

The Cancer Surveillance and Information Summit

Executive Summary

In 2004, C-Change sponsored a Cancer Surveillance and Information Summit that brought together 86 experts from the broad field of cancer surveillance. Its overall purpose was to seek ways to reduce the burden from cancer through the full application of information. Specifically, the Summit sought to review the current state of the science, identify near and long-term contributions to the surveillance enterprise, identify barriers to progress and needed areas for research and development, develop strategies and plans, and recommend key initiatives, time frames and groups who could move the field forward.

The Summit was built upon the foundation created by the 2001 Cancer Surveillance Futures project. The 2004 Summit distilled lively debate among the attendees from presentations on the information infrastructure, patient privacy rules, and applications of new technology to patient care into a plan for action.

The future will bring some fundamental changes in cancer surveillance that will be advanced by information technology, the increased use of the internet, and new regulations governing personal privacy. The future holds the promise of addressing the demands of clinicians eager for information, the requirements of researchers for increased depth and breath of cancer information, and the public's need for a better understanding of the risks of cancer and the options available to them for prevention and treatment.

To prepare for the future, Summit conferees made a number of suggestions that were subsequently reduced to seven primary recommendations. These were then prioritized as follows:

1. **Data Standards.** *Data standards are required for data collection and reporting to permit valid, consistent, and comparable information.* This task will require the hard work of many individuals and organizations in the surveillance field. The recent agreement by major registries and coding systems on common stage specifications is a model for future action in data standardization. To move this recommendation forward, all groups setting data standards, such as NAACCR, HL7, SNOMED, and caBIG, must be convened to create an inventory and work toward common terms and specifications.

2. **Expanded Scope for Cancer Surveillance.** *An expanded vision for cancer surveillance goes beyond cancer registration to include, risk factor data, pre-neoplastic events, quality indicators, and patient-centered outcomes.* Linkage across data sets (registries, administrative data, biospecimens, and genetic information) and mechanisms for linkage at the individual level is essential. This vision needs to be embraced by all entities within the surveillance enterprise.

3. Leadership. *The activity of collecting and disseminating cancer surveillance information requires leadership and financial support.* Sustained support is needed for the cancer surveillance infrastructure to make comprehensive cancer control programs possible. Such support usually comes from government, but may also derive from voluntary agencies, foundations, and professional societies (many of which are collaborators in C-Change). The Centers for Disease Control and Prevention (CDC) play a critical role in supporting state-based comprehensive cancer control planning, but individual states may not participate because of funding shortfalls and lack of trained personnel, thus undercutting the potential benefits to those states as well as the nation. Central leadership is needed to guide activities by individual agencies and organizations. The Presidential appointment of a National Health Information Technology Coordinator in May of 2004 (Dr. David Brailer) provides such a leader and an appropriate overall administrative entity to oversee the development of cancer surveillance in the future. It may well be that cancer could be a model for the development of information systems for other chronic diseases over the next decade.

4. Incentives. *Incentives are needed for participation in expanded surveillance activities.* These may include accreditation, reimbursements, and provider certification for participation. The provision of such incentives may come from several sources, both in and out of government, like CMS, ASCO, ACoS, ASTRO, NCQA, and the JCAHO.

5. Health Disparities. *Health disparities need to be addressed across the spectrum of cancer surveillance by adopting measures of SES as well as age, gender, race and ethnicity into national datasets and medical record systems.* Again, multiple entities such as HRSA, the VA, private health systems, and insurers must be engaged in this undertaking.

6. Surveillance Tools. *Surveillance data must be more readily available for clinical and public health practice.* Government, academic, industrial and health care systems must be engaged to develop and implement tools, for comprehensive cancer planning. Expanded, or new, systems are needed to monitor newly developed consensus measures for the quality of cancer care [NQF] and for other metrics that reflect quality on a personal level (e.g. quality of life). Advances in information technology and vehicles such as the Internet are advantageous in packaging and delivering information in an effective and efficient manner.

7. Legislative Mandate. *A legislative mandate may be needed to authorize the collection of patient-centered data and other data elements under an expanded scope of surveillance.* Currently reporting of minimal demographic and tumor specific information is mandated by the laws of most states. In order to collect information on the quality of care, including patient-centered factors such as the quality of life or satisfaction with care, affected individuals need to be interviewed or surveyed. It may be necessary to expand legal mandates to such individually identifiable data for improved public health including cancer surveillance.

These recommendations have been reviewed and approved by the C-Change Board of Directors.

The planners and attendees of the Summit believe that the energy generated by the Summit must be sustained. Coming down from the Summit has meant participants and members of the larger cancer research community have found support to systematically approach the priorities highlighted above.

The next step is to engage critical players in implementing the top priority, that of achieving standards across the cancer surveillance enterprise including coding, data collection, procedures, and information dissemination. Already the C-Change Access to Quality Cancer Care Team, under the leadership of Dr. Holly Howe, has taken on this task and is proceeding with a major planning effort in the current year for a meeting to address the critical issues involved in setting standards for cancer surveillance and information.

Four papers, generated by the Summit's plenary speakers, provide the background and justification for moving forward with these next steps. Edward Shortliffe and Ed Sondik reflect on the opportunities and challenges presented by the evolving informatics infrastructure and its role in cancer surveillance. Dean Sittig introduces some exciting applications of advanced clinical information technology to medical practice and cancer surveillance, Dennis Deapen reminds us that one of the major challenges will be balancing issues related to privacy and confidentiality of personal data with public health needs as we move into the future. Finally, Robert Hiatt builds on these three papers and the history of cancer surveillance to date in presenting his view of the future of cancer surveillance as it could be realized through a process leading from the seven recommendations summarize above. These manuscripts are currently under review by a major cancer journal.