD³, Ginny Meadows, MSHI, RN-BC¹⁶, Maria Michaels¹⁷, Vivek N. Narra M.S., Pharm. D.¹⁸, Kelly W. Reeves, BSN, RN, UXC¹⁹, Phillip Warner¹⁰, Kensaku Kawamoto, MD, PhD¹⁰

¹RTI International, Durham, NC; ²Health Hats, Boston, MA; ³Agency for Healthcare Research and Quality, Rockville, MD; ⁴EBSCO Health, Ipswich, Massachusetts; ⁵HLN Consulting, LLC; ⁶CEO Pain Care Labs Atlanta GA; ⁷Elimu Informatics Inc., Richmond, CA; ⁸First Databank, Inc; ⁹Oregon Health & Science University, Portland, OR.; ¹⁰University of Utah, Salt Lake City, UT; ¹¹Cognosante, Columbia, MD; ¹²Rutgers University, Newark, NJ; ¹³iON Informatics, LLC, Eagle, ID; ¹⁴Zhen Research; ¹⁵Klesis Healthcare, Durham, NC; ¹⁶The MITRE Corporation, McLean, Virginia; ¹⁷Centers for Disease Control and Prevention (CDC), Atlanta, GA; ¹⁸University of California Davis Health, Davis, CA; ¹⁹Atrium Health, Charlotte, North Carolina

Introduction

With the advent of interoperability standards such as Health Level 7 International (HL7) Fast Healthcare Interoperability Resources (FHIR), CDS Hooks, and Clinical Quality Language (CQL), patient-facing clinical decision support (PCCDS) seems imminent. However, integrating effective PCCDS into clinical care remains stagnant. In 2019, the Agency for Healthcare Research and Quality (AHRQ)-sponsored PCCDS Learning Network chartered the Patient-facing CDS Application Development Work Group (PFWG) to develop recommendations to address these two barriers, with chronic pain management chosen as an exemplar use case. Through an open, multi-stakeholder process that engaged 102 representatives from healthcare, industry, and academia, and a panel of 10 patient advocacy experts, this Work Group developed recommendations for patient-centered design across 4 axes: plan, communicate, adjust, and support. The group also developed recommendations around interoperability, developed a prototype PCCDS application integrated with the Epic® electronic health record (EHR), and identified features essential for any minimum viable product to contain. If applied broadly, the recommended features should help teams develop and deliver patient-facing CDS applications that are both useful and interoperable.

Attendees to this session will be apprised of 1) methods for engaging patient advocates in a user-centered design approach to application development; 2) the features a patient-facing CDS application should include to meet the needs of patient users; and 3) the core technical considerations to address in order to use a standards-based approach in the development of a patient-facing CDS application which can interface with the patient portal of an electronic health record system.

Traditional CDS applications have focused on clinicians despite the potential for patient-facing CDS to engage the ultimate beneficiary of these tools: the patient. In addition, patient-facing CDS systems are in limited use and have limited uptake in part because they are poorly integrated into the EHR environment and have limited use among patients. There is a need for the development and integration of patient-facing CDS solutions that are seamlessly integrated with EHRs and the clinical workflow that engage patients directly in their care.

Methods

Subject matter expert (SME) recruitment. Calls for participation in the PFWG were sent via email to the PCCDS Learning Network mailing list and to several related list serves (HL7 and AMIA). Interested parties were asked to complete an online form with basic demographic information, availability, and interest in serving on the PFWG.

PFWG goals. The PFWG was chartered to address two primary goals: 1) development of a set of patient-centered usability design guidelines for patient-facing PCCDS applications; 2) development of recommendations for enabling interoperability of such applications with EHRs and their patient portals, as well as implementation of an initial prototype application to validate the feasibility of the recommended approach. Pain management was used as an exemplar use case to focus discussions.

PFWG deliberations. A total of 18 web conference calls were held biweekly between March 22, 2019 and October 25, 2019. All participants were asked to contribute both during and between meetings and to volunteer to present work of their own to the broader group on CDS-related initiatives. Patient advocates were actively engaged. Final report-out and vetting of the recommendations occurred during the PCCDS Learning Network Annual Conference on October 21, 2019.

