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Use of clinical care registries to facilitate research study recruitment.

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Abstract Disclosures

Abstract

129

Background: We developed IRB-approved secure research registries for our Breast Imaging and Breast Care Clinics at Moores UC San Diego Cancer Center, as part of the UC statewide Athena Breast Health Network. Our clinical care registries securely store patient-reported intake data, which are summarized and uploaded into the medical record for patient care. Following consent, data are securely maintained in a separate research registry. In addition to facilitating quality assurance data collection, these registries aim to 1) maintain a data-rich research registry, 2) offer patients research opportunities, and 3) facilitate participant screening and recruitment into research studies. Methods: Breast Imaging or Breast Care clinic patients complete an online clinical intake form prior to their appointment, either at home or using an iPad in clinic, and are given the opportunity to be involved in research. Patients are asked for site-specific consent to keep personally identifiable intake data in a research registry, for consent to be approached about providing a biospecimen sample, and for consent to be contacted for future research opportunities. Data from consented participants are pulled into secure databases available to study personnel. Results: Participants to date include 4,480 patients, of whom 3,246 consented to use of data for research (72%), and 2,627 have agreed to be contacted for future research opportunities (59%). In a pilot biospecimen collection protocol, 46% of patients agreed to be approached and we have collected over 360 blood or saliva and 51 tissue samples. Additionally, with the use of future contact consent, we have facilitated recruitment of more than 370 participants to multiple lifestyle and survey-based clinical studies. Conclusions: Patients are willing to participate in research, especially in a research registry that requires little additional time on their part.

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research registries allows collection of a variety of data elements useful for prescreening participants for research studies, including body mass index, age, menopausal status and breast cancer diagnosis. Data- and participant-rich research registries facilitate efficient screening and recruitment for other research studies.

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