# Translating research into improved outcomes in comprehensive cancer control<sup>†</sup>

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#### **Abstract**

A key question in moving comprehensive cancer control (CCC) plans into action is, to what extent should the knowledge gained from investments in cancer prevention and control research influence the actions taken by states, tribes, and territories during implementation? Underlying this 'should' is the assumption that evidence-based approaches (i.e., a public health or clinical intervention or policy that has resulted in improved outcomes when scientifically tested), when implemented in a real-world setting, will increase the likelihood of improved outcomes. This article elucidates the barriers and opportunities for integrating science with practice across the cancer control continuum. However, given the scope of CCC and the substantial investment in generating new knowledge through science, it is difficult for any one agency, on its own, to make a sufficient investment to ensure new knowledge is translated and implemented at a national, state, or local level. Thus, if greater demand for evidence-based interventions and increased resources for adopting them are going to support the dissemination initiatives described herein, new interagency partnerships must be developed to ensure that sufficient means are dedicated to integrating science with service. Furthermore, for these collaborations to increase both in size and in frequency, agency leaders must clearly articulate their support for these collaborative initiatives and explicitly recognize those collaborative efforts that are successful. In this way, the whole (in this context, comprehensive cancer control) can become greater than the sum of its parts.

#### Introduction

In moving comprehensive cancer control (CCC) from planning into action, a key question centers on the extent to which the knowledge gained from national and state investments in cancer prevention and control research should influence the actions taken as state CCC plans are being implemented. Underlying the 'should' in this question is the assumption that evidence-based approaches (i.e., an intervention or policy that has

resulted in improved outcomes when tested in scientific studies), when implemented in a real-world setting, will increase the likelihood of improved outcomes. Achieving better outcomes might depend on incorporating a number of measures into the goals and objectives of state CCC plans.

Relevant goals include:

- (1) Reduced cancer incidence through:
  - risk reduction (behavior change).
  - increased practitioner delivery of cancer prevention messages.
  - policy and environmental changes that support both individual behavior and practitioner behavior change (e.g., increased tobacco product excise taxes and investment of these resources to support reimbursement for clinical preventive services).
- (2) Earlier stage of disease at diagnosis of some cancers through:

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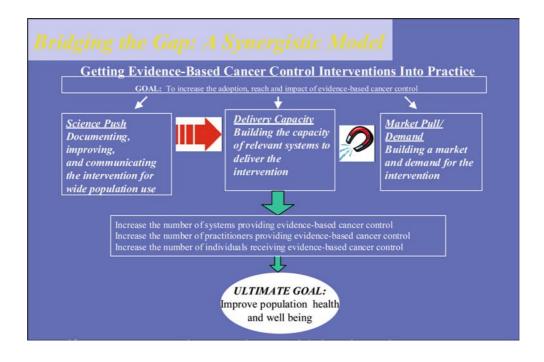
- increased awareness of, more positive attitudes toward, and use of screening services.
- increased access to cancer screening services.
- increased practitioner adoption of cancer screening practices.
- increased practitioner and patient follow-up of abnormal screening findings or signs and symptoms of cancer.
- (3) Reduced cancer-related morbidity and mortality through:
  - increased access to and provision of state-of-thescience diagnostic and treatment services, including participation in clinical trials, particularly where conventional care continues to prove ineffective (e.g., for pancreatic cancer).
- (4) Improvements in quality of life of cancer survivors through:
  - increased access to and practitioner adoption of evidence-based cancer survivorship and palliation interventions leading to improved quality of cancer survivorship and better palliation in those terminally ill with cancer.

A number of factors limit the acceptance and use of evidence-based approaches in the public health and clinical practice communities [1, 2]. These include, (1) although the efficacy of particular intervention programs may be tested in a single study, rarely do the findings from single studies provide definitive evidence to recommend the underlying approach on a broad scale; (2)

knowledge from science sometimes conflicts with knowledge from field experience, and many conceptually appealing approaches developed in the field have never been tested in research; (3) experience and training vary enormously across national, regional, state, and community-based service delivery organizations [3]; and (4) the implementation of some evidence-based approaches requires resources that are unavailable in many communities. Addressing the challenge of moving EBIs into practice, Orleans, Gruman, and Anderson [4] have proposed a push-pull-infrastructure model to help conceptualize both the challenges and opportunities for moving lessons learned from science into practice (see Figure 1).

As noted in Figure 1 [5], pushing knowledge from science into practice must be accompanied by both an increased demand for evidence-based intervention approaches and an increase in the capacity of the infrastructure to deliver evidence-based interventions (EBIs) [6]. When all three factors work in concert, both the number of systems and practitioners providing EBIs and the number of individuals receiving EBIs should increase, ultimately leading to improved outcomes. In this paper, we review selected challenges and opportunities for improving push and increasing pull to achieve the ultimate goal of improving population health and well being through CCC.

The primary focus of the approaches reviewed herein focus on the dissemination and implementation of evidence-based approaches to the prevention and early detection of cancer. However, given that CCC includes



the full spectrum of interventions including diagnosis, treatment, palliation, survivorship, and end-of-life care, it is important to note that the context of cancer control can dramatically influence the process by which evidence-based interventions may be disseminated and implemented. The three main practice contexts for CCC are (1) public health practice, (2) primary care practice, and (3) oncology specialty practice (i.e., surgical, medical, and radiation oncology). These practice contexts vary widely with respect to mechanisms for pushing research knowledge into practice (i.e., knowledge transfer), creating demand for evidence-based interventions (pull), and having the resources and infrastructure for integrating the lessons learned from science with the practical experience of service delivery.

