PS1-21:

Developing New Products to Support Patient-Centered Cancer Communication: A Case Example from the Cancer Communication Research Center

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Background/Aims: The Cancer Research Network Cancer Communication Research Center (CCRC), one of five National Cancer Institute-funded Centers of Excellence in Cancer Communication Research, had the unique opportunity to collaborate with colleagues from the National Cancer Institute (NCI) to conduct real world testing of an NCI-developed decision aid. This abstract describes the feasibility and small scale implementation testing of the NCI-developed cancer prognostic tool, the Cancer Survival Query System (CSQS). **Methods:** A web-based prognostic tool, the CSQS was developed by the Statistics Research and Applications Branch of the NCI in 2008. It was designed for physicians to use so they could better understand and communicate with cancer patients valid estimates of their cancer survival within the context of all causes of death. Our research team at the CCRC has completed stage one feasibility testing of the CSQS tool in four health care delivery systems and will soon begin a small-scale implementation study of this tool in three health care delivery systems in Colorado. We are also proposing a more structured process of product development and developed a comprehensive plan for the dissemination and implementation of CSQS. **Results:** A total of 57 providers from four health care delivery systems participated in formal usability testing and semi-structured interviews. Providers perceived CSQS as a well-designed tool that has the potential of increasing provider efficiency delivering prognostic information, and improving patient experience and understanding of this information. Feedback from these providers informed the revision of the CSQS content and format, and the development of a structured, large-scale dissemination and implementation plan. An ongoing small-scale follow-up study is testing strategies for the dissemination and implementation of this web-based decision aid. Findings available to date from both studies will be discussed in this presentation. **Conclusions:** Development of decision aids that support patient-centered communication requires a multi-step, iterative process and the early engagement of multiple stakeholders including potential users and organizational decision makers. This case study exemplifies different aspects of this process and illustrates lessons learned in this area from the work in the CCRC.

Keywords: Decision Aids; Cancer; Implementation

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PS1-22:

A Systematic Review of Web-Based Cancer Prognostic Calculators: Can They Support Patient-Centered Communication with Cancer Patients?

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Background/Aims: Information about cancer prognosis is a main topic of interest for cancer patients and clinicians alike. Prognostic information can help with decisions about treatment, lessen patients' uncertainty and empower them to participate in the decision making process. Calculating and communicating cancer prognostic information can be challenging due to the high complexity and probabilistic nature of the information. Furthermore, prognostic information is further complicated by the potential interplay between cancer and other comorbid medical conditions. The purpose of this presentation is to present findings from a systematic review of web-based interactive prognostic calculators and assess how they might support patient-centered communication of prognostic information with cancer patients.

Methods: A systematic review of web-based cancer prognostic calculators was conducted using web search engines, peer-reviewed manuscripts, and expert input. Calculators had to be interactive, focus on cancer, available in English, and provide information about probabilities of survival/mortality, recurrence, spread, or clinical response to treatment. Eligible calculators

were reviewed and abstracted for content, format, and functions of patient-centered communication and findings were summarized in a tabular format for comparison. The abstraction guide was pilot tested by all abstractors and was refined using a consensus approach. **Results:** A total of 22 eligible web-based cancer prognostic tools including 95 individual calculators for 88 distinct cancer sites were identified and abstracted. Thirteen of the tools recommended patients as potential direct users; all other tools were designed for clinicians. Outcomes presented will include: 1) general description of calculators, including cancer type, designated users, types of data elements used in prognosis prediction, and validation, 2) calculator interface data entry features, and graphic output, 3) interpretation of prognosis and additional resources, 4) strengths and limitations in supporting patient-centered cancer communication about cancer prognosis. Examples from selected calculators will be demonstrated throughout the presentation. **Conclusions:** A large number of web-based cancer prognostic calculators have been developed and are available for use by cancer specialists and patients. The ability of most of these calculators to support patient-centered calculators around cancer prognosis is limited by their design and content and the degree to which they include and present information in an actionable way.

Keywords: Patient-Centered Communication; Prognosis; Decision Aids

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PS1-23:

Capitalizing on the HMO Cancer Research Network (CRN): The Optimal Setting to Conduct Studies of Rare Complex Diseases

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Background/Aims: Rare cancers are challenging to study, both epidemiologically and clinically, as it is difficult to ascertain enough cases to achieve adequate statistical power or to be representative of a vast range of exposures. Further, as the complexity of unraveling the natural history of disease has increased, a large investigator team with diverse expertise is required to optimize the scientific contributions that can be mined from research projects. The HMOCRN provides a setting that can overcome these barriers. Although many studies evaluate all lymphomas combined, lymphoma consists of over 50 rare histological subtypes with varying incidence and survival rates and epidemiological features. Ideally, each histological subtype should be considered separately in etiological studies, but even the most common, diffuse large B cell lymphoma, has a SEER incidence of only 7.5 per 100,000 in men and 5.0 per 100,000 in women. Other lymphoma types range in incidence from <0.1 cases per 100,000 for NKT cell lymphoma to 2.8 per 100,000 for Hodgkin's Disease in all race-sex groups combined, to the highest rate found for a population subgroup, only 8.8 per 100,000 for multiple myeloma in African American men. **Methods:** We have assembled a multi-disciplinary team interested in lymphoma and pharmacoepidemiology that includes investigators with clinical, epidemiological and biostatistical expertise from six HMORN sites, two US universities, the NCI, and an international investigator who first initiated the project. **Results:** Combining data from these HMOCRN sites from 1998-2008, we ascertained 1479 Hodgkin's Disease cases, 3385 multiple myelomas, 771 T-cell lymphomas, (including 390 mycosis fungoides cases and 158 mature T-cell lymphomas), 3000 chronic lymphocytic leukemias, 1357 mature B cell lymphomas, 3883 diffuse large B cell lymphomas, 2188 follicular lymphomas, and 992 marginal zone B cell lymphomas. **Conclusions:** These numbers provide a unique opportunity to analyze many of the lymphoma subtypes as well as consider multiple confounders and effect modifiers, thus highlighting the strength of the HMOCRN setting for the study of uncommon diseases. Further, such multi-site studies allow for variation in study population geography and patient and treatment diversity, as well as embrace intellectual capital from numerous HMOCRN investigators and external collaborators.

Keywords: Epidemiology; Rare Diseases; Lymphomas

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