ECRS

Workshop I

Workshop title: Implementing patient-reported outcomes in routine clinical practice.

Organized by: Andrew Wickers, PhD, Department of Epidemiology and Biostatistics, Memorial Sloan Kettering Cancer Center

Description:
It is widely accepted it would benefit patients to implement patient-reported outcomes (PROs) in routine clinical practice. There is considerable evidence that clinicians underestimate patient symptom burden and, of course, clinicians cannot evaluate patients unless they are in clinic. Several randomized trials show that patients who provide PRO to their clinicians, particularly if doing so from home, experience lower symptom severity – due to earlier intervention – and, in the case of cancer, greater survival. Paper and pencil PROs are not generally practicable in routine care; the advent of the internet has dramatically changed our ability to make PROs part of routine care. That said, implementation of PROs in clinical practice is far from straightforward: it is not a case of simply setting up an electronic portal, uploading a questionnaire and letting the rest take care of itself. The first problem is that PRO instruments were generally developed for use in the research setting and are often inappropriate for clinical care. There are generally too lengthy, often use overly complex language and their results apply to group averages, not individual patients. Hence, PRO instruments need to be adapted to the clinical setting. The second problem is that there is no point in giving patients PROs if they don't complete them. Patients will only do so if the perceived burden is outweighed by the perceived benefit. Hence, patient burden has to be minimized – both in terms of survey length and in terms of number of clicks and access – and patient benefit maximized: patients need repeated reminders that their answers will be used to inform their clinical care. But that can only be true if clinicians access a patient's PROs and this will only occur if, again, benefits are perceived to outweigh harms. Benefits to clinicians are maximized but providing PRO data in an attractive, rapidly comprehensible format along with added value, such as prediction models; harm is minimized by ensuring that PROs are easy to find and easy to use. As is so often the case in medicine, ideas are easy, implementation is hard: if we want to maximize the potential of PROs for our patients, we have to do the difficult work of getting into the weeds of patient behavior and clinical workflow.

Learning objectives:

By the end of the workshop, participants should be able to

1. Describe at least three ways in which research questionnaires need to be adapted before used in routine clinical practice
2. Outline key issues that influence patient compliance
3. Identify critical factors in provider participation

Target audience:
Anyone interested in using patient-reported outcomes in clinical practice.

Description of presenters:
Dr. Andrew Vickers' research falls into three broad areas: randomized trials, outcomes research and molecular marker studies. A particular focus of his work is the detection and initial treatment of prostate cancer. Dr Vickers developed a statistical model to predict the result of prostate biopsy, work that has led to commercial test that is clinically available through Opko Diagnostics. In other research, he has established the strong predictive value of mid-life prostate specific antigen (PSA) for long-term prostate cancer mortality, shown that PSA velocity is not of benefit for risk prediction in localized disease, conducted modelling studies questioning the aggressiveness of cancers found by image-guided targeting and demonstrated that genetic risk prediction should focus on the endpoint of cancer morbidity and mortality, rather than cancer incidence. In his capacity as Co-Director of the PRO-CEL Core Facility, Dr. Vickers spearheads a number of innovative informatics initiatives throughout MSK, including integrating patient-reported outcomes (PROs) in routine care. and the Amplio surgical quality assurance system. He has a special interest in how PROs developed for the research setting need to be adapted for clinical use. His work on randomized trials focuses on methods for integrating randomized trials into routine clinical practice, including the development of "two-stage" consent. This work has led to several large, randomized trials being completed at MSK rapidly, and at low cost. Having developed decision curve analysis in 2006, Dr. Vickers' methodological research centers primarily on evaluating diagnostic and prognostic tools, including machine learning. Dr Vickers has a strong interest in teaching statistics. He is course leader for the MSK biostatistics course and is author of the introductory textbook "What is a p-value anyway?"