# **Background & context**

Synthesizing science

On the push side, the systematic review of the thousands of scientific publications, published in hundreds of research journals that are relevant to CCC, is critical to the assimilation and integration of knowledge from cancer research. Systematic reviews of the scientific literature differ from narrative reviews primarily by explicitly defining the inclusion and exclusion criteria, based on the scientific rigor of the primary studies. As such, these critical literature reviews assist in identifying implementation approaches for which an existing body of scientific evidence seems to justify more widespread programmatic and policy implementation. Two examples, focused primarily on prevention and early detection of cancer and supported by national CCC partners, are the Guide to Clinical Preventive Services, addressing primary care practice, and the Guide to Community Preventive Services, addressing public health practice.

Complementing these two reviews are a plethora of systematic, narrative, and expert opinion reviews across the cancer control continuum (for example, see http://cancercontrol.cancer.gov/d4d/info\_er.html and http://www.cancer.gov/cancertopics/pdq/cancerdatabase). There is little published data on how these other evidence reviews are disseminated and evaluated with respect to their influence on practice. However, it may be reasonable to assume that public health, primary care, and oncology specialty care practitioners who are aware of these different evidence reviews may have some confusion and consternation when different reviews, based on different levels of evidence, make different recommendations about the same intervention or approach to controlling cancer.

The Guide to Clinical Preventive Services (Clinical Guide)

This is a compilation of the recommendations of the U.S. Preventive Services Task Force (USPSTF), an independent panel of private sector experts in primary care, clinical prevention, and methodology [7]. The Clinical Guide includes a broad array of prevention topics important to primary care practice, including cancer prevention; the USPSTF recommendations address primary and secondary preventive services performed in primary care settings or recognized in primary care settings and referred to specialists. The USPSTF comprises 16 experts who come from the clinical fields of general internal medicine, family medicine, pediatrics, obstetrics and gynecology, behavioral medicine, and nursing. Although independent, the USPSTF has been supported by U.S. Department of Health and Human Services (DHHS) since its inception; since 1995, it has also been supported by the Agency for Healthcare Research and Quality (AHRQ).

The mission of the USPSTF is to provide evidencebased recommendations for the provision of preventive services to apparently healthy individuals in the primary care setting. Primary and secondary preventive services addressed by the USPSTF include screening, counseling, immunizations, and preventive medications. The methodology of the USPSTF is rigorous and was the original model for the Community Guide's methodology. The methods involve a series of steps: (1) creating an analytic framework and set of key questions that determines the scope of the literature review; (2) performing a systematic review all of the relevant literature answering the set of key questions; (3) quality-rating bodies of literature supporting each key question; and (4) balancing the net benefits and harms of a specific preventive service. The recommendation is then linked to a letter grade that reflects the magnitude net benefit (balance of benefits and harms) and the strength of the evidence supporting the provision of a specific preventive service [8].

In the context of cancer control, recent recommendations have included screening for colorectal, ovarian, bladder, lung, pancreatic, oral, and testicular cancer; counseling against tobacco use; counseling for sunscreen use; immunizing for Hepatitis B virus; using chemoprevention of breast cancer; and using vitamin supplements for cancer prevention (see http://www.ahrq.gov/clinic/cps3dix.htm#cancer for recent cancer prevention recommendations). Using lung cancer screening as an example, the USPSTF created a set of key questions, beginning with one overarching question: Does lung cancer screening result in decreased mortality from lung cancer? Because no evidence directly answered this overarching question, a chain of intermediate key

questions was systematically searched: What is the accuracy of screening tests? When cancer cases are detected thorough screening, how effective is subsequent treatment in preventing cancer-specific mortality or overall mortality? And what harms are caused by screening for and treating lung cancer? For the Task Force to recommend screening for a particular cancer, for example, each link in the chain of evidence must be supported by evidence and there must be fair- to good-quality evidence for moderate to substantial net benefit from provision of the service (benefits must outweigh harms).

# The Guide to Community Preventive Services (Community Guide) [9]

It is developed under the leadership of the Task Force on Community Preventive Services (Community Task Force). This independent, nonfederal task force is made up of a group of 15 experts with a wide range of disciplinary backgrounds, practice settings, and research experience. The Community Task Force approves topics, methods, and conclusions for *Community Guide* reviews and uses those reviews to support recommendations. The Community Task Force is supported by DHHS and has a primarily CDC-based staff.

The Community Guide thoroughly searches the scientific literature for topic-relevant studies, evaluates their quality according to established criteria, and draws conclusions based on the overall strength of the body of evidence and the size and variability of reported effects [10]. The Community Task Force makes recommendations for public health practice and policy using an explicit process for linking evidence and recommendations. In addition, the Community Guide identifies promising interventions that have not been adequately researched, thus helping to inform the public health research agenda.

Topics for reviews are selected by the task force in consultation with a wide range of stakeholders. The task force makes its choices on the basis of the public health burden of the problem, how preventable it is, how it relates to other public health initiatives, and the current level of research and practice activity in public health, clinical, and other settings. Topics addressed in the initial set of *Community Guide* reviews included health risks such as tobacco use, physical inactivity, unhealthy sexual behaviors, and violence; specific health conditions such as cancer, diabetes, vaccine-preventable diseases, and motor vehicle injuries; and broad social and environmental determinants of health such as education, housing, and access to health care.

The continuously updated and expanded body of recommendations and the research agenda formulated by this rigorous process have been posted on the Internet and included in various publications since 1999. Together, they constitute a highly valued and objective evidence-based resource for guiding current and future public health research and implementation activities. In addition to sections on community-based tobacco control and physical activity interventions, the *Community Guide* is publishing sections on community-based interventions for dietary change, sun safety, and breast, cervix, and colorectal cancer screening promotion, as well as informed decision making interventions for use when current information is insufficient for making a clinical recommendation for or against screening (e.g., for prostate cancer).

