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Appendix: Content Summaries of Selected Best Papers for the 2020 IMIA Yearbook, Special Section on Ethics in Health Informatics

Antonio MG, Petrovskaya O, Lau F

Is research on patient portals attuned to health equity? A scoping review

J Am Med Inform Assoc 2019 Aug 1;26(8-9):871-83

In this scoping review, the authors assessed how research on patient portals addresses health inequity. They sought to understand the health equity concepts explicitly and implicitly addressed in patient portal research; identify gaps in such research; assess whether eHealth-related inequities are acknowledged in patient portal research; and identify strategies to reduce health inequities that are being tested in such research. The authors used the eHealth Equity Framework (eHEF) to identify search terms and searched CINAHL, MEDLINE, Embase, and Scopus for "patient portal" plus various health equity terms (*e.g.,* socioeconomic factors, digital divide) to identify articles to include in the review. They then independently reviewed the 65 articles meeting the inclusion criteria. Using the eHEF for analysis, they identified four themes: 1) eHealth policies, governance approaches, and cultural and societal values may further inequities; 2) providers and patients differ in preferences for portal use based on social position; 3) diverse user-centered designs facilitate equitable portal implementation; and 4) intermediary strategies for promoting portal use among populations are frequently suggested. The authors note that published work focuses on barriers to portal use, which shifts responsibility for addressing barriers to those who already experience the largest health disparities and potentially obfuscates the effect of social, technical, economic, and political factors on outcomes. The authors conclude that the informatics community must focus on developing equitable strategies at the policy, practice, research, and implementation levels to drive change.

Lehmann CU, Petersen C, Bhatia H, Berner ES, Goodman KW

Advance directives and code status information exchange: a consensus proposal for a minimum set of attributes

Camb Q Healthc Ethics 2019 Jan;28(1):178-85

Advance directives (ADs) benefit patients and their families by improving care and quality of life, and by making it more likely that patients have the end-of-life experience they desire. However, the use of ADs and the communication of code status happen infrequently, and documenting ADs and code status in the electronic health record (EHR) remains difficult. Members of the American Medical Informatics Association's Ethics Committee determined that a minimum data set for the storage and exchange of code status information could support greater use of ADs, and they performed an environmental scan to identify existing resources that could facilitate such documentation in the EHR. Through multiple conference calls, work group members achieved consensus around a proposed minimum data set with links to the HL7 C_CDA Advance Directives Module. Data categories include information about: 1) the organization obtaining the code status information; 2) the patient; 3) supporting documentation; and 4) the desired code status information including mandatory, optional, and conditional elements. These three types of elements prevent the creation of an incomplete document that will not support achievement of patients' goals end-of-life while managing the clinical burden associated with creating such documentation. The resulting data set facilitates communication of patient goals and preferences across multiple providers and health care settings. It is intended that the identified data elements function as a starting point for discussion among informaticians, physicians and staff, and EHR vendors.

Pisani AR, Kanuri N, Filbin B, Gallo C, Gould M, Lehmann LS, Levine R, Marcotte JE, Pascal B, Rousseau D, Turner S, Yen S, Ranney ML

Protecting user privacy and rights in academic data-sharing partnerships: principles from a pilot program at crisis text line

J Med Internet Res 2019 Jan 17;21(1):e11507

Collaborations between academic researchers and technology companies historically have been difficult to develop because of differing needs and goals related to data privacy and security, intellectual property, technical requirements, ethics, and other issues. Companies and academic institutions often are subject to different regulatory requirements, and companies may incur costs from sharing data for noncommercial use without gaining commensurate benefits from such activity, making companies reluctant to do so. This paper describes an 18-month pilot undertaken by a non-for-profit technology company with 20 research teams at 18 universities in which data from a crisis text line was shared for research purposes. Design, development, and implementation of principles and protocols for ethical, secure sharing of crisis text line user data were the main objectives of the work. To accomplish this, the company created a data ethics committee, identified policy barriers and potential ways to address them, publicized the initiative, revised the policy, and launched the pilot. After program completion, the company evaluated it against other potential program models and modified its approach as appropriate. This paper describes the resulting 3-step set of guidelines for working with academic research organizations, which focus on 1) define the value and suitability of data and institutions for data-sharing programs; 2) choose a model for collaboration involving data sharing; and 3) identify the most appropriate institutional structure and develop technical approaches for ethical, secure data sharing. The paper also describes how internal evaluation of the pilot indicated successful achievement of its primary goal, shares principles and processes that may be useful to other companies, and suggests other data-sharing models that may work better in other circumstances.