

*UNC School of Public Health leads  
national discourse on patient-centered  
approach to health care*

# Changing the system

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## When UNC School of Public Health alumnus Clarence Pearson's 38-year-old son, Scott, was diagnosed with cancer in March 2001, he was admitted by his family physician to one of the best hospitals in New York City, in fact, one of the best in the world, for treatment.

The facility became one of seven acute care and rehabilitation hospitals where Scott would receive various types of treatment and rehabilitation during the next seven months for malignant melanoma.

"Every time, each institution would start a new record," said Pearson, who counted 45 different physicians on his son's medical bills during the course of the last months of his life. "No one was there to oversee the continuity of Scott's treatment from institution to institution." Once Scott was admitted to the first hospital, neither Pearson nor Scott ever heard from the family physician again – even after Scott's death.

Further complicating matters was the fact that physicians were reluctant to offer options or straight answers about Scott's prognosis to Scott or his family. And even though Pearson visited his son every day, he said he met only five of the 45 physicians who oversaw his treatment. In short, both Scott and his family were excluded from information and decision-making opportunities about his care.

The experience left Pearson and his wife Laurie Norris convinced that the system needed to change. And in its place, a new way needed to be forged, one where patients and families could be informed advocates for their own care.

To advance such changes, Pearson and Norris created a special UNC School of Public Health fund dedicated to fostering patient-centered care. Over the past three years, their gift has united national health care leaders from across the country in a dialogue to develop specific ways to change the system.



Scott Pearson with his father, Clarence.

Much of this discussion has taken place at two Patient Advocacy Summits (one in 2003 and another in 2005) sponsored by the UNC School of Public Health and attended by physicians, administrators, public health practitioners, health educators, researchers, consumer advocates, lawyers, social workers, policy activists, patients and parents-turned-activist from across the country.

"Patient-centered care refers to all the ways we can help patients become partners in their own care, even when they are very sick and at their most vulnerable," said Dr. Jo Anne Earp, a professor in the School's Department of Health Behavior and Health Education, which organized the two conferences. "The healthcare system is confusing and alienating to many patients and they often have trouble tracking down good information about their illnesses. Frequently, they are not aware that they have a choice of treatments or what the consequences are of choosing one treatment over another. A patient-centered approach begins

with the assumption that when patients have full knowledge, they can make good decisions about their care that best accord with their own values.

The patient-centered approach to health care covers research areas familiar to public health professionals, including provider-patient communication, patient education, health literacy and care coordination. Increasingly, however, discussions of patient-centered care encompass access to and support for alternative therapies, the value of online support groups, and even the ways a hospital's architecture can promote patients' health and well-being. None of these are applicable, however, if people cannot access care when they need it. Thus, policy-level factors feature prominently in advocacy discourse and were the subject of extensive discussions at the 2005 conference.

Participants at the 2005 conference also discussed early drafts of papers that conference attendees had submitted on topics such as e-health, community activism and health communication. The papers helped conference participants define what is known about health advocacy and outline questions still needing answers.

Earp and other UNC researchers are now collaborating with academics and practitioners from around the country to develop a textbook on effective health advocacy based on the conference papers.

The book will be geared toward physicians and graduate students pursuing public health master's degrees and will highlight what patients are already doing to take control of their own care and how providers can help.

"We have a fractured medical care system," said Elizabeth French, who coordinated both conferences and is an editorial associate in the School's Department of Health Behavior and Health Education. "We believe that one of the best ways to improve the system is through the pressure of effective advocacy." ■