Results

Membership and participation: A total of 102 subject matter experts (SMEs) volunteered to serve on the PFWG. Participation averaged about 20 members per biweekly call, and 34 members contributed to at least 8 (45%) of the 18 calls or otherwise made substantial contributions to the PFWG deliverables including this manuscript. Of these 102 members, 33 were affiliated with academic institutions, 32 with consulting firms, 10 with government, 48 with research organizations, 5 with EHR vendors, and 31 with a health system (many participants had overlapping roles). The PFWG was co-chaired by a patient advocate (DV) and a clinical informaticist engaged in standards development (KK).

Patient engagement: Beyond the working group calls, one of the PFWG co-chairs (DV) refactored interim recommendations into lay patient language then engaged his network of contacts in the patient advocacy community to refine the recommendations. This engagement included email and list serve-based communications as well as an invitation to a Work Group call for highly engaged members of the community.

Recommendations for Patient-Centered Design: The PFWG members, and in particular the patient advocates, identified four feature areas for developers to focus on in creating patient-facing CDS applications: 1) **Plan:** Set goals (both personal and clinical) and associated integrated care plan based on circumstances, preferences, values, and shared decision making; 2) **Communicate:** Enable seamless multidirectional communication between clinical and lay teams; 3) **Adjust:** Record, manage, track, evaluate and prioritize to adjust integrated care plan and personal and clinical outcomes; and 4) **Support:** Engage clinical, peer, and community support for the integrated care plan

Minimum Viable Product (MVP) Features: Based on the patient-centered design principles, the PFWG identifies features of an MVP applied to the domain of pain management. The PFWG determined that an MVP should enable a patient-centered pain management care plan that is accessible to all relevant stakeholders, has appropriate access controls, is updatable by stakeholders including patients themselves, and is trustable (e.g., so an emergency department physician can identify and trust the latest physician-validated plan on opioid therapy for breakthrough pain).

Recommendations for Interoperability and Prototype Implementation: The PFWG identified SMART on FHIR as the recommended approach for integrating with EHRs and their patient portals. The HL7 CQL and CDS Hooks standards were also identified as potential standards to leverage in patient-facing CDS applications. A demonstration SMART on FHIR application for opioid morphine milligram equivalence calculation, which uses CDS Hooks for the underlying knowledge encapsulation, was successfully implemented and integrated with the Epic® EHR.

Conclusion

Patient-facing CDS applications can be developed in a standards-based way to leverage information in EHRs and integrate with the patient portal. Such CDS applications should provide support in four core areas: planning, communicating, adjusting, and supporting patients and their care. Engaging patients and patient advocates is critical for developing useful patient-centered tools in health care.

Discussion

Future directions and next steps for this work should include a focus on the concept of an integrated and coordinated care plan which includes the people at the center of care. Further, we need to identify and spread what is working (and some of what is not working). We also need to keep in mind that there is a lag in aligning needs with the technology to support the right types of solutions. There is also a central issue of misaligned incentives which may be solved in part by value-based care.

Connecting patient-facing CDS applications to EHRs using current standards is achievable. Patient-facing application development must be patient-centered in its design and implementation. Engaging patients in the design process early and often will improve use and satisfaction. Patient-facing CDS applications need to incorporate four core features to support patients: 1) help with planning, 2) support communication, 3) be adjustable, and 4) provide ongoing support of care delivery and management.

At the AMIA Annual Meeting in November, there was a lot of discussion about the development of patient-facing applications. Some of the discussion centered around connecting applications to EHRs, some around encouraging patient uptake and use, and some around design of solutions in the form of end-to-end solutions for patients and their providers to engage in meaningful shared decision making.

References

1. Adler-Milstein, Julia, Nong, Paige (2019). Early experiences with patient generated health data: health system and patient perspectives. *Journal of the American Medical Informatics Association* (26) 10. pp. 952-959. DOI 10.1093/jamia/ocz045.
2. Bates, David W. Kuperman, Gilad J. Wang, Samuel Gandhi, Tejal Kittler, Anne Volk, Lynn Spurr, Cynthia Khorasani, Ramin Tanasijevic, Milenko Middleton, Blackford (2003). Ten Commandments for Effective Clinical Decision Support: Making the Practice of Evidence-based Medicine a Reality. *JAMIA* (10) 6. pp. 523-530. DOI 10.1197/jamia.M1370.