National Registry of Effective Programs and Practices (NREPP)

To help professionals in the field and the public become more aware of scientifically defensible prevention and treatment programs for behavioral disorders, the Substance Abuse and Mental Health Services Administration (SAMHSA) created the National Registry of Effective Prevention Programs in 1996 (later renamed the National Registry of Effective Programs and Practices). SAMHSA, which partners with some of the national organizations involved in CCC, identifies evidence-based programs through the NREPP [11] by screening and identifying intervention programs (including tobacco and alcohol control) that may eventually be judged through peer review as promising, effective, or model programs. NREPP conducts rigorous scientific reviews yielding a repository of evidence-based programs that are then promoted and disseminated by other SAMHSA units.

NREPP reviewers, working in teams of three, rate program submissions on a set of criteria that compose and recognize the tenets of sound research design. Independently, reviewers score programs on criteria related to the quality of the intervention, quality of the evaluation, consistency of results, and 'disseminability.' Programs rated on these criteria are then categorized as Effective, Promising, or Insufficient Current Support. Though programs rated as Promising and Effective both receive recognition from SAMHSA, effective programs receive the most attention and promotional dollars from SAMHSA for dissemination.

# Evidence reviews in oncology practice

In the context of oncology practice, there are a number of different and, to some extent, competing approaches to reviewing the scientific evidence for the diagnosis and treatment of cancer patients. For example, at the federal level, the National Cancer Institute (NCI) provides cancer information summaries for patients and physicians through its Physician Data Query (PDQ) system [12]. These summaries, developed and periodically updated by expert panels of clinicians and research scientists, cover in great depth topics such as treatment options for adult and childhood cancers, side effects of cancer treatment, management of cancer-related complications and pain, complementary and alternative medicines, and clinical trials. They also include information on genetics, prevention, screening and early detection. As such, they overlap and sometimes provide different information compared with systematic evidence reviews such as the *Guide to Clinical Preventive Services*.

Covering many of the same topics, and using similar expert panels for review of the research evidence, are Clinical Practice Guidelines from the American Society of Clinical Oncology [13], Clinical Practice Guidelines from the National Comprehensive Cancer Network (NCCN) [14], and consensus standards endorsed by the National Quality Forum [15]. A key challenge for oncology practitioners in interpreting different sets of guidelines and standards of cancer care is the difficulty in comparing the processes by which research evidence was weighed and interpreted by different bodies of experts.

# Dissemination & implementation

Systematic reviews

USPSTF recommendations and their supporting systematic literature reviews are disseminated in print and electronic forms. The recommendations, targeted to an audience of primary care clinicians, are publicly available on the AHRQ Web site at www.preventiveservices.ahrq.gov; subscribers to the AHRQ Prevention Listserve receive the recommendations by e-mail immediately upon their release. Subscribers to a print version of the recommendations receive an Incremental Guide that disseminates the recommendations every six months. To reach academic clinicians and researchers, recommendations and the accompanying systematic literature review appear in peer-reviewed journals such as the Annals of Internal Medicine, Annals of Family Medicine, and American Journal of Preventive Medicine. To reach practicing clinicians, these recommendations are printed in trade journals such the American Journal of Nursing and the American Family Physician. AHRQ provides a downloadable point-of-service PDA tool for clinicians called the Interactive Preventive Services Selector; this PDA program is publicly available on the AHRQ Web site. For those clinicians who prefer a book

for their offices, a clinician's pocket guide of recent recommendations (2001–2004) was published and disseminated in 2005 [16].

The Prevention Dissemination and Implementation Program (Put Prevention into Practice) is located at AHRQ. The program is designed to increase the use of appropriate clinical preventive services based on the USPSTF recommendations. Working through partnerships with public (federal, state, tribal, local) and private organizations that share the goal of healthier people through prevention, the program facilitates systems' incorporation of clinical preventive services into routine care through user-driven tools. For example, the Prevention Dissemination and Implementation Program has worked with Partnership for Prevention, a nonprofit organization, to host a Health Professionals Roundtable on Preventive Services where representatives from primary care organizations convene to discuss shared strategic messaging to their membership around prevention. Another recent partnership example occurred between AHRQ and the National Business Group on Health (NGBH). NGBH, with financial support from the Robert Wood Johnson foundation (RWJ) and technical support from AHRQ, created, marketed, and disseminated an Employers Guide to Preventive Services. This print and electronic resource translates and disseminates the USPSTF recommendations to employers, highlighting steps that employers and benefits managers can take to promote disease prevention and health promotion. In addition to working through private partnerships, the Prevention Dissemination and Implementation Program engages in DHHS initiatives, including Healthy People 2010 [17] and Steps to a Healthier US.

Audiences for the *Community Guide* are diverse. They include people who plan, fund, or implement services and policies for health care systems, communities, and states, such as staff members of public health departments or health care delivery systems; purchasers of health care or public health services; governments and foundations; community organizations; and academic institutions.

Community Guide recommendations are disseminated in a variety of ways. Community Guide reviews are published in a family of products that include a book (Guide to Community Preventive Services) [9], journal articles, and a Web site (http://www.thecommunityguide.org) that includes summaries of reviews, links to published articles, and other resources. All Community Guide evidence reviews have been published in the American Journal of Preventive Medicine, along with expert commentaries; Community Guide recommendations are summarized in the Mortality and Morbidity Weekly

Report (MMWR) Recommendations and Reports Series, and additional reports have been published in other journals. The Centers for Disease Control and Prevention (CDC) has also supported dissemination of findings to practitioners and researchers through various media such as sharing findings at meetings and workshops, incorporating selected findings and research gaps in research and program guidance, and working with partners to promote additional dissemination. In general, most of the dissemination efforts for both the guides reflect largely a PUSH approach, with only limited resources available to increase demand or address infrastructure barriers to the implementation of evidence-based interventions.

