Symposium Report

C-Change
Cancer Surveillance and Information Summit II:

From Cancer Diagnosis to Cancer Information in Real Time

Sponsored by:
American College of Surgeons/Commission on Cancer
National Cancer Institute
Centers for Disease Control and Prevention
C-Change

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C·Change
Collaborating to Conquer Cancer

Cancer Surveillance and Information Summit II
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Table of Contents

Executive Summary 1

Welcome and Overview 4

Plenary Session I: A Glimpse Into the Future 6

Meeting Objectives, Agenda, and Process 11

Plenary Session II: Where Do We Go From Here? 11

Plenary Session III: The Information We Need or Desire 16

Plenary Session IV: Achieving Federated Databases 22

Plenary Session V: The Action Plan 26

Appendix 34

- Maps
- Table of Recommendations
- Table of Commitments
- Graphical Summary of Summit
- Participants List

Executive Summary

In February 2008, C-Change convened the Cancer Information and Surveillance Summit (CSIS) II, which brought together approximately 50 experts in the fields of strategic forecasting and cancer surveillance. The Summit built on the foundations of the 2001 Cancer Surveillance Futures Project and the 2004 CSIS I. The purpose was to develop a series of stakeholder-driven actions to enhance the connection between the public health cancer surveillance spectrum and the emerging electronic medical record system. The stakeholder-driven actions will be designed to create timely and meaningful information flow, enhance surveillance tools, and address the societal cancer burden.

Summit attendees engaged in dynamic discussions about the future of cancer surveillance, the role of electronic medical records, patient privacy, and emerging technologies. Presentations centered on the future of electronic communication and cancer medicine; possible future steps from the perspectives of medical care, electronic medical records, and public health surveillance; information needs from the patient-, population-, and survivor-perspective; and achieving federated databases.

Summit participants made a number of recommendations that were coalesced into nine primary recommendations and then prioritized:

1. Market the value of cancer surveillance. Public awareness of cancer surveillance databases needs to be raised, the public's fear of government use of individual/personal health data must be reduced, researchers' awareness needs to be raised, and a use case among a broad base of partners needs to be developed. Specific actions to close these gaps are to develop: advertising, marketing, and education campaigns; use cases; stories; and communication strategies. Potential goals are to develop public buy-in of the value of cancer surveillance, foster public trust in cancer surveillance, develop a sense of providing something for the common good, and counterbalance privacy advocates that result in a negative effect on cancer research.

2. Transform registries. A tangible need is to make registry information available at the point of healthcare service and to scale the information available from population-based registries to the available resources to maintain a high quality surveillance enterprise. Specific actions to close this gap are to: evaluate current variables in surveillance for relevancy, utility, and cost; enable registries to focus on thematic areas (e.g., survival, quality of cancer care, incidence statistics) within the cancer surveillance spectrum; and create a demonstration project of point of service and registry. One potential goal is to enhance the value of cancer registries and the cancer surveillance spectrum by refocusing on priority data variables, and another is to develop a sustainable model that enhances the utility of registries for patient care.

3. Improve the coordination of surveillance and clinical data needs for quality improvement. Tangible needs are to: identify necessary data and adapt to changing information needs; identify the multiple sources and locations of data by understanding opportunities for synergies between resources and the potential for error or conflict; and identify and address multiple efforts to collect complete, accurate, and timely treatment data. Specific actions to address these gaps are to: assemble registry leadership, groups interested in personal health records, and clinical groups to form multidisciplinary teams to map "as is" versus "to be" data needs; access the

capacity to collect and assemble these data; and move reporting closer to real time for surveillance and providers for continuous quality improvement. Potential goals are to: focus the use of surveillance and clinical registries toward the measurement of processes of care and outcomes, define a universal template for the collection of treatment, and develop systems and processes so that information is readily available to patients and physicians.

4. Improve the utility of existing cancer surveillance methods using advanced tools. Tangible gaps include the fact that existing data are underutilized and that there are polarized perspectives of the usefulness of consumer-based, research-based, or public health-based data systems. Specific actions to close these gaps include: developing quasi-intelligent systems to extract, use, and link data; identifying expert panels to draft a set of criteria for databases; providing funding options for developmental work; developing and using advanced tools other than artificial intelligence; developing and testing new mathematical or statistical models to enhance data in existing surveillance systems; promoting data use and sharing; and using examples to demonstrate cost savings. Potential goals are to: improve the utility of surveillance data (e.g., identify underserved populations for breast cancer screening using registry data); accelerate the use of registry data; search for breakthroughs for risk, diagnosis, and treatment; render data to be machine readable, usable, and possibly computable for all purposes (e.g., statistical, epidemiological, patient care); and develop a proof-of-principal approach that yields at least three examples of utility.

5. Develop a "Cancer Patients Like Me" Web Site to engage patients in submitting data that can enhance registries. One tangible need in this area is data exchange between patients, providers, and surveillance systems for mutual benefit. To overcome this, one specific action is to develop a voluntary, interactive Web site that will collect patient-provided data (e.g., risk, screening history, follow-up, quality of life, etc.) and provide information and/or support to patients (e.g., very specific survivor statistics, such as age, race, stage, cell type, tumor grade, cancer subsite, for "patients just like me"; support blogs and/or sites; individual data query support) using Web-based population surveillance data. The potential goals are to develop a new data stream for registries and patient-friendly sources, develop public trust, demonstrate the importance of cancer surveillance data, and provide open information for all stakeholders.

6. Create financial incentives. The tangible gap in this area is the financial barrier to the adoption of electronic medical records and their linkage to public health surveillance systems. To address this, financial incentives (e.g., tax incentives) could be developed and implemented that are designed to foster the adoption of electronic medical records and their linkage to public surveillance systems. The ultimate goal is the increased adoption and expansion of the electronic medical record and its linkage to public health surveillance systems.

7. Examine the need and opportunity for legislative policy regarding privacy and security. There is no existing legislation or regulation to protect personal privacy in the United States, thus, a tangible need for health privacy regulations exists with the emphasis that health data should be used for the benefit of patients and not against them. The data must be available to create information for the benefit of society. To accomplish this, current protections and needs will be identified, and the national health privacy law recommended by the National Committee on Vital and Health Statistics will be explored. Although government agencies need to involved

in the initial discussions regarding privacy regulations, nongovernmental organizations must implement the recommended actions.

8. Focus on workforce development and recruitment. Currently, there is a need for the cancer surveillance workforce to develop skills for future demands related to technology and infrastructure and to attract new workers to the field. To address this, skill sets necessary for the future should be identified, education and training should be developed to meet evolving needs, and national recruitment efforts should be initiated. The ultimate goal is a workforce that can support future and emerging needs for cancer surveillance.

9. Achieve shared meanings. Cancer incidence standards have recently been incorporated into vocabularies and standards beyond the North American Association of Central Cancer Registries, Inc. standards. Specific actions needed now are to support ongoing activities, ensure progress is maintained, and harmonize ontologies and value sets. Potential goals in this area are to ensure that cancer incidence data and registries are ready for interoperability with other data sources, support the existing movement with interoperability and consensus, and ensure that linkages will result in synergistic information for better decisions by researchers, surveillance experts, physicians and other providers, and policymakers.

The next steps are to determine what organizations will assume responsibility for the planning and execution of the above recommendations. C-Change will determine which of the recommendations have a value-added proposition for their organization and assume responsibility for their planning and execution. It will encourage individual member organizations to take responsibility for the planning and execution of the others that do not fall within the C-change priorities. The role of cancer surveillance should be kept in the forefront of the C-Change collaborative environment, and advocates must provide leadership in this area to keep the momentum moving forward. Efforts have coalesced during the last few years and are moving toward the original goal of a synergistic method to engage organizations and individuals within the organizations to accomplish shared goals and make a difference. Passionate and committed individuals are needed to keep the cancer surveillance issue alive.

WELCOME AND OVERVIEW

Welcome

Armin Weinberg, Ph.D., Intercultural Cancer Council
Tom Kean, M.P.H., C-Change

Dr. Weinberg, a member of the C-Change Board of Directors, welcomed the participants to the Cancer Surveillance and Information Summit (CSIS) II and explained that C-Change was founded in 1998 as the National Dialogue on Cancer. It brings together the private, public, and not-for-profit sectors, and its members represent more than 130 different organizations whose missions relate to cancer research, control, and/or patient advocacy. C-Change provides a great opportunity for the three sectors to collaborate in a unique manner to make a difference in cancer-related issues. Its mission and vision is to eliminate cancer as a public health problem at the earliest possible time by leveraging the expertise and resources of its membership. C-Change exists to accelerate the discovery and implementation of comprehensive solutions to the urgent societal burden of cancer. The organization brings collective expertise and resources, through a community of leaders, to solve issues that its members cannot solve alone while enhancing the effectiveness of its member organizations. Furthermore, it is rooted in the nonpartisan participation of leaders from all sectors.

C-Change members have learned that significant advancements are made by bringing leaders together to discuss issues, research solutions, and find methods to collaborate. C-Change has been instrumental in helping the Intercultural Cancer Council (ICC), whose origins were dedicated to increase awareness and address population disparities in the cancer burden. Because the core of C-Change is collaboration, ICC is no longer a solo voice in addressing these disparities, which touch everyone. Dr. Weinberg has found the opportunity to work with leaders at all levels remarkable. Leaders from the National Cancer Institute (NCI), other National Institutes of Health (NIH) institutes, and major organizations in the private sector have worked together in ways that previously had not been thought possible. Although it is not always easy, collaboration increases the opportunity for progress.

Mr. Kean, Executive Director of C-Change, thanked attendees for their participation and the Summit Steering Committee for its efforts in planning the symposium. Dr. Holly Howe, Chair of the Summit Steering Committee, has been a strong advocate for surveillance issues for many years and was a major impetus for this Summit. C-Change, NCI, the American College of Surgeons (ACoS) Commission on Cancer (CoC), and the Centers for Disease Control and Prevention (CDC) have provided direct support for the symposium.

The essence of C-Change is to bring together leaders from the three sectors and ask: What is not happening—in terms of cancer-related issues—that the groups can collectively work on together? What can be accelerated by collaboration? Currently, C-Change is fostering 19 initiatives that accelerate research, improve access to quality cancer care, and support state, tribe, and territory cancer control efforts. Each of the initiatives has been identified as needing collaborative action or having a collaborative opportunity to accelerate action.

This Summit provides an opportunity for multisector representatives to identify breakthrough opportunities that will significantly move actions forward to the next level and the next challenge. This group can build on the recommendations previously set forth by other bodies (e.g., CSIS I, the Cancer Surveillance Futures Project) and make them more specific. The opportunity to accelerate discovery and implementation exists and can be driven by stakeholder resources to reach the ultimate goal of fostering societal benefits. It is necessary to remember that this Summit is a starting point for participants to move one or two critically important recommendations forward. These recommendations should not focus solely on funding or what the government or C-Change can do; they should be based on what actions can move the field forward. A follow-up report will be produced, and decisions will be made about what roles C-Change may best play in implementing the recommendations. Because the recommendations will be presented to varied audiences, they should include straightforward language and clear outcomes. The challenge is to identify and develop a series of stakeholder-driven actions to enhance the connection between public health surveillance systems and emerging electronic medical record systems, avoid duplication with the work others are performing, address gaps in which no work is being done, and identify unique opportunities to accelerate action that is already underway.

Overview of the Summit and Introduction of Maps

Holly L. Howe, Ph.D., North American Association of Central Cancer Registries, Inc.

