

**Commentary:
“Involving the Public In Clinical Research”**

Myrl Weinberg, CAE, President
National Health Council
1730 M Street NW Suite 500
Washington, DC 20036
mweinberg@nhcouncil.org

The National Health Council is a private, nonprofit umbrella organization of 110 national health-related organizations that works to bring quality health care to all people, especially those with chronic diseases and/or disabilities. Its core membership includes 50 of the nation’s leading patient groups, such as the American Cancer Society, American Diabetes Association, Easter Seals, Alpha-1 Foundation and the American Autoimmune Related Diseases Association. Collectively, these patient groups represent approximately 100 million people. Other Council membership categories include professional and membership associations, nonprofit organizations with an interest in health, and business and industry.

The Council and its patient group members deeply understand the important role of clinical research in finding relief from, and hopefully a cure for, specific illnesses. Some of our patient group members help recruit participants for clinical research through their Web sites or other communications and some maintain a database or patient registry of potential research participants. Many provide funding directly to researchers and research institutions. Patient groups also review clinical research results and promote informed decision making by distributing vital information to patients and their families.

Involving the public in clinical research is an important part of the Council’s efforts to transform the health care system into one that enables patients and their families to play an increasingly central role in their health care decisions. We believe that clinical research should be patient focused and is best achieved through a partnership between informed and respected research participants and a coordinated clinical research team.

Increasingly, research participants expect -- and sometimes demand -- that they have a role in the creation of the research agenda and in the design, review, and translation of the research. More people are aggressively accessing medical research and health information, and pressing to put research findings into practice.

NIH Director, Dr. Elias Zerhouni, has stated that, “engaging the public in the clinical research enterprise is a strategic imperative.” In short, the public has a pivotal role to play in putting research findings into practice, helping to speed up the clinical research process, and making sure it is efficient. Yet, significant challenges remain.

According to CenterWatch, about 81% of all clinical trials are delayed by one to six months because of difficulties in enrolling participants, with another five percent postponed six months or more. As hard as it is to attract participants, it’s even tougher to keep them. Three million Americans complete clinical trials each year, but 90% of trials started are not completed due to high participant drop-out rates.

A recent Harris-Interactive poll showed that only a small percentage of the U.S. adult population has ever participated in a clinical trial, but 77% say that if asked they would consider taking part. Knowing the reasons why some choose to sign up for clinical trials and what encourages or

hinders others from taking part, is vital as we attempt to fully engage the public in this process. The poll also identified issues that influence the decision of large numbers of people including: convenience, minimal side effects, situations where the benefits outweigh the risks, and the hope of a cure.

In addition to understanding what motivates and discourages clinical trial participation, it is critical to have well informed and effective advocates within the clinical research enterprise. Public opinion often drives policy, which can speed up or slow down the pace of research. Effective partnerships between research participants and coordinated clinical research teams are a practical way to create passionate advocates for science policy.

By organizing and regularly updating clinical trial results in a format that is quick and easy to access, the British Medical Journal Publishing Group's *Clinical Evidence* – is an important tool to bring together patients and the health care professionals that serve them. For patients living with chronic illnesses and/or disabilities, the opportunity to become informed and work as part of a coordinated team with their physician and other health care professionals using the latest advances in clinical research not only gives them peace of mind, it increases their chances of receiving the most appropriate care available today.

This commentary was commissioned by United Health Foundation.