National Registry of Effective Programs and Practices (NREPP)

The SAMHSA National Dissemination System (NDS) promotes and enhances capacity-building opportunities for communities wishing to implement evidence-based programs identified by SAMHSA's National Registry of Effective Programs and Practices (NREPP). Composed of five principle components, the NDS is an interdependent system that identifies, reviews, and promotes the widespread adoption and replication of evidencebased programs. A key feature of the NDS is its recognition that making evidence-based intervention programs available to community-based practitioners is necessary but not sufficient to ensure adoption. Training and increased funding to support the dissemination of materials are also needed to sustain the adaptation and adoption of program services based on science. The additional training and financial support for dissemination may be a model that the national partners should consider adopting for CCC programs.

Promotion occurs via the NDS's Model Programs Dissemination Project (MPDP). Once a program is identified as Effective, the developers of the intervention program are asked if they will support dissemination efforts by providing training and (limited) technical assistance to service delivery staff considering the adoption of the program. Only after the program developer has agreed to work with SAMHSA does the Effective program become a Model Program. If the developer lacks the willingness or capacity to assist in program dissemination, the program status remains Effective.

Training and Technical Assistance for SAMHSA Model Programs are offered by either the program developer through the MPDP or by one of SAMHSA's training and technical assistance centers. These technical assistance centers sponsor program training as well as training of trainers. As such, the MPDP is designed to increase the ability of health care professionals to deliver NREPP Model Programs within various practice settings.

Implementation. Informing the public of what works and providing technical assistance and training are only useful if there is an impetus for program implementation. The real-world demands of paying for training, phasing out old programming, and energizing staff to use new approaches complicate the easy adoption of new programming, regardless of its proven outcomes. SAMHSA uses two means of encouraging communities to employ evidence-based intervention programs: substance abuse prevention block grants and State Incentive Grants.

Block grants totaling \$340 million are awarded to every state for substance abuse prevention activities. State Incentive Grants, on the other hand, are competitive three- to five-year grants awarded on top of block grants for the sole purpose of integrating and institutionalizing substance abuse prevention and treatment services in a coordinated, comprehensive package. Thus, SAMHSA, given its service support mission, provides substantial support for integrating evidence-based interventions into the health care infrastructure.

CDC's planning and implementation program for CCC has provided a competitive, objectively reviewed award (i.e., cooperative agreement) to all states. If additional federal CCC resources are considered in the future, the combination of CCC implementation grant funding supplemented by a separate competitive peer-review grant award program may be worth considering for providing states the incentive to use evidence-based intervention approaches in their implementation efforts.

TRIO Program & the Cancer Control PLANET Web Portal

With a focus on 'outcomes-based management,' DHHS is focusing efforts to more effectively move research into practice. Consistent with this DHHS focus, the NCI has developed the Translating Research into Improved Outcomes (TRIO) program, which uses three distinct approaches for moving cancer prevention and control intervention research findings into practice:

- Use and communicate cancer and behavioral surveillance data to identify needs, track progress, and motivate action.
- Collaboratively develop tools for accessing, and promoting adoption of, evidence-based cancer control interventions.
- Support regional and local partnerships to develop models for identifying infrastructure barriers, expanding capacity, and integrating science into CCC planning and implementation.

The TRIO initiative incorporates multiple projects in an effort to increase the adoption of evidence-based programs. In January 2002, the NCI's TRIO program began the development of a trans-DHHS project that incorporated all aspects of this initiative. Working with federal partners (i.e., CDC, AHRQ, and SAMHSA, along with the American Cancer Society [ACS]), NCI developed and launched the Cancer Control PLANET (Plan, Link, Act, Network with Evidence-based Tools) Web portal [18]. PLANET is the first multi-agency CCC resource to provide access to evidence-based cancer control planning data and program resources that can help cancer control planners, health educators, program staff, and researchers design, implement, and evaluate evidence-based cancer control programs. Topics currently on PLANET include breast, cervical, and colorectal cancer screening; tobacco control; nutrition; physical activity; sun safety; and informed decision making about cancer screening.

Cancer control planners, program staff, and researchers share similar goals: to reduce cancer risk, the number of new cancer cases, and the number of deaths from cancer, as well as to enhance the quality of life for cancer survivors. Prior to the launch of PLANET, however, there were no systematic, easy-to-access tools that all could use for developing evidence-based cancer control programs. PLANET was developed in response to this need and includes access to products that have been tested with support from peer reviewed research grants.

PLANET is designed to systematically walk users through five specific steps necessary to design, implement, and evaluate evidence-based cancer control programs. Each step links a user to a Web site sponsored by one or more of the national partners.

Step 1: Assess the cancer and/or risk factor burden within a given state.

State Cancer Profiles (incidence data are provided by CDC's National Program of Cancer Registries and NCI's Surveillance, Epidemiology, and End Results program; mortality data are from CDC's National Center for Health Statistics, and risk factor data come from CDC's Behavioral Risk Factor Surveillance Survey).

Step 2: Identify potential partner organizations that may already be working with high-risk populations within a region or state.

The ACS, CDC, and NCI Regional and State Program Partners in CCC and researchers with cancer control grant funding from ACS, CDC, or NCI, listed by state and content areas of expertise.