Dr. Howe welcomed participants and thanked them for their attendance. She explained that many of the decisionmaking discussions during the Summit would be based on discussions from the first evening's plenary session. The first CSIS, held in 2004, was a futuring meeting to discuss cancer surveillance issues as they related to and could be impacted by emerging and future technologies. During the Summit, six recommendations were made and prioritized. The highest priority recommendation, data standardization, is the focus of CSIS II. Data standardization: is required for data collection and reporting to permit valid, consistent, and comparable information; will require the work of many individuals and organizations in the surveillance field; and will need input from all groups setting data standards to create an inventory and work toward common terms and specifications. The challenge is how the three sectors will work together to establish a standard that is meaningfully compatible among all users. Within the public health surveillance arena, there is a solid history of developing, adhering to, and adopting common standards. The future efforts need to go beyond registries and must include all aspects of the cancer surveillance spectrum, which begins with a healthy individual who has risk factors and exposures and is followed by cancer screening and diagnosis, treatment, survival and related issues, palliation, and mortality. The desired outcomes of CSIS II are to identify gaps and barriers in the flow of information, determine responsible parties to fill the gaps, and increase recognition that electronic systems must also help the patient.

Dr. Howe explained the various maps provided to the participants. Map 1 (see Appendices1 for Maps) describes the current situation, starting with the patient-provider encounter. This encounter represents the diagnosis and from there proceeds through many clinical entities, reflecting the complexity of cancer. From the patient-provider encounter, the ultimate goal is surveillance information via the aggregation of data. Many groups are working toward standardization to enable the flow from diagnosis to useful public health information.

Map 2 provides a schematic of real-time surveillance information. There is a demand for more timely data for a variety of purposes (e.g., making treatment decisions, evaluating programs, and monitoring the burden of the population). Cancer is not diagnosed and treated at a single point in time. The goal of cancer surveillance is not to document the *process* of diagnosis, but rather the outcome of all diagnostic tests and procedures. It is necessary to realize that the concept of "real time" in the surveillance arena involves a delay so that data from all relevant patient contacts are available and consolidated to achieve meaningful and important outcome information. Cancer diagnosis and treatment can span weeks and months before all relevant information is accrued on a single tumor. Real-time information will come to the registries from many different hospital departments (e.g., pathology, surgery, administration, laboratory), and the registries will record and consolidate all of the information. This will increase the burden of the central registries to accumulate and compile data and will be very labor intensive. In an alternative map for real-time surveillance, data accumulate and are consolidated in the medical arena and then, after diagnosis, are sent to the state central cancer registries so that meaningful cancer information—the ultimate goal—is available. Standardization is a significant issue for real-time surveillance. The North American Association of Central Cancer Registries, Inc. (NAACCR) has consensed standards for several groups (i.e., ACoS, NCI, CDC, Canadian Cancer Registry, and local population-based registries), but there also are various standards within hospitals, including clinical and radiology terminology and ontologies. Clinical information is very important for understanding cancer diagnosis; therefore, the question of who will set the needed standards in this arena is important.

Map 3 includes the entire cancer surveillance continuum, not just incidence. Additionally, it may be desirable to broaden the continuum to include additional factors such as other chronic diseases, infectious disease, accidents, and so forth. It is necessary to link each step of the continuum so that two systems "talk" to each other via compatible architecture and vocabulary. The architecture must be communicable, syntactically interoperable, and linkable. At a deeper level, it is necessary to ensure that linkages between the databases are meaningful and semantically interoperable; standard definitions and compatible coding schemas contribute to this. The greatest challenge is standardizing the vocabulary, as it relates to their shared meanings and compatible ontologies. Other organizations outside of registries also are working on standardization; it is important that cancer registries be included in this dialogue.

PLENARY SESSION I: A GLIMPSE INTO THE FUTURE

The Future in Electronic Communication

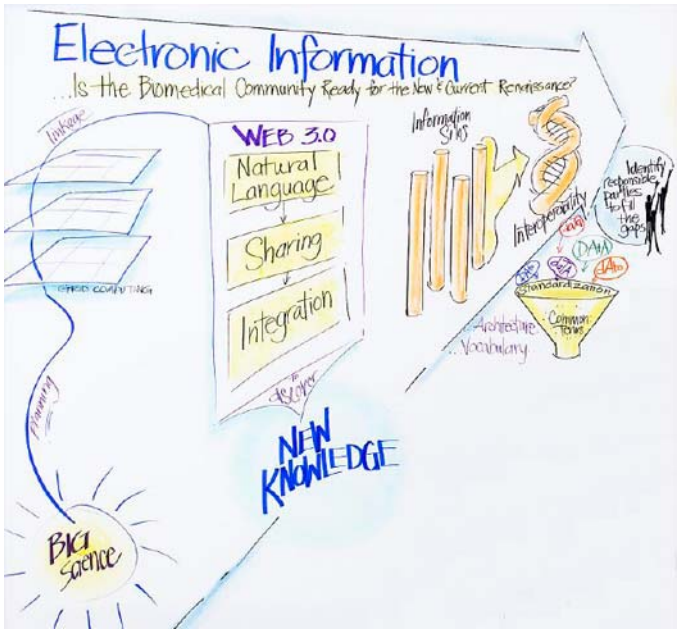
Peter Schad, Ph.D., National Cancer Institute

Dr. Schad, Health Informatic Coordinator for NCI's Division of Cancer Control and Population Research, provided a definition of the World Wide Web. The Web contains islands of biomedical information with no standardized infrastructure currently or in commercial development; discoveries are not intuitively dominant. A transition from the early Web 1.0 to Web 2.0 involved the evolution of Web sites from isolated information silos to sources of content and functionality. Web 2.0 is marked by open communication, interactive applications, and the freedom to share and re-use information; one relevant example of this is NCI's caBIG™ (cancer Biomedical Informatics Grid™). The hallmark of Web 2.0 is its facilitated collaboration and

sharing between users; the biomedical community must determine how this can be utilized. The creation and evolution of the Web has caused a new Renaissance. Dr. Schad recommended the article, "The Semantic Web in Action" (*Scientific American*, December 2007, pp. 90–97), which provides a good medical example of this Renaissance.

Several books and articles are available that highlight how businesses are changing their business structures and discovering new collaborative opportunities. An article of particular note for the health field is "The Emerging Web 2.0 Social Software: An Enabling Suit of Sociable Technologies in Health and Health Care Education" (*Journal of Health Information and Libraries*, 2007;24:2–23). The current transition to Web 3.0, involving grid computing, is another consideration. In general, grid computing treats all resources as a collection of manageable entities with common interfaces that allow for functionality, including accessibility via open protocols. Grid computing in the medical community, however, is not the same. It involves linking databases to increase data availability, sharing, and exchanging; these are easier accomplished with semantic interoperability. Social collaboration is changing the way people send and receive information to and from each other. There are, however, caveats to open accessibility and sharing, such as the absence of credentialing and the need to translate technical and scientific knowledge to the lay public.

The transition to Web 3.0 has tremendous implications for the medical community, but some obstacles that must be overcome include the absence of shared ontologies and vocabularies, the redundancy and lack of coordination in field-initiated research, disincentives for team science, the lack of coordinated presentation to policymakers and planners, and the excessive lag time from discovery to delivery. Standards and vocabularies are crucial requirements because without standards several challenges arise: population data are noncomparable; systems cannot interchange data; secondary data uses, real-time health surveillance, and linkage to decisions support are not possible; and health outcomes cannot be expanded to individuals and policymakers. The incidence of rare childhood leukemia in Woburn, Massachusetts, and lung cancer incidence along the Mississippi River are two examples in which real-time data could have affected health outcomes.



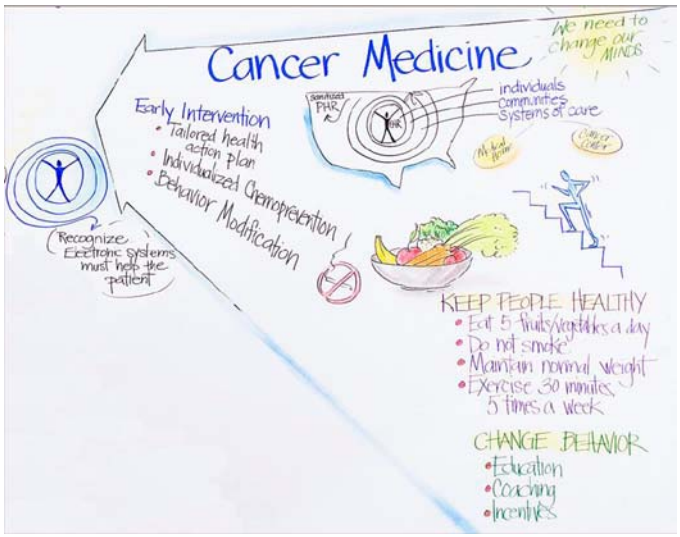
The Future in Cancer Medicine

William Rowley, M.D., Institute for Alternative Futures

Dr. Rowley, Chief Operating Officer of the Institute for Alternative Futures, described a service available to patients that allows genome analysis for 20 hereditary conditions. Patients who use this service and learn that they are at increased risk for certain conditions may approach their physicians for recommendations; the physicians may be unprepared to answer these questions.

Online searches may yield information about ongoing studies, but can the results be extracted to the patient population that the physician is serving? One solution may be the creation of an invitational, trusted, secure, and purposeful database to track patients with similar conditions. Such a database could provide preventive advice online and educate physicians about genetic medicine as it evolves, allowing physicians to use this information to help their patients. Patients could be followed over time, and their individual information, including treatments and interventions, could provide a wealth of knowledge about matters such as lifestyle and cutting-edge therapies. If risk can be identified, early intervention would allow for a tailored health action plan, individualized chemoprevention, and behavior modification.

Behavior modification may be a significant challenge, but it has been shown that four behaviors have the power to prevent many chronic diseases: (1) eating five fruits and vegetables a day, (2) not smoking, (3) exercising 30 minutes per day at least five times per week, and (4) maintaining a normal weight. Americans, however, are very resistant to behavioral changes; for example, only one in nine patients adopts healthier day-to-day habits following coronary bypass surgery. How can people be encouraged to change their habits so that risks can be managed? One method may be education, accomplished through the use of group counseling sessions, television, the Internet, and video games. Ongoing coaching, via data tracking and a "virtual life coach" or avatar, also could help accomplish this. Another possible method by which to modify behavior is to provide incentives. Frequent virtual monitoring at home that allows individuals to watch models of their bodies behave in various scenarios may provide incentives for healthy behaviors and disincentives for unhealthy behaviors. To change behavior, it is necessary to know what works and for whom; to answer this, long-term comprehensive data are needed. Data can be captured best from personal or electronic medical records. Patient identifiers would be eliminated before the comprehensive, standardized data are entered into research study databases.



To keep communities healthy, it is necessary to understand the problems and available opportunities to intervene. Community health data can be acquired from many sources, including personal and electronic medical records (with patient identifiers removed), personal and environmental biomonitoring data, and metrics of the social determinants of health. Health is not just the mere absence of disease, but a product of a healthy environment that includes mental, emotional, and spiritual well-being; community and family support; a healthy body; and a safe, healthy environment. This is highlighted by a study in Glasgow, Scotland, that tied health to postal codes (i.e., neighborhoods); those living in neighborhoods with less support and increased social stress were less healthy than those living in supportive neighborhoods. Significant health disparities also are seen in the United States (e.g., higher breast cancer mortality rate among black women).

