There is a paucity of data on the quality of cancer care in our nation, as recently emphasized in a report by the Institute of Medicine, and recognized by the National Cancer Institute (NCI). To collect data on patterns of care and guideline concordance in our nation’s cancer centers, 4 years ago the National Comprehensive Cancer Center (NCCN) launched its first shared national outcomes research study. City of Hope National Medical Center (COH) was selected as the Data Coordinating Center for this critical outcomes project, and created an Internet-based outcomes research database system to collect data from participating cancer centers nationwide. Data are entered directly over the Web, or submitted over the Internet via File Transfer Protocol (FTP).

The first cancer site chosen to establish proof of concept was breast cancer, due to the high incidence and large public health impact. The goal is to determine whether cancer centers are following the NCCN evidence-based guidelines for the standards of care, and the results of receiving treatment in this setting. Project initiation required a full year’s effort to come to consensus over a standard data dictionary, conduct the database modeling among committee members cross-country, and to develop and deploy Internet-based technology, with strict levels of confidentiality and security.

After the first several months of data collection, a survey was conducted to measure user satisfaction with the Web-based system. This identified previously unrecognized database connectivity problems, leading to a subsequent major reconfiguration of the system. A follow-up survey determined that this re-design had resolved the connectivity problems.

The first years of the project have been quite successful, with data on more than 6,000 patients accumulated and analyzed to date, revealing unexpected and important treatment pattern data. These data are routinely fed back to both the cancer centers and the guideline committees, to allow performance improvement at the sites to take place as needed. The next cancer site to be studied was lymphoma, funded by a $1 million unrestricted grant from Genentech. The lymphoma data dictionary, data model, and Web interface were developed in approximately half the time needed for the first cancer site, due to our earlier experience with these processes, and streamlining of communications among the committee members nationwide. Recognizing that ultimately we want to study all major cancer sites, the data model was re-engineered to become an integrated cancer site data model, allowing rapid extensibility and scaleability to different diseases.

The next challenge was to determine whether the same data collection and feedback loop can be implemented in the community oncology setting. In December 2000, the NCI awarded COH a one-year grant to test the feasibility of collecting similar patterns of care and outcomes data in 5 community affiliates. This involves the development and testing of new methods of data collection. We have analyzed the workflow and practice patterns in the community offices, to allow us to create a Graphical Decision Support Interface (GDSI) to provide data capture and decision support at the point of care. We also are piloting the use of scannable forms (Cardiff TELEform) as an alternative mode of data collection that may be practical in this setting.

The study design calls for a pre-post implementation analysis of the effect of decision support on treatment practices, and randomized comparisons of the various modes of data collection, Web-based, GDSI, and TELEforms.

For this theatre-style demonstration we will not only demonstrate the technology, but also discuss the human organizational and information structure factors that must be considered to successfully collect, pool, and analyze data across these varied settings. These processes have resulted in automated systems for successful outcomes research, and collaboration both nationwide and at the local community level. Collecting outcomes measures in a timely and efficient manner via such systems has the potential for greatly improving the quality of care being received by cancer patients throughout the country.