

# On TRACK: Medical Research Must Consider Context and Complexity

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The online TRACK discussion since the last issue is remarkable in 4 aspects. First, it exhibits a high degree of interactivenss—in addition to individual comments, conversations have developed among readers and between readers and authors. Second, these conversations demonstrate a depth and richness that amplify the original articles and tie them to other literature and ways of knowing. Third, almost half of recent comments pertain to articles in previous issues of *Annals*. This shows that readers are creating ongoing threads of reflection and discussion. Finally, an important crosscutting theme is identifiable across several threads of discussion of individual articles.

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## CROSSCUTTING THEME

The discussion of several very different articles highlights the need for a new paradigm to guide medical research based on understanding the complex interactions among illnesses as they are experienced by patients and as they are encountered in primary care.

The discussion<sup>1</sup> of a study of primary care research networks<sup>2</sup> and the author's response<sup>3</sup> reveals some of the intended and unintended consequences of current approaches to medical research. Centralization of research infrastructure, while efficient in the short term, may have the long-term negative consequence of disengaging the perspective of front-line clinicians, thus reducing the applicability, transportability, and uptake of research findings, "... by diverting attention toward the consideration of one disease at a time, and neglecting the complex interplay of multiple diseases and local contexts that are commonly the concern of primary care practitioners."<sup>3</sup>

Commentary by Hahn<sup>4</sup> provides related insights into the need for evidence that is patient oriented as well as disease oriented.<sup>5</sup> The limited relevance of narrowly defined disease evidence diminishes the applicability of guidelines based on this evidence. In the specific example of chronic obstructive pulmonary disease,<sup>6</sup> Hahn notes that:

"Historically, COPD studies have been systematically designed to enroll nonrepresentative patient populations. This is because North American lung specialist researchers have chosen to adopt a 'splitting' approach to asthma and COPD. Only smoking-associated COPD patients are enrolled in COPD studies, and only 'pure' asthma patients (who do not smoke and who do not have concomitant COPD) are enrolled in asthma studies. These choices have created an orphan population (estimated to be as much as 50% of lung disease patients) that is not studied at all. Add to this the other stringent exclusion criteria of most asthma and COPD studies, and you will find that, at best, 1 in 10 or 20 (in one example of which I am aware, 1 in 240) of the remaining asthma/COPD patients are actually enrolled."<sup>7</sup>

Hahn goes on to note that studies have determined 2 types of COPD: 1 type related to smoking and another caused by asthma with chronic airway obstruction. This perspective, well referenced in the commentary,<sup>7</sup> calls for a new paradigm for COPD research. How many other clinical topics are there for which current evidence-based guidelines are a poor fit with the ways in which patients actually experience their illness and seek care? There is a profound need for primary care clinician investigators to observe carefully in practice and to use those observations to generate and critically evaluate novel, relevant research paradigms.

Other discussions of the exclusion of patients with multiple comorbidities from clinical trials,<sup>8-10</sup> as well as concern about the limited consideration of adverse effects in systematic reviews,<sup>11,12</sup> call not only for new research approaches but also for caution in using existing evidence to guide pay for performance.<sup>13</sup>

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## ENRICHING DISCUSSIONS AND INDIVIDUAL OBSERVATIONS

The essay by Leeman and Plante entitled "Patient-Choice Vaginal Delivery?"<sup>14</sup> stimulated a well-referenced discussion that brings together and interprets

multiple kinds of evidence.<sup>15-19</sup> Klein<sup>16,17</sup> in particular highlights biases in the way studies are designed and data are interpreted to emphasize the risks of vaginal birth and to minimize the risks of cesarean delivery.

Comments by Kreps<sup>20</sup> and Kreuter<sup>21</sup> greatly enrich our understanding of how to promote personalized, effective, system-supported, and sustainable health behavior change messages. Together with the research study by Goldman et al,<sup>22</sup> this discussion identifies new areas for research and shows how risk information can be effectively presented.

The study that validated a measure to assess patient trust in medical researchers<sup>23</sup> stimulated very useful on-the-ground questions, ideas, and references for addressing the recruitment, retention, and engagement of people from minority groups in research.<sup>24,25</sup>

In his online comments, Lamberts<sup>26</sup> reports new data on the prevalence, treatment, and comorbid factors affecting treatment of pneumonia and dementia in Dutch general practice. His observations provide a frame for interpreting the cross-cultural study of physician treatment decisions for demented nursing home patients who develop pneumonia.<sup>27</sup> They also provide insights into cross-country comparisons of euthanasia and the role of the family physician.

In response to a family medicine update,<sup>28</sup> a patient's daughter provides an important caution as we develop systems to improve care.<sup>29</sup> Rebecca Argenti's experience shows that no amount of systems support or technology can substitute for listening to the patient and being alert to and acting on changes in the patient that are reported by family members. Her experience is a reminder that as we develop systems to support proactive provision of preventive and chronic illness care, we need to make sure that our rush to provide care supported by scientific evidence does not crowd out sensitive attention to the patient's and family's concerns.

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