Individuals who view themselves as a valued member of society are healthier, whereas disadvantaged individuals have increased disease and mortality.

Providing equal access to healthcare is one step toward eliminating these disparities, but it is not the only solution. Despite the existence of a national healthcare system and equal access to care in Scotland, some neighborhoods still were identified as unhealthy compared to others. Many factors influence health: general socioeconomic, cultural, and environmental conditions; living and working conditions; social and community networks; individual lifestyle factors; and constitutional factors such as age, gender, and genetic makeup. A healthy society with effective cancer care for all Americans will not exist until the social determinants of health are addressed. Electronic medical records and their associated databases can help accomplish this.

Dr. Rowley described an example of an individual with risk factors who changes his behavior with the help of a company incentive program that promotes prevention and wellness. The example involved online interactive health risk assessment, a secure electronic medical record, productive medical team interactions, and effective use of technology. In this example, the individual's medical team is a collaborative team that provides a continuous, coordinated healing relationship focused on prevention and effective, evidence-based interventions. The company incentive plan provides financial incentives to the patient and the medical team. This type of patient-centered medical treatment focuses on prevention and behavior change, proactively monitors health risks, and provides effective management of diseases, with the capacity to support individuals with cancer.

True cancer care must include a strong relationship between a solid primary care team and the cancer center. In turn, the cancer center requires the use of electronic medical records and participation in research studies to investigate pharmacogenomics and the complex interactions of multiple oncogenes. Because there is an increasingly wide range of therapeutic options, many types of data are needed. Also needed are fast methods to document early efficacy, effective patient navigator support, empowered home self-care, and more types of tests to monitor for recurrent cancer. Additionally, those cancers that cannot be cured must be treated as a chronic disease with the promotion of quality of life and longevity as the primary goal; in these cases, heavy dose therapies will need to be monitored.

Cancer is the result of the complex interactions between genetic, environmental, and behavioral factors, and the best method to accelerate knowledge of these factors is via database mining of long-term prospective data from large cohorts of at-risk individuals. To track individuals from precancer to a cancer outcome, electronic medical records from willing individuals must be obtained. Therefore, society should accept an obligation to share personal data in a protected manner to win the fight against cancer. There is a great opportunity for the cancer community to facilitate personal health data collection and data mining research to accelerate this knowledge. Dr. Rowley challenged the participants to conceive a vision for the next 5 to 10 years regarding the prevention, diagnosis, and treatment of cancer. He provided the following recommendations for doing so:

- Go beyond the traditional cancer registry role to collect prospective data on future risk.

- Strongly advocate for effective, widely used electronic medical records by creating data security, privacy, and discrimination standards by compelling the government to pass genetic protection laws.

- Market to cancer patients the importance of sharing personal health record and genetic data and participating in research studies.

- Bring the cancer community together to promote, share, and aggressively utilize these data to accelerate new knowledge in cancer prevention and treatment.

Questions and Discussion

The discussion centered on the more technical aspects of the presentations, including grid computing, avatars, and the evolution of the Web as it relates to information sharing.

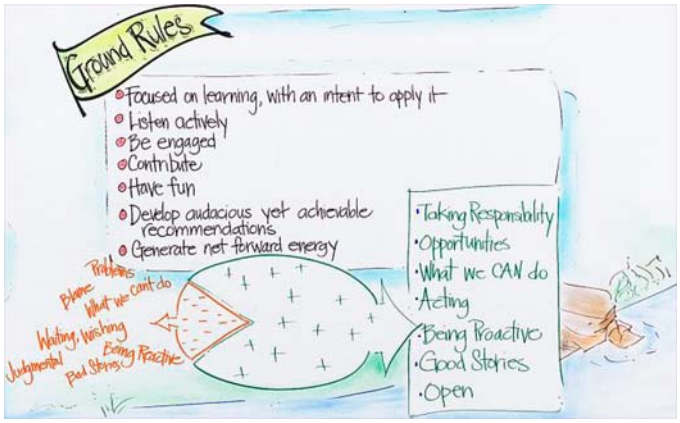
C-Change may have a stake in accelerating grid computing because the technology currently exists, and the integration of disparate types of data—such as single nucleotide polymorphism, genomic, and epigenetic data—will be the challenge. This will require mathematic modelers to form a common grid in terms of staging data, terminology, and so forth that will allow harmonization and sharing of data. The question is how ontologies, terminology, and categories will be harmonized.

An avatar has two definitions in the current internet context: (1) a graphic identity taken by an individual, usually a caricature, that represents the individual in a digital environment, and (2) a graphic identity, other than the individual, that the individual uses as their agent to explore cyberspace, gather information, and provide advice. To be effective, an avatar must be intelligent, contain a great deal of knowledge, and communicate with the individual. Gradually, as they evolve, avatars will have personalities that match the individual. Children and younger individuals will grasp this concept and embrace it. Although avatars in the future will be increasingly sophisticated, increased knowledge of how to use avatars will allow individuals to be comfortable with them.

The evolution of the Web from a static to a dynamic entity allows for greater choices for information sharing. To date, the cancer community has rarely, in a systematic manner, engaged the population in a discussion regarding sharing personal information; most have been in a risk management context. The cancer community must discuss the technological aspects of encouraging personal data sharing, but different conversations with the public also must occur to market this point of view. There must be a commitment by the cancer community to drive this message home. Individuals use their computers and personal digital assistants for almost every aspect of their life; knowledge of these tools exists. Therefore, the cancer community must determine that it is a worthwhile effort to build trust within the population so that they feel safe sharing their personal data and using these technologies in the health arena. The Web community already is starting to gather information, and physicians must embrace this technology. Social technology is drastically changing how information is received and exchanged and how individuals view their own privacy. An excellent reference for understanding this change is *Wikinomics: How Mass Collaboration Changes Everything*, a book by Don Tapscott and Anthony D. Williams.

MEETING OBJECTIVES, AGENDA, AND PROCESS

Dr. Clem Bezold, Chairman of the Board and Founder of the Institute for Alternative Futures, explained that he would act as moderator for the facilitated discussions. The objectives of the Summit are to: accelerate the successful incorporation of the complete spectrum of cancer data, including data patient care and public health surveillance, into a national architecture of syntactic and semantic interoperable electronic medical record systems; accelerate and document the process of interoperability of all risk, diagnostic, treatment, and surveillance information into electronic systems for recording, documentation, and transmission; create action plans for each domain across the cancer surveillance spectrum from risk to mortality that improves syntactic and semantic interoperability among them; and create a future vision of an interoperable cancer surveillance system in the context of risk and treatment at the individual and population perspectives. The ultimate goal of the Summit is to create a short set of recommendations to accomplish the above objectives. As promoters of enhanced cancer information and surveillance and its effective use, participants will provide input on how to obtain advice and support from key government, vendor/technology, and healthcare leaders on cancer surveillance goals, objectives, and strategic approaches, ultimately generating net forward energy. Net forward energy is a condition in which the participants at a meeting with established shared objectives focus their attention and energy on what is needed to achieve the objectives. There may be criticism or uncertainties, but the energy focused on moving forward far outweighs the energy focused on obstacles.



PLENARY SESSION II: WHERE DO WE GO FROM HERE?

Electronic Health Record Perspective in Interoperability

Carol Diamond, M.D., M.P.H., Markle Foundation

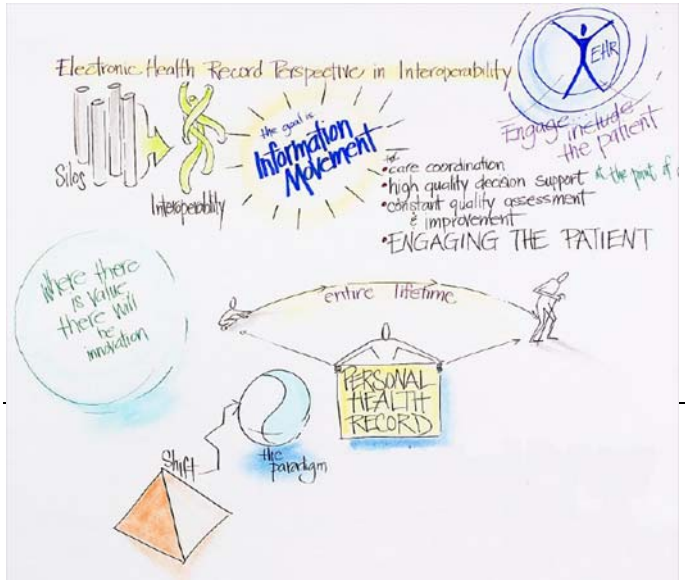
Dr. Diamond, Managing Director of the Markle Foundation's Health Program, posed two questions: Where are we on the road to interoperability? Where do we need to go? The goal of healthcare information technology (HIT) is to make better decisions at the point of care, and interoperability of these systems is important for better care coordination, high-quality decision support, constant quality assessment and improvement, and engaging the patient. Connecting for Health (http://www.connectingforhealth.org) has been operated by the Markle Foundation since 2002 and is a collaboration between the private, public, and not-for-profit sectors. The goal is the sharing of health information data, and the collaboration catalyzes changes on a national basis to reach the goal of creating an interconnected, electronic health information infrastructure to support better health and healthcare. To accomplish this, the three meaningful and necessary areas of focus are: (1) technology standards and adoption, (2) policy framework for successful implementation, and (3) the role of the consumer. The organization proposed a Common Frame-

work of privacy and technology attributes that achieves interoperability and portability while addressing the importance of protecting the privacy and security of information; the Framework was tested in three geographic areas.

Agencies such as the CDC, the Agency for Healthcare Research and Quality (AHRQ), the Human Resources and Services Administration (HRSA), and the Centers for Medicare & Medicaid Services (CMS) are involved in state and federal HIT initiatives. Congressional and state-level HIT bills exist as well. Although much progress has been made, it has been slow because the majority of providers do not use electronic medical records, very few communities have operational health information exchanges, published standards specifications are not adopted, and Certification Commission for Healthcare Information Technology (CCHIT) certification does not yet address interoperability. Many of the challenges identified in 2002 remain today, including technical, policy framework, financial, and educational barriers.

Personal electronic records will not be a one-size-fits-all solution because different people have different needs. Currently, because health information is located in many locations (e.g., hospitals, laboratories, primary care physician and specialist offices, etc.), it is difficult for individuals to retrieve all of their health information. The goal is for the patient to become the information hub in a system that is accessible, private, secure, interactive, and fulfils patient needs. The caveat is that electronic personal health services have the potential to become a disruptive technology. Despite this, there is a national trend toward the implementation of electronic medical records.

Currently, provider portals reach approximately 15 to 20 percent of patients to whom they are offered, and patients show more interest in specialized products. Personal health records are "tethered" to provider information and pharmacy data and are populated from claims data. In more sophisticated systems, patients are auto-enrolled in education programs for their medications and conditions. In some cases (e.g., Brown & Toland Medical Group), physicians may add or edit adherence programs for their patients. Although some may question electronic data supplied by the patient, physicians in the current paper-based world utilize patient intake questionnaires received from the patient; this involves the same level of trust. Examples of online electronic medical record repositories are the National Digital Medical Archive (http://www.ndma.us), FollowMe™ (http://www.followme.com), and MiVIA™ (http://www.mivia.org). Specific information needs also must be considered. The core question is: What does the patient need? Web sites that offer patient diaries, blogs, and other types of support can help determine patients' needs. The PatientsLikeMe™ Web Site (http://www.patientslikeme.com) provides a wealth of information and support to patients. Disease progression that clinicians cannot provide can be found at this Web site. Research using the data found on this site can benefit from a richer data set and an engaged patient population overcoming some of the current challenges to the traditional approach to initiating a research study, which involves identifying a candidate population, raising the necessary



funding and approval and implementation lag times.