Step 3: Determine effectiveness of different intervention approaches.

Guide to Community Preventive Services (federally sponsored).

Guide to Clinical Preventive Services (source: AHRQ). Step 4: Find research-tested programs and products.

Research Tested Intervention Programs (source: NCI and SAMHSA) based on peer-reviewed cancer prevention and control research grants from ACS, CDC, and NCI and peer-reviewed publications of the intervention outcome data. Programs are submitted to NREPP, reviewed, summarized, and posted, with most program materials available free of charge.

Step 5: Plan and evaluate your program.

Guidance for CCC (source: CDC).

State Plans for CCC (source: ACS, CDC, and NCI). Put Prevention Into Practice (source: AHRQ).

A key feature of the PLANET portal is that on most of its linked Web sites, users are encouraged to 'contact us' to provide the PLANET sponsors continuous feedback about what is working and not working on the PLANET and what may be missing, and to update contact information about resources for implementing CCC. Thus, the PLANET was designed as a Web tool that views the users of these Web resources, the public health and clinical practice communities, as partners with the PLANET-sponsoring agencies and, as such, represents the sponsors' commitment to continuous quality improvement through research-practice partnerships.

Evidence reviews in oncology practice

In contrast to the Cancer Control PLANET, where the agency partners agreed to integrate their agencyspecific evidence-based resources into a 'one-stop' Web portal and then worked together to promote the use of PLANET resources by the agencies' various constituencies, the different evidence reviews and clinical guidelines for the diagnosis and treatment of cancer patients can only be found on the respective standalone Web sites of the American Society of Clinical Oncology, the National Cancer Institute (PDQ), the National Comprehensive Cancer Network, and the National Quality Forum. This fragmented approach to the dissemination of oncology practice research evidence makes it more challenging to sort out consensus from conflict across agency recommendations. On the other hand, given the overlap of content across these multiple sources of clinical research evidence, if a breakthrough or innovation is reported in the scientific literature, having information available through multiple sources may increase exposure to the new research evidence.

#### Methods for evaluation

#### Guide to Clinical Preventive Services

The electronic and print versions of the *Clinical Guide* have been evaluated over time through informal interviews as well as formal surveys and focus group testing [19]. Evaluation has revealed the following:

- (1) Most primary care clinicians are aware of the US-PSTF recommendations and acknowledge the scientific rigor with which these recommendations are made. Clinicians also believe that evidence-based guidelines should be used appropriately within the context of local standards of care and clinical judgment.
- (2) Clinicians access evidence-based guidelines variably and have differing preferences regarding the best format and dissemination mechanism for the guidelines. Most prefer multiple modes of dissemination including print, electronic, and/or hand-held device programs (e.g., for PDAs), as well as integration into continuing medical education programs. In terms of information formatting, clinicians prefer brief bulleted and boxed information highlighting key practical tips for quick reference during patient visits.
- (3) One of the greatest challenges clinicians report when implementing the USPSTF recommendations is how to interpret and apply information regarding 'I' (i.e., insufficient evidence) recommendations. Although clinicians are often frustrated with 'I' recommendations, they acknowledge the importance of an independent panel stating the evidence without using expert consensus processes to make a judgment about a service (in the absence of sufficient evidence).

#### Guide to Community Preventive Services

A range of formal and informal methods have been used to assess the need for the *Community Guide*; awareness of and reactions to the methods, process, and findings; uptake of recommended practices; and impacts [20–22]. More evaluations are underway or planned.

In general, and across evaluations, the body of this work has suggested

- (1) Having rigorous information on the effectiveness of interventions is important in deciding whether to implement them, but other information is also important, and the availability of evidence-based recommendations alone will not assure their implementation.
- (2) Levels of awareness of the *Community Guide* among target groups leave much to be desired,

- although among those who are aware, methods, process, and conclusions are generally well regarded.
- (3) Community Guide recommendations have been useful in helping some groups increase the use of some evidence-based approaches.

#### NREPP-NDS

Outcome Monitoring is the final step in the NDS. Though not implemented in every community across the country, the use of evidence-based programs continues to grow in popularity and is increasingly a requirement of various funding bodies. Still, it is vital to know whether or not the outcomes achieved in the 'lab' (so to speak) are realized in the hands of those who replicate the programs. To partially address these issues, SAM-HSA implemented a Prevention Program Outcome Monitoring System (PPOMS).

Canvassing roughly 1000 schools, coalitions, and community-based organizations, PPOMS surveyed how programs were implemented and adapted in the field. Quantitative and qualitative data obtained from PPOMS about outcomes achieved, fidelity, and adaptation of particular programs can inform NREPP and the NDS. Adaptations and modifications that yield outcomes similar to those obtained by the program developer will be noted on promotional materials and SAMHSA's Model Programs Web site, and they will be conveyed as well to those who are carrying out the training and technical assistance for those programs. PPOMS data have proven to be an important source of feedback for SAMHSA, program developers, and the dissemination field.

To date, NREPP, NDS, and MPDP have been responsible for increasing the number of people exposed to effective, evidence-based programs tenfold. In 2001 approximately 1.2 million people in the United States participated in evidence-based prevention programs. By the end of 2002, this number had grown to 12.3 million. This rapid increase is largely attributable to states observing early successes in the State Incentive Grant program and using this evidence to require at least some portion of the larger block grant (in 27 states) to be allocated for evidence-based, proven effective prevention programs. As noted previously, the SAMHSA model of grant support, training, and technical assistance, as well as support for the PPOMS surveillance system to monitor the adoption of evidence-based interventions, may be a useful approach for the national partners in CCC to consider in the future, resources permitting.

