

Making it BIG

By Cori Vanchieri

Through shared data, a new NCI program aims to speed delivery of innovative care. Community practices with patients in clinical trials stand to benefit greatly.

The National Cancer Institute (NCI) is moving full steam ahead to create a World Wide Web of cancer research. They call it caBIG—cancer Biomedical Informatics Grid—with expectations that it will transform cancer research in a big way.

The project, which was launched in February 2004 as a 3-year pilot, aims to provide an infrastructure and standards to make data sharing much easier for cancer researchers in the laboratory and in the clinic. The ultimate goal is to speed the delivery of innovative approaches for the prevention and treatment of cancer.

NCI has taken on the monumen-

tal task of weaving together data from the cottage industries of biomedical research and clinical trials, in which each team collects data using its own unique language, and every cancer center builds its own software and clinical trials management systems. In this patchwork quilt, interoperability is a foreign concept, volumes of valuable raw data are not used effectively, and resources are wasted because of duplicated effort.

CaBIG will speed cancer research, remove bottlenecks, and get researchers talking and sharing data using a standard language, says Mary Jo Deering, PhD, director for informatics dissemination at the NCI Center

for Bioinformatics, which oversees caBIG. That should eventually translate into better treatment options for patients.

Benefits for community practices

For clinicians involved in clinical trials, the potential benefits may come sooner. CaBIG includes pilot tests of clinical trials recruitment tools (see box). In addition, it is developing tools that can enable community oncologists with patients in clinical trials to collect, manage, and report their patient data. Tools designed to meet the diverse data management needs of the clinical research com-

Easier access to clinical trials

One pilot project developed in the field and now supported by the National Cancer Institute is a personalized clinical trials matching tool. It was conceived by two breast cancer patients who wanted to make it easier for other patients to find clinical trials. They brought their idea, called BreastCancerTrials.org, to the University of California at San Francisco (UCSF) Breast Care Center, where a prototype was developed.

Patients who register with BreastCancerTrials.org enter information online about their diagnosis and treatment to create a personal health record. Then, a matching algorithm finds the trials with eligibility criteria that fit the patient's profile; matches are displayed in a password-controlled message center with instruc-

tions on how to contact the investigators. Patients also receive alerts by e-mail when a new trial matches their needs. During this pilot phase, the database is limited to breast cancer trials in the San Francisco Bay area and Sacramento, California.

"Patients are able to self-report a fairly detailed breast cancer history into the application," says Ellyn Cohen, PhD, UCSF Project Manager for BreastCancerTrials.org. "The goal is to decrease the burden on patients looking for trials and to give researchers access to patients who are really motivated to enter studies. The program also screens patients so that those who contact the investigators are more likely to be eligible."

This search engine "goes miles further than existing tools, such as

clinicaltrials.gov," says Dr. Deering, because the patient doesn't have to scroll through long lists of breast cancer trials. Rather, they get a specific list of studies for which they may be eligible.

The tool launched on May 31, and to date, more than 110 patients have completed a personal health record, says Dr. Cohen. The UCSF team plans to assess patient satisfaction, the ease with which patients can use the personal health history tool, and whether they actually go on to enroll in a clinical trial. They are also conducting a study with patients from UCSF to see how accurately they enter their health data. Says Dr. Cohen, "We want to know if we're providing patients with enough help."

munity will facilitate adverse events reporting, laboratory data exchange, and regulatory reporting.

Dr. Deering says the mantra is “collect once, use often.” Ultimately, data collection should be seamless. She says she can imagine a community oncologist collecting data on the effects of nausea medication for a study, for example. That information gets entered once, but can be used wherever else it needs to go, with the patient’s permission. The information could flow in the other direction too: a community oncologist could have access to a patient’s prior records (including care during a clinical trial)—subject to patient permission and privacy and security protections.

A huge task

Devising the standards, putting the infrastructure in place, and developing the software is a mammoth task. To date, 500 people, mainly at 50 of

the NCI-designated cancer centers, have been doing the work. “We’re still developing the software infrastructure,” says Dr. Deering. “We’re trying to reach out to those entities that have the staff and skills to help us build applications or that have data sets they can contribute.” The initial building phase should last another year.

Several tools are already available on the caBIG website. Most have catchy names such as caARRAY (a microarray tool), and caIMAGE (an image repository of human and mouse pathological images). CaWorkbench is a suite of tools for loading, visualizing, and analyzing gene expression data.

NCI has begun reaching out to SPOREs—Specialized Programs of Research Excellence—and to NCI’s Clinical Trials Cooperative Group Program. Dr. Deering suggested that oncologists interested in getting involved start by visiting the caBIG Web site (see box) to see whether

there is an area that interests them. They are welcome to join any of the teleconferences. Another option is to check the list of participating cancer centers and make contact there. “This is an open process,” says Dr. Deering. “As we develop activities in translational research, the input will come from those people who group together on teleconferences and meetings to talk about needs. We really do want more clinicians participating; we’re well aware that while we’re in this building phase, we are getting the self-proclaimed geeks—more PhDs than MDs.”

For more information on caBIG, go to <http://cabig.nci.nih.gov/>. This expansive Web site lists upcoming teleconferences and meetings and provides links to white papers and scores of tools and applications available for review.