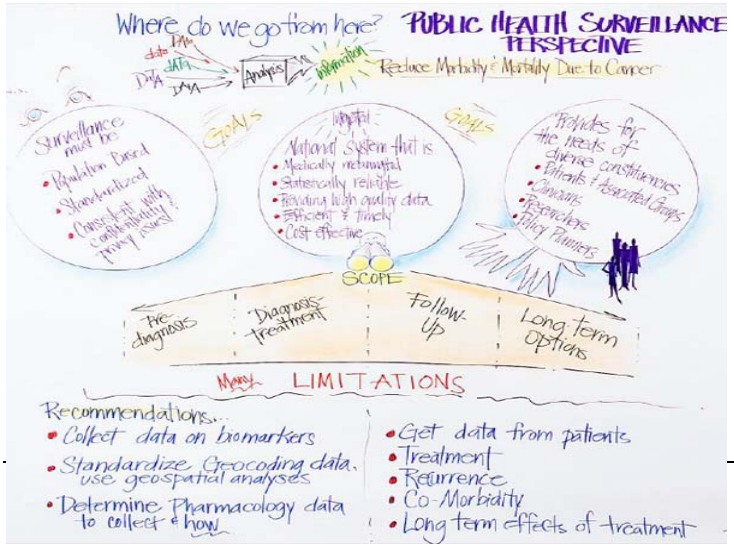
It is important to remember that the patient must be included in initial conversations regarding HIT. The opportunity at hand is to find ways to enable all the patient to make better decisions by leveraging a unique population and its affinity for information. Efforts should begin now, while there is opportunity, despite the fact that semantic interoperability is not yet in place. The focus should be on incremental opportunities in which cancer information sharing can have a dramatic impact on outcomes. The ultimate goal is to provide patients with access to and possession of information about their own health.

Public Health Surveillance Perspective

Carol Kosary, M.A., National Cancer Institute

Ms. Kosary, a mathematical statistician in NCI'S Cancer Statistics Branch, explained that the ultimate goal of public health surveillance is to reduce morbidity and mortality caused by cancer. Surveillance must include population-based data that is standardized in terms of rules, procedures, definition, collection, and processing so that meaningful comparison is possible. It is important to remember that surveillance must be consistent with confidentiality and privacy issues. There is a tangible need for an integrated national surveillance system that is medically meaningful, statistically reliable, comprised of high-quality data, efficient and timely, cost effective, and can provide for the varied needs of diverse constituencies, such as patients, clinicians, researchers, and policymakers. The system should monitor data across the cancer surveillance map including patient history (e.g., risk factors), prevention, diagnosis, treatment—including short- and long-term treatment effects—recurrence, and survival. Stakeholders must develop methods to leverage currently existing electronic medical records and other informatics tools to achieve these goals.

Current sources of data are central cancer registries, hospital-based databases, periodic national and state population-based surveys, consortia and networks, and clinical and administrative databases. Data are being made available through NAACCR, but central cancer registry data have limitations. Although data from hospital-based databases are not population-based and rates cannot be calculated, the data still can be useful. Survey-based data have many limitations, including various changes over time, the existence of biases, and samples sizes insufficient to support local area estimates. Attempting to link data is challenging, but some administrative databases, such as Medicare, Social Security Administration, and motor vehicle administration databases, are attempting linkages. Unfortunately, administrative databases may not provide data for all individuals, or data may not be available without complex negotiations and charges, if at all. Data from consortia and networks such as the Cancer Research Network, the National Breast and Cervical Cancer Early Detection Program, and the Breast Cancer Surveillance Consortium are good but also have limitations. In terms of clinical data, laboratory data are not collected opti-



mally by central cancer registries, and data from physician offices currently are not supplied to the registries.

The current maps demonstrate the complexity of determining what information is needed and from where it must be obtained. A remarkable amount of information exists that must be parsed and investigated to determine which pieces of meaningful data should be collected. It is difficult to know what might be significant in the future, because it is a complex and moving target. Because all data are not good, stakeholders must consider the data before acting. This is important because data repositories are the foundation on which to build meaningful information and move forward, and the foundation must be solid. Questions to consider are: What biomarkers are important? What biomarkers will be meaningful in the future? What biomarkers are predictive and prognostic? How can geocoding of residences and facilities be standardized? What type of pharmacological data should be collected? What types of recurrence data should be collected? What type of data should patients report? What are the best methodologies to collect these data? Can these data be trusted? These are complex issues, particularly recurrence data because often there is a series of recurrences in other areas of the body. Longevity of data is necessary, because some side effects to exposure may not manifest themselves for decades.

There are many rich sources of data that provide statistics on incidence, survival, and trends. Stakeholders need to determine which data are needed, what questions should be answered, and how to meet the challenge. There is a potential in having additional data items on a population basis, including opportunities for greater impact. Informatics is vital to achieve public health surveillance goals, particularly in times of decreasing registry funding.

Medical Care Perspective: Enhancing the Clinical Relevance of Cancer Registries and Cancer Surveillance

Stephen Edge, M.D., FACS, Roswell Park Cancer Institute

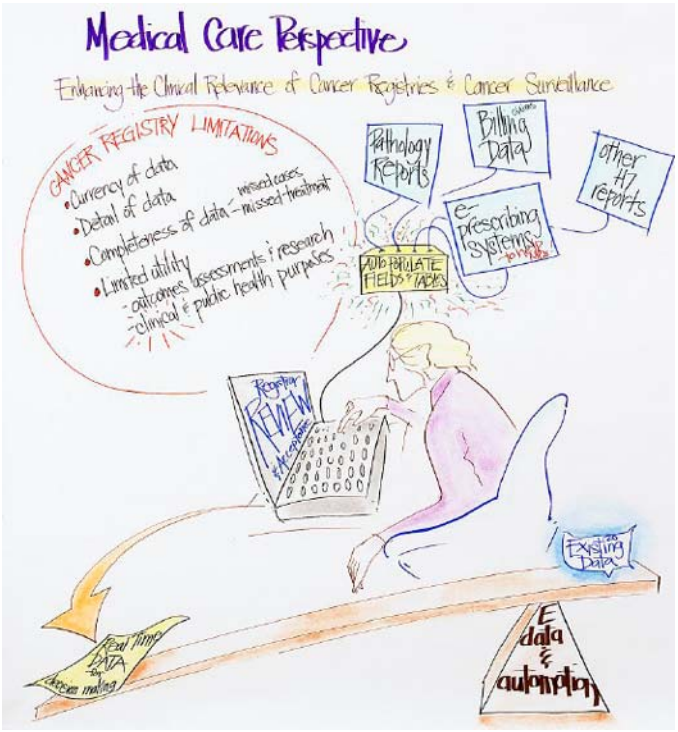
Dr. Edge, Chair of Roswell Park Cancer Institute's Department of Breast Surgery and Medical Director of its Breast Center, highlighted some of the limitations of current cancer registry data, which are near- to mid-term issues versus the long-term goals outlined in Dr. Rowley's presentation. Currently, there is a 4- to 6-month lag in reporting from hospitals, which affects the timeliness of data. Additionally, until registries are useful to providers, there will be no buy-in on their part. Provider input, opinions, and needs must be heard. There is limited utility of current cancer registry data for outcomes assessment and research and for clinical and public health purposes. To provide clinical utility to providers, the purpose of surveillance must be defined and feedback provided; this engages the providers in the process. Cancer care is a complex and often chaotic web, especially for patients. Registries must help clinicians navigate this web so that they can provide support for their patients: "Help the doctor, help the patient."

Clinical detail is required to address the effectiveness of therapeutic regimens versus efficacy as determined in clinical trials. Clinical trials are needed to assess efficacy in younger, healthier, and otherwise nonrepresentative subgroups of the population. Cancer registries, however, provide the best opportunity to collect data about the general population. Because of the increase in cancer survivors, survival time is no longer sufficient as the sole outcome measure. Therefore, cancer registries are the logical clinical data repository for cancer survivors, and the opportunity to provide survivors with information should be considered as well. The challenge to enhancing

the clinical relevance of cancer registries is that cancer data traditionally are received from hospitals, but hospital registries may miss cases or important information (e.g., treatment details). Studies suggest that missed treatment information may represent biases based on reporting source and location; therefore, nontraditional registry sources may be needed to capture necessary treatment information.

Leveraging existing sources may be a tool to enhance registries and serve patients. Leveraging billing data is one attractive source that the CoC is pursuing. Because oral hormone and chemotherapy are not likely to be captured in billing data, it would be useful if pharmacies and/or insurance companies notified physicians if prescriptions are not refilled. For example, patients stop tamoxifen for a variety of reasons and do not always report this to their physicians; notification by the pharmacy and/ore insurance company would be helpful. Another challenge is the lack of efficiency and data overload of registry staff, who must manually screen and enter data. There are, however, several electronic data sources available at the hospital level, including pathology reports, claims data, and other HL7 reports. Automating data requires checks and balances; the registry should verify administrative data.

Dr. Edge highlighted two examples that are useful in illustrating the clinical utility of current data. One example is staging systems that is designed to collect and store raw data on prognostic factors and should allow import and export of these data to and from the registry and the clinician to allow a prediction on the value of therapy and a prognosis. The second example is use of real-time cancer registry data collection to enhance care delivered to patients and reduce systems failures, particularly those that result from disparities, by applying a tracking system to eliminate disparities. These examples illustrate how cancer surveillance can be used to enhance quality of care.



In summary, the increasing availability of electronic data provides an opportunity to meet existing challenges. Judicious use of electronic data and automation coupled with highly focused and efficient human review offer significant advantages to current cancer registration processes. Cancer registration must increase its value by increasing the clinical relevance of cancer data, enhancing data completeness and detail, and maintaining or improving the efficiency of data collection while reducing cost and improving timeliness.

Facilitated Discussion

There are three types of patients in terms of information gathering: those that need to control information, those that seek information to make decisions, and those that passively allow

providers to make decisions. The discussion focused on developing strategies to market to the various patient-types. A system is needed that will provide information to providers and patients while allowing patients to make their own decisions. Additionally, it is helpful to provide outcomes information to physicians. Because information regarding diagnosis, treatment, and epigenetics of cancer is always changing, it is difficult to determine what data are needed to provide physicians and patients with the ability to make decisions. Physicians and registries should help each other determine information needs and the best methods for acquiring information. It was noted that electronic medical records are not meant to be a replacement for provider-kept information, but to be a tool for patients. As such, electronic medical records need to have information of interest to patients. Therefore, it is not necessary to design the electronic medical records by patient-types; patients themselves will be the driver. There is a paradigm shift from a focus on merely collecting high-quality data to using these data to effect an outcome; the objective is to foster the ability to *use* data.

The next discussion centered on financial incentives to increase health information exchange. There is a disincentive for keeping people healthy, because this reduces the amount of reimbursable items and decreases overall revenue. The current model, fee-for-service, was developed for acute-care scenarios and was not designed for chronic diseases. Although fixing this model will be difficult and need long-term commitment, the greatest opportunity for improvement is providing the patient with the necessary tools. Currently, efficiencies for adopting HIT do not accrue to the provider, so this disincentive also must be overcome.