#### Cancer Control PLANET

Evaluation of PLANET was incorporated from the beginning. The PLANET Web portal was designed using the standards of Web usability. The first prototype was presented on paper to focus groups in June and August 2002. Feedback on the initial design was incorporated into a simple wire-frame model that was tested in an online usability test in November 2002. Based on user feedback from the first round of usability testing, a prototype Web portal was developed and additional usability tests were conducted between November 2002 and February 2003. The PLANET was launched in April 2003 and, as new features have been added, additional rounds of usability testing have been conducted. A key feature of the PLANET launch was suggested by users: that a training program should be offered to ensure that, in their role as intermediaries or linking agents [23], the users would be able to take full advantage of the resources on the site.

Web Trends, a standard Web site evaluation tool, is currently used to collect monthly usage data. This tool automatically tracks the number(s) of unique visits to the Web sites and identifies pages viewed and length of visit. The average monthly number of unique visitors increased 39% between 2003 and 2004 (4/03-9/03: 1450, and 4/04-9/04: 2015). A key challenge to the evaluation of PLANET is determining how the information from PLANET is being used. For example, on Step 4 of the PLANET, the Research Tested Interventions Programs (RTIPs) Web site provides users with access to programmatic material that has been tested in a peer-reviewed research grant-funded project and has outcomes data published in a peer-reviewed journal. Users can both download material and adapt the material for use in their setting, or they can order a CD-ROM of the programmatic materials free of charge.

To date, 27 (of a total of 48) cancer prevention and control programs are currently available free of charge via CD-ROM on RTIPs, with a total of 187 program products. Beginning in October 2003 and continuing through February 2005, 13,289 program summaries were viewed on RTIPs, 3480 RTIPs program products were downloaded, 623 users were directed to a program developer's Web site to obtain copyrighted product materials, and 283 users ordered RTIPs program materials on CD-ROM. The most frequently downloaded (DL)/ordered (ORD) programs were (1) the Forsyth County Cancer Screening Project (FoCaS) (582 DL/23 ORD) [24], (2) Seattle's 5 A Day Worksite Nutrition Intervention (337 DL/23 ORD) [25], and (3) Physicians Counseling Smokers (331 DL/21 ORD) [26].

Future evaluation efforts will focus on developing a framework, similar to SAMHSA's Prevention Program Outcome Monitoring System (PPOMS), to estimate the spread of the use of research-based information from the PLANET and the adoption and implementation of EBIs from RTIPs.

#### Research evidence in oncology practice

Several efforts are under way to evaluate the variation in quality of cancer care that are or could be related to the dissemination of clinical research evidence. NCI has been leading a trans-DHHS effort to develop metrics of cancer care quality through the Quality of Cancer Care Committee (QC³) [27]. Launched in 1999, QC³ was designed to make cancer care a working model for quality-of-care research and application. The initiative includes a four-point research plan to improve the state of the science for defining, monitoring, and improving the quality of cancer care. The plan was approved by the secretary of DHHS and made an integral part of the department's overall quality improvement initiative.

Another NCI effort is the Cancer Care Outcomes Research and Surveillance Consortium (CanCORS) [28]. CanCORS supports prospective cohort studies of 10,000 patients with newly diagnosed lung or colorectal cancers who are recruited in geographically diverse populations and health care systems. The project will address how characteristics of patients, providers, and the systems delivering care affect what services patients receive for the management of cancer and its sequelae, as well as the relationship between cancer-related clinical practices and outcomes. Thus, the uptake of innovations in quality cancer care based on research can be tracked in special studies like CanCORS.

Similar to CanCORS, but focused on breast and colorectal cancer, the National Initiative on Cancer Care Quality (NICCQ) was initiated in 2000 by the American Society of Clinical Oncology [29]. The goals of the NICCQ are to develop potential measures of quality of cancer care, ascertain current practices, and design the first phase of a prototype quality monitoring system. Using the American College of Surgeons (ACoS) national cancer database, a registry of incident cancer cases from ACoS-approved cancer-care hospitals, data from 5000 patients diagnosed with breast or colorectal cancer during 1998 were collected and are being analyzed. One key challenge in tracking the impact of clinical research dissemination efforts nationally is the lack of a population-based surveillance system, like SAMHSA's PPOMS, that captures the detailed variation in the quality of cancer care that both the CanCORS and NICCQ special studies are able to examine, albeit in large but limited populations of patients with three specific cancers.

#### **Barriers to success**

#### Guide to Clinical Preventive Services

AHRQ's Prevention Dissemination and Implementation Program has gathered information about clinical challenges to evidence-based prevention implementation from a series of focus groups consisting of primary care clinicians from Practice-Based Research Networks. These clinician focus groups have provided rich feedback to the program and are assisting AHRQ in designing and developing its user-driven tools and programs [30]. Potentially reversible challenges to implementation of evidence-based cancer prevention strategies cited by these clinicians include lack of (1) linkages to community resources, (2) delivery system support, and (3) clinical information support (e.g., reminder systems, electronic health records). Other barriers include limitations in the state of the science and conflicting guidelines. Conflicting guidelines, for example, challenge implementation because clinicians may have difficulty determining the methodologies of each specific guideline (e.g., consensus opinion, evidencebased, evidence-informed) and deciding which guideline to implement in their practices. Furthermore, clinicians reported that clinical practice is largely guided by local standards of care; many clinicians feared that deviation from local standards could result in medical liability suits.

# Guide to Community Preventive Services

There are a number of challenges in implementing evidence-based public health approaches. The most fundamental is how to rapidly increase the quality and availability of the public health evidence base, both in terms of individual studies and good quality syntheses. About half of *Community Guide* findings have resulted in conclusions of insufficient evidence. Too many currently employed strategies have been inadequately tested, and these gaps are greater for public health than for clinical medicine.

