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Highlights

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The importance of consumer- and patient-oriented perspectives in biomedical and health informatics

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An American Medical Informatics Association position paper reporting a clinical informatics practice analysis[1] leads off this issue of *Journal of the American Medical Informatics Association* and is contextualized by an editorial from Doug Fridsma[2] in which he notes that "Recognition of the unique set of knowledge and skills associated with clinical/health informatics practice will create opportunities and raise expectations for informatics professionals." Regarding expectations for informatics professionals, the clinical practice analysis includes multiple specific tasks related to consumers and patients with associated areas of knowledge such as social determinants of health, use of patient-generated data, and consumer-facing health informatics applications (eg, patient portals, mobile health apps and devices, disease management, patient education, behavior modification). To emphasize this aspect of our field, I highlight other articles in this issue that explicitly reflect a consumer- or patient-oriented perspective.

Bajracharya et al[3] examined patients' experiences of completing a 39-item family history via a patient portal; the results were summarized and integrated into their electronic health record (EHR). About one-third of 4223 patients who completed the family history also completed an online survey. Inductive analysis of free-text responses generated 5 main themes. On the positive side, patients described feeling empowered through sharing their family history and anticipated future predictive value from having the information integrated into the EHR. However, although the history tool was considered easy to use, it was also characterized as tedious, with some respondents raising concerns about validity (eg, not reflecting the complexity of family history) and privacy (eg, possible influence on insurance and employment). These findings suggest not only the continued promise of such an approach, but also the need for solutions that better address patient concerns.

Harle et al[4] conducted a randomized trial that compared the primary outcomes of patient-reported satisfaction and subjective understanding in 3 e-consent conditions for future research use of identifiable EHR data: interactive trust-enhanced e-consent to an interactive-only e-consent and a standard e-consent (no interactivity, no trust enhancement). Additional secondary outcomes included objective knowledge, perceived voluntariness, trust in medical researchers, and consent decision. Over 94% of participants agreed to share their health record data and reported moderate-to-high satisfaction and subjective understanding. There were no statistically significant differences in outcomes among the 3 consent conditions. However, Black participants and those with lower education reported lower satisfaction, subjective understanding, knowledge, perceived voluntariness, and trust in medical researchers and experienced a longer time in the consenting process. In addition, Hispanic as compared with non-Hispanic participants also reported lower trust in medical researchers and spent more time on the consent process. While the overall consent rate was high, these findings suggest the need for novel solutions to improve the disparities related to the consent process so that consent is truly informed.

Patient-powered research networks (PPRNs) are a core component of the National Patient-Centered Outcomes Research Network and serve as a valuable resource of a variety of patient-generated data including those that are self-reported. Agiro et al[5] implemented privacy-preserving record linkage processes for PPRN member and health plan enrollee data, compared linked and nonlinked members, and measured disease-specific confirmation rates for specific health conditions. They found that PPRN membership and health plan data can be successfully linked using privacy-preserving record linkage methodology and that health plan data can be used to confirm self-reported diagnosis from the PPRN. This method for confirming self-reported diagnosis of members may expedite patient selection for research opportunities and shorten study recruitment timelines.

In the consumer health informatics area, Lee and Kim[6] conducted a small randomized trial that compared 2 methods of app selection (Method of App Selection based on User's Needs [MASUN] vs app selection based on high worldwide use) on health-related factors of women with dysmenorrhea and premenstrual syndrome. The number of symptom relief methods did not differ significantly between groups, but users of the app selected based on MASUN showed significant improvements in overall satisfaction, app outcome expectancy, the number of days with records, app social influence, intent to recommend, and the possibility of behavioral or cognitive changes in their symptom management. Perhaps owing to increased awareness, dysmenorrhea pain increased in the MASUN group. An app selection process designed to match potential apps to the needs of target users offers promise to influence health-related factors.

Aligned with Fridsma's contention that recognition of the unique knowledge and skills will raise expectations of our informatics practice, I argue that we must elevate attention to consumer- and patient-oriented perspectives to ensure that we are doing what matters most to advance health and health equity.

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