It was noted that data collected must be relevant to patients. Many patients use data that may not be as accurate as desired, but using data is the best method for "cleaning" the data. If the goal is simply to collect data, there is no incentive to clean; the objective must be to use data. If stakeholders focus too much on the data that are missing, however, excellent uses of the data will be overlooked. Using data to direct limited cancer control resources effectively to the populations in greatest need will be of the greatest benefit to clinicians and patients. Using data more effectively should be a focus. Electronic systems have their shortcomings, and there must always be a human element to interpret the data and create useful information. Focusing on how to generate value for those who provide data will increase the quality of data and provide the incentive to report complete, timely, and accurate data to the registries; the physician should be a key stakeholder in this process.

PLENARY SESSION III: THE INFORMATION WE NEED OR DESIRE

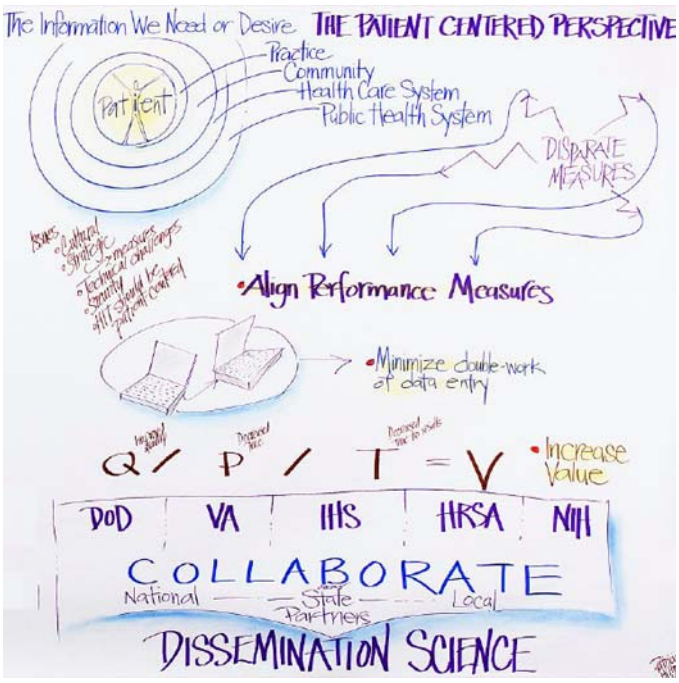
The Patient Centered Perspective

Ahmed Calvo, M.D., M.P.H., Health Resources and Services Administration

Dr. Calvo spoke as the father of a child diagnosed with leukemia and as the son of a father who died from leukemia. He encouraged participants to think on a practical level and include the patient as part of the team. Resolving the interoperability issues of HIT is not a technical problem at this time, but a matter of willpower. Additionally, collaboration must be improved on all fronts. The current prevalent system of care delivery is centered on private practice and primary care, and sometimes from a patient or parent's perspective these practices often appear to be working in a vacuum. This delivery system can be expanded into a Community-Oriented Patient

Centered approach so that decision support involves the practice *and* the community. This model is known as the Expanded Care Model and is based on the original Chronic Care Model described by Dr. Ed Wagner. In the Expanded Care Model, a wider set of self-management activities is incorporated so that the Internet or mere word of mouth referrals from social networks are not the main sources of self-management information. In this approach, patients are not merely expected to be "compliant" with the doctor's orders but are instead are seen as an integral member of the healthcare decision team. An activated patient is one of the expectations and goals of the healthcare activity in this model. A prepared, proactive community also is critical to improve public health and reduce health disparities. Cultural issues also must be addressed. A challenge that is in need of resolution despite the model is that some hospital cultures encourage parents with ill children to be with the child during treatment, whereas others discourage or forbid the practice.

Public health and personal health are intertwined, complementary paradigms. The individual, family, and community all have a stake and a right to access their health information. To address this, there is an evolving national performance measures matrix; data, technical, and security standards also are evolving. Past HIT systems were physician-centric, because of billing issues, but evolving HIT systems must be patient-centric. Stakeholders are in a position to ask for it all in terms of individual, community, and overall systems. One example of an open source project is a chronic management system used by the Veteran's Health Administration and Department of Defense.



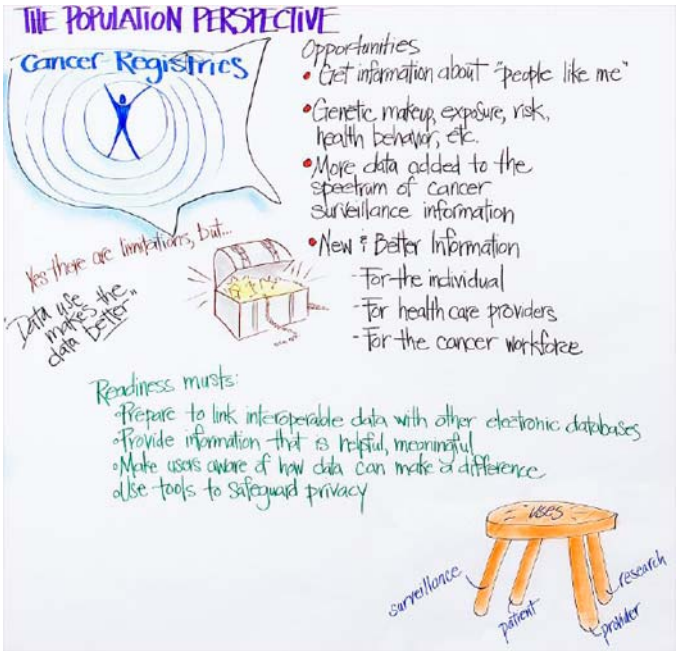
Practical goals to achieve include the alignment of disparate performance measures and minimization of the double work of data entry. Additionally, stakeholders should strive to increase quality, decrease price, and/or increase timeliness; each of these contributes to the increased value of the system. Better collaboration between the Veteran's Health Administration, the Department of Defense, the Indian Health Service, HRSA, and NIH will lead to better collaboration between national, state, and local partners. Appropriate indexes of performance also must be considered. No matter how excellent most of a patient's treatment is, if the individual does not receive necessary followup in a timely matter, then the quality of the overall patient's experience decreases and can be measured as decreasing. There are various indices of quality of healthcare. Quality can be weighed, indexed, and tracked, but this is a challenge in terms of gathering of data and the appropriate statistical aggregation thereof. Another challenge is the need for a resolution regarding epistemology concerns that currently are being debated in quality improvement. Some believe only certain knowledge (e.g., knowledge gained from randomized controlled trials) is valid, whereas others believe that insights from "realistic evaluation" using experiential learning

processes are valid. There is confusion about the fact that within the spectrum of epistemology, randomized controlled trials answer questions that are on one end of the spectrum and that experiential learning answers questions on another other end of the spectrum. These ideas are not actually in opposition to each other, but as these concepts are currently being examined, it will take some time to achieve understanding. Lastly, it should be acknowledged that funding difficulties and cultural biases are both barriers to the interoperability of electronic health records and community health records. The ultimate goal of truly improving outcomes is an important one that must be pursued at both the population level and in regards to personal health records.

The Population Perspective

Holly L. Howe, Ph.D., North American Association of Central Cancer Registries

Dr. Howe explained that data from physician encounters, diagnostic tests, clinical records, and healthcare facilities are aggregated in state and regional central registries, national cancer surveillance programs, and international programs. Standardization, such as uniform data standards and codes, has enabled surveillance. Objective data quality thresholds are applied before data aggregation; NAACCR uses registry certification and a fitness-for-use evaluation before using member data for surveillance. Current obstacles to data aggregation are declining government financial support, increasing case reports, and evolving questions, especially in terms of what data items are needed and meaningful for surveillance. The timeliness of annual updates, communication, and reporting is one current challenge, and another is the interoperability of cancer registration standards with electronic medical records. Getting public health cancer registry standards into the Cancer Data Standards Repository (known as caDSR) is a major accomplishment in this direction. Additional challenges include managing in an electronic environment uncertain terminology and absent or differing standards of other disciplines and acquiring meaningful information from health records. There is a need for more information, including more specific information, on each cancer case. There must be increased flexibility to respond to information needs more quickly. Additionally, more specific population information, such as Census, demographic, and at-risk population data, is needed.



Cancer surveillance is about producing useful and meaningful information while recognizing that information needs and inquiries change. The goal is to continue to produce relevant, useful information about new issues using new tools and technologies. In the future, individual information will be tailored and retrievable so that patients will be able to find answers to their specific questions, including prognosis. Providers will be able to offer more individualized treatment and utilize new prognostic factors. As both cancer diagnoses and survival increase, the size and skills of a cancer workforce will increase; surveillance data will help define

workforce needs, including where, how many, and what types of providers will be needed. More data will allow for the improvement of: cost-benefit and efficiency of interventions, identification of populations at risk, application of specific and effective strategies for at-risk populations, and collection of screening and early detection data for addition to the cancer surveillance continuum. Policymakers will be able to enhance their decisionmaking. Key tools for these goals are linkage of information from multiple sources that have semantic interoperability. Interoperable data will allow the ability to conduct public health surveillance of expanding factors, such as risk, exposure, and survivorship.

To prepare for the future, registries must be prepared to link interoperable data with other electronic databases and provide information that is helpful and meaningful. Users must be aware of how these data create useful information that can make a difference. Gatekeepers must have the technical, political, legal, and ethical tools to safeguard privacy. The future of surveillance includes expanding information, increasing knowledge, and creating opportunities. Data will be increasingly relevant, informative, used, and applied.

The Survivor's Perspective

Caroline Huffman, M.Ed., LCSW, Lance Armstrong Foundation

Ms. Huffman, Lance Armstrong Foundation (LAF) Senior Program Officer, explained that the LAF is uniquely poised to be a leader in the cancer survivorship domain. The LIVE**STRONG** Survivorship Center of Excellence Network was envisioned in 2004 and made operational in 2005. It brings together individual cancer centers to harness the expertise, experience, creativity, and productivity of leading NCI-designated Comprehensive Cancer Centers to significantly accelerate progress in the field of cancer survivorship. Members of the Network collaborate to provide essential direct survivorship services and increase the effectiveness of survivorship care through research, development of new interventions, and sharing of best practices. The two hallmarks of the effort are that: (1) centers work together so that the whole is greater than the individual parts, and (2) each center has community affiliates that impart community knowledge to increase the quality of the research. The eight network members work with 21 affiliates across the United States; these affiliates are community nonprofit organizations that provide direct services to traditionally underserved cancer survivors.

Patients and survivors have expressed serious concerns about the privacy and security of medical information while also expressing great demand for a written Cancer Treatment Summary and Care Plan, which they believe would greatly facilitate their ability to maintain positive health and

manage the chronic health conditions related to cancer and its treatment. Such access would empower survivors to actively participate in their long-term care. The Cancer Treatment Summary and Care Plan, which will be branded the "LIVE**STRONG** Cancer Treatment Summary & Care Plan," must be: adaptable to a wide diversity of survivors with different cancers having undergone different treatments, accommodating of varying literacy levels or language barriers, and usable in both academic medical centers and community oncology practices. The goal of the LIVE**STRONG** Survivorship Center of Excellence Network is to address a compelling public health challenge by creating a Care Treatment Summary and Care Plan for adult cancer survivors. LAF is working toward a free and open-source Web-based tool, which hopefully will be available for national dissemination by the end of the year; Google and IBM have expressed some preliminary interest in partnering in this effort. The fundamental message is that it is important to actively engage survivors without preconceived notions and truly listen to them.