Second, use of evidence-based approaches should be more encouraged. Many well-supported interventions seem to be underutilized. How to move scientific evidence higher on the list of issues considered by decision makers and how to reduce barriers to introduction of evidence-based approaches should be explored. A third challenge is how best to integrate evidence-based interventions with comprehensive program planning. Even well-documented evidence-based programs cannot simply be taken off the shelf and made successful without further effort. Evidence-based interventions must be adapted in the context of community needs, objectives, and resources; they must be well implemented; and they must be periodically reassessed and, if necessary, further adjusted to ensure that they are reaching their expected goals. Finally, work must be continued to ensure sustainability once success is achieved.

A fourth challenge is how to better inform decisions when there is convincing evidence of the importance of a health problem but a lack of convincing evidence about what to do about it. In this case, some decision makers will adopt a 'first do no harm' standard and recommend additional high-quality research before recommending action. Others will believe that taking no action is unacceptable. Practitioners and policy makers will frequently have to make decisions in the absence of conclusive scientific evidence. When such decisions are made, they should be informed by the best available science, integrated with the tacit knowledge from real world experiences of practitioners and clients, and then they should be studied or evaluated to help strengthen the evidence base.

Finally, producers and users of the information need more education in evidence-based program implementation, population health, and related decision making about programs and policies and investment in them. For everyone who has a role in deciding how to attack a public health problem, systematic review results provide a point of departure, a counterweight to other proposals with limited rationales, and a confidence builder that there are good choices with high likelihood of improving health compared with other available alternatives.

#### NREPP

Barriers to success are manifold:

- (1) Effective programs, often developed by academicians, may often seem plain to the eye. These programs sometimes compete with aggressive salesmen armed with glossy commercially packaged programs that may or may not have a substantive evidence base. Systems buy materials and programs in bulk, with gloss sometimes winning out over substance.
- (2) When communities are deciding about program adoption, lack of community ownership can derail the use of effective programs. Despite the many commonalities across communities in terms of

- population needs and decreasing resources, each perceives itself as unique. Their preference is often for 'home-grown' programs.
- (3) Inertia is the greatest impediment to any type of change, including introducing new programs. Everyone has been trained and can implement the programs already in place. The perceived burden accompanying change may facilitate the maintenance of programs that are not optimally effective.
- (4) Programmatic change can introduce real burdens, including required trainings, new costs, and challenges to traditional methods. Often, these real burdens are perceived as too great and the benefits of change are undervalued.
- (5) There is a perception that evidence-based programs are far more expensive than those that are currently being used. This is largely an awareness problem. Purchasers usually fail to factor in the dollars and resources already being expended on programs, some of which may have never worked. They also sometimes fail to consider the cost savings that can accrue by implementing effective programs. Last, they often believe that staffing needs are the same for field implementation as were required for program development and efficacy trials. They forget that adaptation is possible and that, as least as far as Model Programs are concerned, developers can and do help.

#### Cancer Control PLANET

While the development of the PLANET Web portal makes finding and using knowledge from research and finding EBIs easier for many potential users, many of the same issues described previously apply to the use of scientific knowledge from the Web. In addition, the PLANET was designed with community health practitioners in mind, assuming that this audience would have time to deliberate before making decisions about what to implement as part of a CCC plan. As such, the PLANET Web site is not user friendly for primary care practitioners, whose need for timely cancer prevention and control information is tied to individual patient encounters. To address this barrier, NCI is working with AHRQ and HRSA to design a clinical version of the PLANET that can deliver in real time the necessary information for the patient management environment of a primary care practice setting.

The PLANET also has limited information for Alaska Native and American Indian populations and U.S. territories trying to develop and implement CCC plans for their medically underserved populations. As more

research is conducted in partnership with these populations, more knowledge will be available to populate PLANET for broader dissemination and implementation of evidence-based programs.

Finally, cancer prevention and control researchers have not been fully cognizant or necessarily positive about their role in supporting the PLANET. For example, convincing researchers to provide access to their research-tested intervention program (RTIP) materials can be a challenge. Researchers may be leery of relinquishing control of materials they have developed. They may not have time to respond to requests for intervention program materials, may feel that these materials require additional testing, or may want to control their distribution. Communicating the process for providing intervention program materials and alleviating concerns that the materials will be out of the researchers' control once they are submitted may help increase the number of programs that are submitted annually to the RTIPs portion of the PLANET.

# Research evidence in oncology practice

A central concern for moving the knowledge gained from controlled clinical trials into general oncology practice is the characteristics of clinical trials themselves that limit the perceived applicability of the findings to practice [31]. Thus, in drug efficacy studies for example, the distinction between efficacy and effectiveness [32] may be critical to the perceived relevance of the study findings to community oncologists practicing outside of the supportive research environments of academic medical centers or comprehensive cancer centers. Given that oncology practice may be driven as much by provider propensities and personal clinical experience as by explicit knowledge gained from research, new approaches for integrating provider experiences and research findings to inform clinical practice may be critical. In the context of clinical decision making, ensuring that practitioners and patients have all the information they want and need to make informed decisions at the point of care may be important in order to integrate the lessons learned from science with the practical realities of delivering clinical services.

# **Summary & conclusion**

As we consider how to increase the adoption of evidence-based interventions and intervention approaches to support CCC, much of the effort described herein is focused on pushing the adoption of intervention approaches to the public health and clinical practice

communities. On the *Pull* side, efforts to increase practitioner interest in, and demand for, EBIs center on building research-practice partnerships as reflected by, for example, the collaborative PLANET Web portal of the NCI, CDC, ACS, AHRQ, and SAMHSA.