Facilitated Discussion

Participants discussed how to promote data sharing, and the following actions were identified:

- Define priorities.
- Cultivate the next generation of leaders.
- Foster access to datasets.
- Build query systems that do not violate privacy concerns.
- Use patient navigators as information brokers to supply data to registries.
- Improve systems, such as "wiki" systems, that encourage group processing and sharing. A wiki is a computer program that facilitates the creation of collaborative Web sites through the ability to easily create and link Web pages together.
- Increase collaboration between survivorship groups and registries.
- Promote the message that data collection empowers both the individual patient and society.
- Make data more instrumental in decisionmaking.
- Make financial decisionmakers aware of how integral data use can be to save money and direct limited resources.
- Foster support by encouraging registries to commit to using data to answer relevant and meaningful scientific questions.

An example was related about a HRSA-funded project designed to improve various aspects of quality of care. Initially, there was a significant fear regarding data sharing, but what evolved was a community of learners that voluntarily share, work together, and learn—with the

stipulation that information cannot be used against them. As a result of this initiative, Web abilities evolved, subject matter experience increased, and fears decreased. Applying the community-of-learners approach to this problem could be one solution. It also should be noted that medical students (i.e., younger individuals) more quickly grasped wiki concepts than did clinicians (i.e., older individuals). This gap must be considered when employing this approach.

One suggestion was to use mathematical modeling approaches to estimate needs, but as needs are so varied, the challenge is to create useful information that meets all of these needs. Another suggestion was to build on hospital-collected data, but the caveat to this is that as more patients receive treatment outside of hospitals, a complete picture may not emerge. Although the hospital does not need to be the information hub, it should be included in the vision of how data and data sources are tied together. One example of the importance of hospitals is California's hospital-centric emergency preparedness plan. It also is important to remember that the public health perspective is critical to the whole process.

The health disparities collaboration may offer an interesting case study in terms of how registries went from a population medical surveillance tool to a clinical decision-support tool and back again. Is there an opportunity to use this case study for cancer linkages? Another interesting human wiki experience is the group visit, where physicians act as mediators for patient questions. A related example of an unexpected outcome from scheduling was described. One obstetrician scheduled appointments based on patient trimester, which resulted in similar patients being in the waiting room at the same time; consequently, these patients counseled each other as they waited to be seen. A human wiki group is an intriguing idea, but the question is how to operationalize such a concept. Creating a Web 3.0 interaction of similar patients may be one method. It is necessary, however, to remember that in addition to similarities, there are differences in patients. Assumptions regarding similarities must be tested before they are used as the basis of a program.

Based on this discussion, the participants identified the following categories for recommendations to enhance cancer surveillance:

- Public health education in public health surveillance.
- Visibility and value of cancer data.
- Coordination of clinical care and surveillance (eliminate duplication and competition).
- Embrace cancer data sharing from a personal level to public health surveillance outcomes.
- Increase implementation of quality measurement/quality improvement in cancer registries.
- Encourage exploration of wiki methods.
- Collaborative cancer linking (bring together patient with cancer surveillance team).
- Nurturing the community of practice and bringing together multiple disciplines.

- Use-case centered focus (including clinical/patient/data management to present use cases that can be disseminated to stakeholders).

- Ensure recognition that cancer surveillance is a priority in the bigger public health rubric.

- Financial incentives to foster data sharing.

A case-centered focus, like C-Change, involves stakeholders from all three sectors. Building a system that fosters trust will create net forward energy. C-Change can bring together the stakeholders in this vision.

PLENARY SESSION IV: ACHIEVING FEDERATED DATABASES

Federated Databases: Regional Health Information Organizations, Data Security, Confidentiality, and HIPPA

Greg Downing, D.O., Ph.D., U.S. Department of Health and Human Services

Dr. Downing, Program Director for the U.S. Department of Health and Human Services (HHS) Personalized Health Care Initiative, explained that consumer-directed, genomics-based technologies are not only interesting, but an important area in which C-Change can facilitate public input. In 2004, the President issued an executive order that requires HHS to achieve the goal of providing most Americans with access to secure electronic medical records by 2014; the business structure of the United States made this mandate necessary. The government incentives work toward creating a culture that recognizes the value of exchanging health information. Health information exchange can: generate cost savings by decreasing redundancy, provide transparency about healthcare quality and cost, provide data for pay-for-performance, and support public health and emergency preparedness using aggregated measures. Additionally, it can enable quality improvement and Medicare payment reform by making clinical data available for benchmarking and reporting. Currently, Congress is debating the government's role in health information exchange but does provide incentives to increase overall efforts; the National Governors Association and the National Conference of State Legislatures also are involved in this issue.

From a business perspective, market forces have not realized the potential of electronic health information exchange. One reason for this is that the tipping point for participating in data exchange has not been achieved, but this tipping point will emerge naturally if the concept of electronic health information exchange is fostered. Although some activities that can advance exchange and accelerate progress are costly in terms of time and budget, encouraging the demand for using and linking standards can be achieved by demonstrating quality reporting and cost-efficiency outcomes and implementing pay-for-performance programs with efficiency measures. Different exchange models exist, including those that are organizational (e.g., integrated delivery systems, hospital chains), geographic (e.g., Regional Health Information Organizations [RHIOs]), and personally controlled (e.g., health data banks, Google, Microsoft). Most are not focused on government implementation but on how communities cooperate. The challenge for RHIOs is the ability to achieve sustainable business models.

Common exchange standards can lead to the ability to efficiently meet healthcare, individual, and population needs. The term "standards" does not necessarily mean using the same language, but rather understanding the meaning of what is being exchanged. Security and confidentiality issues will minimize exchange possibilities, but this can be overcome. The infrastructure for information exchange includes the concept of the National Health Information Network (NHIN), regional health information exchanges, and electronic medical records. The NHIN is a minimal set of standards and policies to support the secure exchange of health information among health-care organizations, individuals, and population users; the NHIN would facilitate the adoption of electronic medical records. The implementation of standards supports exchange by overcoming the costs of "connecting up" and increasing the value of being connected. Operationalizing the NHIN involves a number of steps and technical capabilities that the government is exploring.

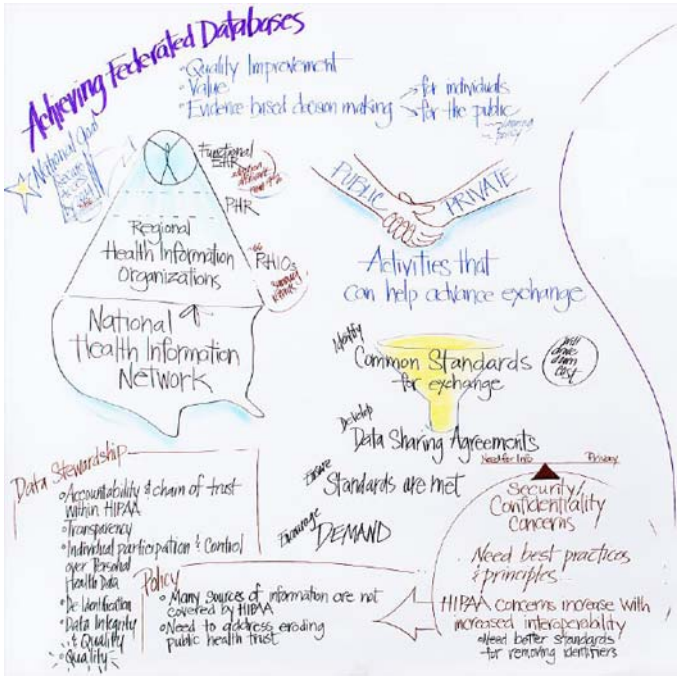
Each state should have at least one RHIO and, in cases where there is more than one RHIO, an overarching, state-level RHIO that coordinates the actions of all other RHIOs within the state. These organizations are based in the healthcare system, and some coordinate with state public health departments. They are nongovernmental, multistakeholder organizations that provide the framework for health information exchange and build trust among users. The ultimate goal of RHIOs is to provide consumers with the information they need about their health and healthcare choices. The CDC works with RHIOs to acquire health surveillance data in a timely manner. A majority of states have community-based HIT projects and have begun efforts to develop RHIOs to achieve interoperable electronic medical record adoption; these efforts are supported by the federal government in a nascent manner. It is not well-defined, however, in what manner RHIOs should best relate to federal HIT efforts. Additionally, there is no information about best practices that are essential to RHIOs or how to cost effectively replicate RHIOs.

Dr. Downing described a robust survey of currently practicing physicians and their attitudes toward HIT/electronic medical record adoption. Availability of electronic medical records varies depending on the definition used: historical, minimally functional, and functional; records meeting the historical definition were the most prevalent in the survey. The survey identified system obsolescence, initial loss of productivity, and legal issues to be the major barriers to electronic medical record adoption. The survey found a significant gap between multiphysician practices and single physician practices; most practices that have adopted electronic medical records have at least five physicians. The government is attempting to provide incentives for more practitioners to adopt electronic medical record systems.

The federal government is embracing several health information exchange programs (e.g., the CDC BioSense Program, CDC's National Center for Public Health Informatics), and the Medical Modernization Act authorizes AHRQ to conduct research to improve the quality, effectiveness, and efficiency of Medicare, Medicaid, and the State Children's Health Insurance Program. The Developing Evidence to Inform Decisions about Effectiveness (DEcIDE) Network, the HMO Clinical Research Network, and practice-based research networks are some AHRQ research programs that are using electronic medical record information. The main purpose of the DEcIDE Network is to develop valid scientific evidence about various aspects of healthcare services. The National Center for Health Statistics (NCHS) convened a workshop in May 2007 that led the CDC to develop Requests for Proposals in this area.

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) provisions promote the electronic exchange of financial and administrative transactions; however, consumer-based transactions may not have these protections. HIPAA regulates covered entities in which money is exchanged for healthcare transactions; free clinics may not qualify. HIPAA regulates the rights and privacy in regard to patient information, but cancer patients generally are more lenient regarding their information. The National Committee on Vital and Health Statistics (NCVHS) is the main statutory public advisory committee to the Secretary of HHS and advises HHS in the areas of health data, statistics, privacy, and national policy. The NCVHS is developing a framework to balance the risk, benefits, obligations, and protections of the various uses of health data that extends beyond HIPAA. The NCVHS is addressing this area because health data now include more clinically rich data beyond claims data. Enhanced use of HIT has many benefits but raises concerns about the potential for harm. HIPAA, although it addresses some concerns, contains conflicting rules. The NCVHS Health Data Stewardship Conceptual Framework is being used to engage a national discussion regarding HIPAA provisions.

To maintain public trust, there are guiding principles for making recommendations on enhanced protection for uses of health data. Protections should: maintain or strengthen the individual's health information privacy, improve individual health and the national healthcare delivery system, facilitate uses of electronic health information, decrease administrative burden, increase the clarity of laws and regulations pertaining to privacy and security of health information, and build on existing legislation and regulations when possible. Draft recommendations have been made that address principles of data stewardship and transparency, oversight for specific uses of health data, transitioning to an NHIN, and additional privacy protections for health data.



Significantly more work is needed on electronic medical record adoption to meet the President's 2014 goal. Major work on access authorities, data security, and authentication must continue. The substantial increase in broadband availability will enhance the potential for large-scale, real-time flow of clinical data. Nonmedical-based health information may support research and future planning. Data standards for research capabilities require substantial attention. Finally, substantial policy work is needed to enable secondary uses of data exchange beyond the current HIPAA privacy rule provisions.

Question and Answer Session

To address the challenges identified in the presentation, C-Change should focus its attention on policies and experiences that enable information to be utilized for larger purposes. Currently, no demonstration models exist regarding surveillance information and how it can be utilized for a broader array of purposes. Overall, privacy is a significant societal issue; many people feel that individual privacy is being lost. Patients must understand how their data support research and influence positive outcomes.

Dr. Downing was asked to comment on electronic medical record vendors and the development of disease site models such as the Effects of Public Information in Cancer (EPIC) Model. Certain vendors are focusing on different disease areas. Other vendors have developed subspecialty core resources that are concerned with integration and evidence-based, clinical decision support capabilities; this is a growing need among providers. Decision-support models need reliable information sources, and meeting specialty needs is important. Credentialing is another important aspect. The extent to which cost efficiency should be built into these systems is an open question.

The participants discussed privacy issues, and why individuals are more comfortable with loss of privacy relating to travel and disaster prevention than with loss of privacy regarding health issues. One reason is that health information is perceived differently than other types of information, and there is still a health and disease stigma in the United States. Thoughtful methods to develop policy around these experiences are lacking. People do not realize how much data are collected about them on a day-today basis, and many do not mind if the result of the data collection is of value to them. In contrast, some individuals, for example, are so concerned that they prefer to pay out-of-pocket for prescriptions to protect their privacy. Also, an example was stated about some communities that have shared information with the promise of benefit and did not receive any feedback or any benefit. People want progress, but they are afraid of the purpose for which information is being used. The community health system has done well linking transient patients; these patients have better portability than insured patients. C-Change can partner with community-based health systems to acquire knowledge about their health information system.

The following questions were posed: What is the relative role of the government and the private sectors regarding privacy? Is it an infrastructure issue? Is it the government's role to coordinate action in this area? What is the right balance? Currently, Congress is ambivalent toward this issue; the major driver is a cost perspective: increase efficiency, increase quality of care, and do not overpay. It is known that people are comfortable with the cost-perspective concept and with integration of standards, and communities and business flourish in situations in which they know where and how to get what they need. Using a nongovernmental agency to take the lead while including government stakeholders in the discussion is believed to be the most efficient method of fostering adoption. One innovative approach is that payers are developing portal systems and meaningful methods of examining value exchange and quality care parameters. The government's ability to oversee standards process in this capacity is in place. Although infrastructure may be a challenge, the government also can play a role in improving the quality of care of federally provided medical services (e.g., Medicare, military, etc.)

One important area in which C-Change should remain active is in advocating the importance of sharing information and explaining the associated benefits. Focusing on this message is especially important because no other group specifically advocates for it. Communities use the information around them to better themselves; C-Change can harness this attribute and deliver the message that providing benefit to others also is noble.

Facilitated Discussion

Dr. Bezold encouraged the participants to supply at least one recommendation to enhance cancer surveillance in terms of electronic medical records.

It was noted that seven dichotomies emerged from the day's presentations and discussions:

1. Individual decisions leading to meaningful outcomes *versus* policy decisions based on (perfect) data.

2. Technical capacity *versus* political will.

3. Consumer led *versus* system led.

4. Being all things to everyone *versus* focusing on key drivers that affect health status.

5. Individual privacy *versus* the common good.

6. Expansion of information capacity *versus* eroding infrastructure for registries.

7. One entity in charge *versus* many entities in charge.

PLENARY SESSION V: THE ACTION PLAN

Discussion of Recommendations and Summary of Needed Actions for Specific Recommendations

Tom Kean, M.P.H., C-Change
Clem Bezold, Ph.D., Institute for Alternative Futures

Mr. Kean noted that the recommendations reflect the changes that have occurred in the 4 years since CSIS I. C-Change will examine the recommendations and determine where the organization can make a value-added contribution; the Board of Directors will be involved in this process. The Summit Steering Committee and C-Change staff members combined the 40 recommendations received from Summit participants into nine recommendations.

The group discussed the necessity of ensuring that patients and their needs are reflected in the details of the recommendations when they are expanded and acted on. Patients from across the cancer surveillance spectrum from healthy to survivors must be considered. An overarching platform is necessary that equally considers patients, providers, surveillance, and clinical and epidemiological research.

Participants discussed regulations regarding patient privacy. C-Change is a unique organization in that it encompasses the government, private, and nonprofit sectors; the organization, as a result of a recent decision, now will be involved in policy matters, including the healthcare reform discussion and debate. The organization will be looking for consensus items when moving forward on policy issues. Based on the discussion at this Summit, there appears to be a high degree of consensus about data security and privacy issues, so these concerns can be carried over into the policy discussions. The NCVHS report, *Enhanced Protections for Uses of Health Data: A Stewardship Framework for "Secondary Uses" of Electronically Collected and Transmitted Health Data*, which can be downloaded at http://www.ncvhs.hhs.gov/071221lt.pdf, addresses patient privacy and data sharing concerns. It is important to note that there still are conflicts with HIPAA and the Common Rule. Although a common goal may be a true healthcare privacy law, this is politically very difficult to achieve, but it may be possible to work under the existing framework toward such a law. Currently, there is no proposal specific to health privacy for which C-Change could advocate, although there are proposals related to general electronic information. Organizations like C-Change are necessary to convince policymakers of the need to move forward with these types of proposals. The group discussed whether examining the need and opportunities for privacy legislation should be added as a 10th recommendation or incorporated and embedded into each of the existing nine recommendations; the ultimate decision was to add it as a 10th recommendation.

The need to distinguish the various types of cancers as separate entities instead of considering cancer as one disease was identified. The need to create a cancer control index that will demonstrate progress (i.e., moving away from surveillance to application) first identified during the Cancer Surveillance Futures Project was mentioned. A similar demonstration project by the Georgia Cancer Coalition is in progress that gathers data via information exchange and provides a dashboard of 52 metrics. Patients, physicians, and nurses support this project.

Following the discussion, each participant was allowed to vote for exactly three different recommendations to determine those that were considered of highest priority. The results, in order of votes, were as follows:

1. Market the value of cancer surveillance—*23 votes*.

2. Transform registries—*23 votes*.

3. Improve the coordination of surveillance and clinical data needs for quality improvement—*18 votes*.

4. Improve the utility of existing cancer surveillance tools using advanced tools—*17 votes*.

5. Develop a "Cancer Patients Like Me" Web Site to engage patients in submitting data that can enhance registries—*6 votes*.

6. Create financial incentives—*6 votes*.

7. Examine the need and opportunity for legislative policy regarding privacy and security—*6 votes*.

8. Focus on workforce development and recruitment—*4 votes*.

9. Achieve shared meanings—*3 votes*.

10. Encourage group processing (i.e., wiki) methods—*1 vote*.

Mr. Kean explained that the mission of the Summit was to enhance the connection between public health cancer surveillance and the emerging electronic medical records system. The recommendations are broadly written; however, the connections are integral to addressing the details of each recommendation when they are expanded and enhanced. Electronic medical records are a very important element of this discussion and of the recommendations. The voting helped to prioritize recommendations for allocation decisions, but recommendations with fewer votes still may be pursued.

The participants discussed each recommendation in further depth, identifying possible challenges and issues associated with the recommendation as well as additional needs, specific actions, potential goals, and organizations not already identified. One discussion focused on the recommendation to encourage group processing (i.e., wiki) methods. Three of the group's recommendations were coalesced into this recommendation. Tangible gaps in this area include the under use of Web-based group processing methods, lack of clinical information and information needed by the patient, and insufficient communication and interactions between researchers/providers and patients/users. Specific actions that can be taken to overcome these gaps include initiating more research on these processes, tracking outcomes improved by these approaches, studying the content analysis of group medical visits to identify elements for a template shared-care plan, and examining the "eBay model" in which information is presented by resource providers and patients "shop" for what they need. A potential goal in this area is to understand the changes occurring to determine if information dissemination can be improved. Organizations that may be able to help in this area include: NIH, AHRQ, HRSA, and the Baylor College of Medicine. This is a means that is evolving in all communities, not just the cancer community, as a method to develop shared knowledge. Instead of being a stand-alone recommendation, this can be highlighted as one technique that groups can use to more rapidly achieve consensus and share knowledge. The group decided that this would be a method incorporated into other recommendations and would no longer be a stand-alone recommendation.

The nine recommendations resulting from the Summit, including needed actions, are presented below.

1. Market the value of cancer surveillance. This recommendation combined 11 similar, individual recommendations. There are tangible needs in this area to raise public awareness of cancer surveillance databases, reduce the public's fear of government use of individual health data, and raise the awareness of researchers. Specific actions to close these gaps are to develop: advertising, marketing, and education campaigns; use cases; stories; and communication strategies. Potential goals in this area are to develop public buy-in of the value of cancer surveillance,

foster public trust in cancer surveillance, develop a sense of providing something for the common good, and counteracting strong privacy advocacy groups. Organizations that should be involved in exploring this recommendation are: C-Change, LAF, the American Cancer Society (ACS), and the American Association of Retired Persons (AARP).

Needed actions: Because support for public health surveillance is decreasing for all diseases, if the marketing is focused on cancer only, this may inadvertently cause a problem with competing marketing strategies. It may be necessary to embed the recognition that cancer surveillance is important into the broader message that public health progress cannot be monitored unless surveillance is done. Involving marketing experts in the conversation may allow both messages to be pursued without either getting lost. The overall approach will be to develop a marketing strategy, which may include a marketing campaign. If the strategy appears to be self-serving, however, this may undermine efforts. Alternatively, the strategy may not be seen as self-serving but as experts conveying knowledge. Regardless, cancer registries should be included in the conversation to provide knowledge and guidance about how to proceed. An additional need to develop a use case among a broad base of partners was identified. Next, the group identified organizations that can move the efforts forward; the organizations that ultimately act on the recommendations may differ from those identified. Additional organizations identified include: the Ad Council, ICC, CDC's National Center for Health Marketing, NAACCR, ACoS, the American Medical Association, the College of American Pathologists (CAP), and other major cancer organizations that benefit from cancer surveillance information (e.g., Leukemia & Lymphoma Society).

2. Transform registries. Three recommendations were combined to form this broader recommendation. The tangible need in this area is to make registry information available at the point of service. Specific actions to close this gap are to: evaluate current variables in surveillance for relevancy, utility, and cost; enable registries to focus on thematic areas; and create a demonstration project of point of service and registry. One potential goal is to enhance the value of cancer registries and the cancer surveillance spectrum by refocusing on priority data variables, and another is to develop a sustainable model that enhances the utility of registries for inpatient care. To evaluate current variables and enable registries to focus on thematic areas, organizations that may assist are: NAACCR, NCI, CoC, and CDC. Organizations that could help develop a demonstration project may include: HRSA, LAF, NAACCR or a NAACCR-member registry, and CoC hospitals.

Needed actions: Potential partnerships should be explored, especially at the provider level. The Georgia Cancer Coalition is using this type of approach; registrars are part of the patient care team, meeting with physicians, nurses, and information technologists to move the data upstream in real time. Vendors also were mentioned as another resource in terms of developing a demonstration project.