In the clinical practice arena, AHRQ's Practice-Based Research Networks (PBRNs) and NCI's community clinical oncology programs (CCOPs) support infrastructures that encourage community-based primary care physicians (PBRNs) and oncology specialists (CCOPs) to participate in practice-based research. This commitment to building community-based research capacity is based, in part, on the assumption that clinicians involved in research will be more open to adopting research-tested clinical interventions. While this proposition has good face validity and some published supportive evidence [33], more study of this approach is needed.

Of all the federal partner programs on research dissemination described herein, only SAMHSA has made a substantial investment in supporting the practice infrastructure for adapting and adopting EBIs. However, given the large number of programs tested in efficacy and effectiveness trials, SAMHSA made the strategic decision to make a substantial investment only in the small proportion of programs found by NREPP to be of sufficiently high scientific and real-world quality to justify the Model Program designation. Moreover, with respect to CCC, only tobacco- and alcohol-control interventions that make the Model Program grade currently overlap with SAMHSA's primary focus on substance abuse and mental health services. Thus, expanding the number and type of cancer control programs where training, technical assistance, and financial support for adopting and adapting evidenced-based approaches and intervention programs may be important in the future.

The national partners in CCC have made a substantial investment in training since 2000 through a series of regional CCC leadership institutes for states, tribes, and territories receiving CDC's CCC planning or implementation grants. Recently, the ACS, CDC, the Intercultural Cancer Council, and the NCI's Cancer Information Service developed a network of regional leadership support teams where field staff and volunteers from each of these four partner organizations are grouped into five regional teams to provide technical assistance to states, tribes, and territories seeking support and advice for implementing CCC plans. The teams have been trained to take advantage of research dissemination tools, like the Cancer Control PLANET, in promoting the adoption of evidencebased approaches to CCC.

Despite the enormous stakes involved in identifying approaches shown to increase the adoption and implementation of evidence-based practices, research has generated little information about the best ways to translate research evidence into practice [34, 35]. Thus, new and expanded efforts to support dissemination and implementation research are needed. For these efforts to be actualized, funding agencies and universities must recognize, support, and reward the importance of dissemination as a fundamental part of the research process and as a legitimate area for study.

As previously noted, there are a number of service delivery contexts in which evidence-based interventions should be more widely adopted and implemented [36]. One of the broadest and most diverse contexts for dissemination might be labeled community health practice settings. These would include a wide range of settings, such as schools, work sites, faith-based organizations, health departments, other health care organizations, and community-based institutions and organizations. The community-based participatory research model may be an effective strategy to use in efforts with community partners from these settings [37]. When communitybased organizations are involved as full partners in study design, implementation, and evaluation of study findings, these organizations may be more amenable to adopting the approaches identified as being effective, as their tacit knowledge about 'what works' will have an opportunity to be evaluated explicitly through research.

Primary care practice settings, such as medical and dental offices, community health clinics, and managed care practices, are important settings for dissemination of prevention and early detection interventions tested through research. Efforts to expand the adoption of evidence-based tobacco-control interventions through direct service delivery or referral to evidence-based smoking-cessation telephone counseling services are examples of how primary care practice settings can serve as a major outlet for the broad exposure of the American public to evidence-base health promotion and disease prevention interventions.

Collaborative partnerships between behavioral scientists, health services researchers, and health care practitioners could expand the theoretical frameworks for and the contextual relevance of dissemination research in both primary care and oncology specialty care contexts. Particularly in the context of oncology specialty care, many assumptions about the effectiveness of continuing medical education are made about the "rapid" spread of innovations in cancer diagnosis, treatment, and palliation. These assumptions need to be tested and new dissemination and implementation approaches may need to be developed [38] to ensure that the benefits of

innovations from clinical research improve the quality of care for all Americans bearing the burden of cancer.

Given the diversity and large number of interventions across the cancer control continuum from primary prevention through cancer survivorship and palliation, it seems unlikely that any single organization or agency with a primary cancer focus will be able to make a substantial enough infrastructure investment on its own to match SAMHSA's knowledge transfer efforts in substance abuse and mental health. Moreover, organizations and agencies that support research may be more likely to support informed decision-making approaches to the adoption of EBIs than the designation of model programs for adoption. Thus, if increased Pull for EBIs and increased Infrastructure resources for adopting EBIs are going to synergistically support the Push initiatives described herein, new interagency partnerships will have to be developed.

One example of such a partnership effort is the shared investment by CDC and NCI in the Cancer Prevention and Control Research Network (CPCRN) [39]. Recently re-competed and expanded, the network consists of eight CDC-funded Prevention Research Centers that are receiving CDC and NCI funding to build a community-based participatory research infrastructure to support replication research, dissemination research, and program evaluation for existing cancer control service programs (e.g., CDC Breast and Cervical Cancer Early Detection Program). Similarly, AHRQ and NCI are co-supporting a program announcement on translating research into practice through dissemination research in the AHRQ Practice-Based Research Network (PBRN) [40].

A key challenge to these partnership efforts is the difficulty of coordinating and collaborating across multiple agencies with differing investment priorities, funding mechanisms, and limited staff experience with interagency cooperation and collaboration. Particularly as agency budget increases flatten or are eliminated, collaborative investments in integrating the lessons learned from science with the lessons learned from practice will become an important option for future consideration. If these collaborations are to increase both in size and frequency, agency leaders must clearly articulate their support for these collaborative initiatives and explicitly recognize those efforts that have proven a success. In this way, the whole of CCC can truly become greater than the sum of its parts.

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