3. Improve the coordination of surveillance and clinical data needs for quality improvement. Eight participant recommendations were combined to create this broader recommendation. Tangible needs in this area are to: identify necessary data and adapt to changing information needs; identify the multiple sources and locations of data by understanding opportunities for synergies between resources and the potential for error or conflict; and identify and address multiple efforts to collect complete, accurate, and timely treatment data. Specific actions to address these gaps

are to: assemble registry leadership, groups interested in personal health records, and clinical groups to form multidisciplinary teams to map "as is" versus "to be" data needs; access the capacity to collect and assemble these data; and move reporting closer to real time for surveillance and providers for continuous quality improvement. Potential goals are to: focus the use of surveillance and clinical registries toward the measurement of processes of care and outcomes, define a universal treatment template, and develop systems processes so that information is readily available to patients and physicians. Participants identified the following organizations to help accomplish these goals: clinical professional societies (e.g., ACoS, American Society of Clinical Oncology [ASCO], American Society for Therapeutic Radiation and Oncology, National Comprehensive Cancer Network, American Joint Committee on Cancer); registry professional societies and agencies (e.g., NAACCR, National Cancer Registrars Association [NCRA], NCI's Surveillance Epidemiology and End Results [SEER] Program, CDC's National Program of Cancer Registries [NPCR]); other specific oncology/registry vendors; and interest groups (e.g., Georgia Cancer Coalition, Georgia Cancer Quality Information Exchange).

Needed actions: Clinicians want hospital-based registries to track outcome and practice patterns. Three groups that would benefit from having a complete treatment summary are clinicians, registries, and patients. The challenge is to develop a strategy to bring these groups together. It is necessary to recognize that "who can benefit" and "who knows what they want" differ. Physicians and registry/surveillance groups once were at odds, but this is being reconciled. It is important to understand that not everyone wants what can potentially be offered; the first step is to understand the history and what the promise for the future may be. If history is ignored, it may accidentally be repeated. One real-life example of coordination is occurring in rural Georgia; because primary breast cancer is a known problem, doctors are tracking incidence rates using central cancer registry data and rigorously screening for early detection. In determining clinical data needs, the filter question is, "If these data are included, how will the world be different?" How this information can be used proactively in planning also is an important consideration. Additional organizations identified during the discussion were: LAF, other survivorship groups, ACoS, CAP, and other clinical societies/professional organizations, and CMS.

4. Improve the utility of existing cancer surveillance tools using advanced tools. This recommendation included seven of the participants' recommendations. Tangible gaps include the fact that existing data are underutilized and that there are polarized perspectives of the usefulness of consumer-based, research-based, or public health-based data systems. Specific actions to close these gaps include developing quasi-intelligent systems to extract and link data, identifying expert panels to draft a set of criteria for databases, providing funding options for developmental work, developing and using advanced tools other than artificial intelligence, developing and testing new mathematical or statistical models, and promoting data use and sharing. Potential goals are to: improve the utility of surveillance data (e.g., identify underserved populations for breast cancer screening using registry data); accelerate the use of registry data; search for breakthroughs for risk, diagnosis, and treatment; render data to be machine readable for all purposes (e.g., statistical, epidemiological, patient care); and develop a proof-of-principal approach that yields at least three examples of utility. Organizations and individuals identified to help in this area include: SEER, NAACCR, population-based cancer registries, CDC, NPCR, ACoS CoC, ACS, the Robert Wood Johnson (RWJ) Foundation, C-Change, and Dr. Schad.

Needed actions: Three examples of advanced tools include models that can improve estimates of missing data, models that use stage of diagnosis to accurately estimate screening penetration to determine where screening resources should be used, and emerging modeling techniques that better understand electronic data quality. A specific example is the Archimedes Model. The group recommended adding "use" to the specific action regarding systems to extract and link data, so that the action is to develop quasi-intelligent systems to extract, *use*, and link data. In terms of potential goals, the data should be usable, and possibly computable, in addition to machine-readable. There have been remarkable examples in the last decade with the emergence of population-based cancer registries and their effects on the populations they serve in terms of specific cancers and cost impacts; these examples should be captured and exploited to ensure an effective marketing strategy. The additional specific action of using examples to show cost savings was added to the recommendation. Additional organizations and individuals identified include: Dr. David Eddy and the individual within ACS that is dealing with Archimedes data sets, Dr. Eric (Rocky) Feuer, NCI's Cancer Intervention and Surveillance Modeling Network (known as CISNET), and Artificial Intelligence in Medicine.

5. Develop a "Cancer Patients Like Me" Web Site to engage patients in submitting data that can enhance registries. This recommendation combined three participant recommendations. One tangible need in this area is data exchange between patients, providers, and surveillance systems for mutual benefit. To overcome this, one specific action is to develop a voluntary, interactive Web site that will collect patient-provided data (e.g., followup, quality of life, etc.) and provide information and/or support to patients (e.g., individualized survivor statistics, support blogs and/or sites, individual query support) using Web-based population surveillance data. The potential goals are to develop a new data stream for registries and patient-friendly sources, develop public trust, demonstrate the importance of cancer surveillance data, and provide open information for all stakeholders. Organizations identified for this effort include LAF, AARP, the NCI Office of Cancer Survivorship, ACS, NAACCR, SEER, CDC, ACoS, the Markle Foundation, RWJ, and HRSA.

Needed actions: Different data sites have different uses, and it can be difficult to determine the proper uses of various data sites; this group could help clarify appropriate uses so that data sets are not overanalyzed and used inappropriately. The Web site envisioned in this recommendation provides dual benefits. First, there is an opportunity for patients to enter their information from risk and exposure through survivorship and then extract information from similar patients. Second, data can be forwarded to the registry, and the registry can provide information to the Web site and its visitors. The high-quality system would be interactive and rigorous. The question of whether to pursue the NHIN arose. Additional organizations identified include: Google Health, Microsoft Health, Center for Information Therapy, Revolution Health, Cancer Care Ontario, and Kaiser Permanente.

6. Create financial incentives. Two recommendations from the group were coalesced into this recommendation. The tangible gap in this area is the financial barrier to the linkage of electronic medical records to public health surveillance systems. To address this, financial incentives (e.g., tax incentives) could be developed and implemented that are designed to foster the linkage of electronic medical records to public surveillance systems. The ultimate goal is the expansion of the electronic medical record and its linkage to public health surveillance systems. Organiza-

tions identified include: the Markle Foundation, CMS, U.S. Oncology, the American Hospital Association, NAACCR, ACoS CoC, ASCO, and the American Academy of Family Practice.

Needed actions: The recommendation, as written, focuses on linkages between electronic medical records and the public health surveillance system. Because there are many barriers to adopting electronic medical records, financial incentives to adopt—not just link—should be established. Tax incentives may be appropriate for those practices that can afford to adopt, whereas a "HIT trust fund" could be created for those practices that do not have the capital to take advantage of the tax incentive. The gap was amended to read, "There is a financial barrier to the adoption of electronic medical records and their linkage to public health surveillance systems." The Association of Health Insurance Plans was identified as another organization that could help with this effort.

7. Examine the need and opportunity for legislative policy regarding privacy and security. It is important to note that there still are conflicts with HIPAA and the Common Rule. Although a common goal may be a true healthcare privacy law, this is politically very difficult to achieve, but it may be possible to work under the existing framework toward such a law. Currently, there is no proposal specific to health privacy for which C-Change could advocate, although there are proposals related to general electronic information. Organizations like C-Change are necessary to convince policymakers of the need to move forward with these types of proposals.

Needed actions: The bottom line is that health data should not be used for individuals and not against them. The earlier discussion of this topic focused on the identification of opportunities to change patterns within existing regulation and the creation of a national health privacy law. Therefore, the specific actions related to this recommendation are to identify current protections and needs and consider the national health privacy law recommended by NCVHS. It is important to understand that government agencies can hold hearings but cannot advocate for a proposed law. There is a fine line regarding government participation in these efforts, but government agencies need to be included to educate other stakeholders about opportunities and needs. Although government agencies may be involved, other organizations will actually act on the recommendations. Organizations identified include: NCVHS, NCHS, CDC, NIH, CAP, ACoS, and advocacy groups (e.g., ACS, LAF, Susan G. Komen Breast Cancer Foundation, Leukemia & Lymphoma Society). Legislators already involved in privacy issues also should be sought out with the help of identified partners.

8. Focus on workforce development and recruitment. This participant recommendation was not combined with other recommendations. Currently, there is a need for the cancer surveillance workforce to develop skills for future demands related to technology and infrastructure and to attract new workers to the field. To address this, skill sets necessary for the future should be identified, education and training should be developed to meet evolving needs, and national recruitment efforts should be initiated. The ultimate goal is a workforce that can support future and emerging needs for cancer surveillance. Organizations that can help with this goal are: NCRA, NAACCR, CDC, NCI, and ACoS.

Needed actions: The Allied Health Professional Reinvestment Act is applicable in terms of advocacy for workforce development and recruitment. The group identified Dr. Maureen Lichtveld (Chair, C-Change Workforce Team) and HRSA as additional resources in this area.

9. Achieve shared meanings. This recommendation combined two participant recommendations. Currently, cancer incidence standards have been incorporated into vocabularies and standards beyond NAACCR's standards. Specific actions are to support ongoing activities, ensure progress is maintained, and harmonize ontologies and value sets. Potential goals in this area are to ensure that cancer incidence data and registries are ready for interoperability with other data sources, support the existing movement with interoperability and consensus, and ensure that linkages will result in synergistic information for better decisions. Organizations identified for this effort are NAACCR and its cancer surveillance partners.

Needed actions: There was discussion whether this recommendation belonged as an actionable item under the advanced tools recommendation or as a stand-alone recommendation. The recommendation deals with ontologies, interoperability, and other factors (not tools) that are necessary to accomplish other goals; therefore, this remained as a recommendation. Much has been accomplished in this area recently, so the focus is more on keeping the momentum going than initiating action. Moving artificial intelligence from the recommendation regarding advanced tools to this recommendation may allow more freedom to develop that area. The concept of harmonization also needs to be emphasized. Additional organizations include: the Healthcare Information Technology Standards Board of Directors (HITSB), CCHIT, and the Healthcare Information and Management Systems Society.

It was noted that it might be useful to develop a use case for the cancer registry system to participate in the government standard harmonization effort that Dr. Downing mentioned in his presentation the previous day. This suggestion initiated a discussion about efforts already underway in this area and appropriate organizations to approach. The American Health Information Community (AHIC) recently asked for input in this area and could be approached if organizations such as HITSB have not been receptive in the past. Dr. Weinberg, a member of the AHIC Consumer Empowerment Workgroup, volunteered to advance this message to the workgroup during a conference call scheduled for later that afternoon. Additionally, approaching AHIC as a unified group could raise the level of priority.

Commitment sheets were provided to Summit participants to secure their involvement in devising and implementing the recommendations in actionable form. C-Change will determine which of the recommendations have a value-added proposition and assume responsibility for their planning and execution. Some recommendations will be forwarded to other organizations, which then will assume leadership.

Dr. Howe closed the meeting by thanking everyone for their attendance; the Summit exceeded expectations. The role of cancer surveillance should be kept in the forefront of the C-Change collaborative environment, and advocates must provide leadership in this area to keep the momentum moving forward. Efforts have coalesced during the last few years and are moving toward the original goal of a synergistic method to engage organizations and individuals within the organizations to accomplish shared goals and make a difference. Participants are encouraged to make a commitment and get involved with C-Change; without this important commitment, C-Change staff leadership cannot move forward. Passionate and committed individuals are needed to keep the cancer surveillance issue alive. Dr. Howe's own time and experience working with C-Change and its leadership and staff has been very rewarding.

Appendix