Howard K. Koh, MD, MPH
Assistant Secretary for Health
U.S. Department of Health and Human Services
Progress Review Overview

- Summarize the burden of Cancer in the U.S. and the role of Genomics
- Provide an update on the progress of Healthy People 2020 objectives
- Examine what is being done to achieve the Healthy People 2020 objectives
# Evolution of Healthy People

<table>
<thead>
<tr>
<th>Target Year</th>
<th>1990</th>
<th>2000</th>
<th>2010</th>
<th>2020</th>
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| **Overarching Goals** | • Decrease mortality: infants–adults  
• Increase independence among older adults | • Increase span of healthy life  
• Reduce health disparities  
• Achieve access to preventive services for all | • Increase quality and years of healthy life  
• Eliminate health disparities | • Attain high-quality, longer lives free of preventable disease  
• Achieve health equity; eliminate disparities  
• Create social and physical environments that promote good health  
• Promote quality of life, healthy development, healthy behaviors across life stages |
| # Topic Areas | 15 | 22 | 28 | 42 |
| # Objectives/Measures | 226/NA | 312/NA | 467/1,000 | 1,200/1200 |
Healthy People 2020

- 42 topic area and 1200 objectives
- Source for reliable, science-based, public health measures
- Can be customized to meet needs of diverse users
- Guided by collaborative stakeholder-driven process
The Burden of Cancer and Role of Genomics

- Cancer is the second leading cause of death in the U.S.
- 12.5 million Americans have had a cancer diagnosis
- $227 billion in costs to the Nation (2007)
- USPSTF - Women whose family history is associated with an increased risk for deleterious mutations in $BRCA1$ or $BRCA2$ genes should be referred for genetic counseling
Presenters

Chair
- Howard K Koh, MD, MPH
  Assistant Secretary for Health, HHS

Data Presentation
- Edward Sondik, PhD
  Director, National Center for Health Statistics, CDC

Cancer Topic Area
- Robert Croyle, PhD
  Director, Division of Cancer Control and Population Sciences, NCI
- Marcus Plescia, MD, MPH
  Director, Division of Cancer Prevention and Control, CDC

Genomics Topic Area
- Muin Khoury, MD, PhD
  Director, Office of Public Health Genomics, CDC
- Carolyn Clancy, MD
  Director, Agency for Healthcare Research and Quality

Community Highlight
- Summer Lee Cox
  Coordinator, Oregon Genetics Program, Oregon Health Authority
Public Health Impact: Cancer

- Cancer is the second leading cause of death in the U.S. after heart disease.
- Although cancer death rates are steadily declining, cancer is projected to be the leading cause of death by 2013.
- The NIH estimated that the 2008 overall costs of cancer were about $201.5 billion.
- Early diagnosis and screening can reduce death rates for some cancers such as breast cancer and colorectal cancer.
- 2 of 5 Americans are estimated to have a cancer diagnosis during their lifetime; approximately 1 in 5 will die from cancer.
Cancer Deaths, 2010

Females
Total = 273,706
- Other 79,136
- Lung/bronchus 70,550
- Breast 40,996
- Colorectal* 25,450
- Lymph/blood 24,813
- Ovary 14,572
- Pancreas 18,189

Males
Total = 301,037
- Other 94,234
- Lung/bronchus 87,699
- Prostate 28,561
- Liver 13,658
- Pancreas 18,699
- Colorectal* 27,409
- Lymph/blood 30,777

NOTES: Data are for selected groupings of ICD-10 codes C00-C97 reported as underlying cause of death.
* Colorectal Includes cancer of the anus
SOURCE: National Vital Statistics System—Mortality (NVSS-M), CDC/NCHS.
Genetics play a role in 9 of the 10 leading causes of death, including:
- Cancer
- Heart disease
- Stroke
- Diabetes
- Alzheimer’s disease

For those at increased risk for hereditary breast and ovarian cancer, or hereditary colorectal cancer, genetic tests may reduce their risk of those cancers through early detection.
Progress Review Data Focus

- Breast and Colorectal Cancer
  - Deaths
    - C-3 Female breast cancer deaths
    - C-5 Colorectal cancer deaths
  - Incidence
    - C-9 Invasive colorectal cancer
    - C-11 Late-stage female breast cancer
  - Screening
    - C-16 Colorectal cancer screening
    - C-17 Breast cancer screening

- Breast and Ovarian Cancer
  - Genetic counseling (1 objective)
    - G-1 Genetic counseling for women with a family history of breast and/or ovarian cancer

Target met | Improving | Little/no change
Colorectal Cancer Deaths, 2000–2010

**Rate per 100,000 (age adjusted)**

- **Black, non-Hispanic**
- **White, non-Hispanic**
- **Hispanic or Latino**
- **American Indian or Alaska Native**
- **Asian or Pacific Islander**

**2020 Target**

**NOTES:** Data are for ICD-10 codes C18-C21 (2000–2006) and C18-C21, C26.0 (2007–2010) reported as underlying cause of death. All data are age adjusted to the 2000 standard population. Multiple-race data were reported by some states; multiple-race data were bridged to the single-race categories for comparability. Persons of Hispanic origin may be of any race.

**SOURCE:** National Vital Statistics System—Mortality (NVSS-M), CDC/NCHS.
**Female Breast Cancer Deaths, 2000–2010**

**Rate per 100,000 (age adjusted)**

- **Black, non-Hispanic**
- **Total**
- **White, non-Hispanic**
- **Hispanic or Latino**
- **American Indian or Alaska Native**
- **Asian or Pacific Islander**

**2020 Target**

**NOTES:** Data are for ICD-10 code C50 reported as underlying cause of death and are age adjusted to the 2000 standard population. Prior to 2003, only one race could be recorded; recording more than one race was not an option. Beginning in 2003 multiple-race data were reported by some states; multiple-race data were bridged to the single-race categories for comparability. Persons of Hispanic origin may be of any race.

**SOURCE:** National Vital Statistics System—Mortality (NVSS-M), CDC/NCHS.

**Obj. C-3**
Female Breast Cancer Deaths, 2006–2010

NOTEs: Data are for ICD-10 code C50 reported as underlying cause of death and are age adjusted to the 2000 standard population. Rates are displayed by a modified Jenks classification for U.S. health service areas. Two lowest categories show health service areas that met target.

SOURCE: National Vital Statistics System—Mortality (NVSS-M), CDC/NCHS.
New Cases of Colorectal Cancer

Rate per 100,000 (age adjusted)

1999

2009

2020 Target

NOTES: Data are for diagnosed incident cases of invasive colorectal cancer (ICD-O-3 codes C18.0-C18.9, C19.9 and C20.9). Data are age adjusted to the 2000 standard population. Persons of Hispanic origin may be any race. I = 95% confidence interval.

SOURCE: National Program of Cancer Registries (NPCR), CDC/NCCDPHP; Surveillance, Epidemiology, and End Results (SEER) Program, NIH/NCI.
New Cases of Late-Stage Female Breast Cancer

Rate per 100,000 (age adjusted)

- Total
- Am. Indian or AK Native
- Asian or Pacific Islander
- Black, non-Hispanic
- White, non-Hispanic
- Hispanic or Latino

Decrease desired

2009

2020 Target

NOTES: Data are for diagnosed incident cases of breast cancer (ICD-O-3 codes C50.1-C50.9) in regional or distant stages. Data are age adjusted to the 2000 standard population. Persons of Hispanic origin may be any race.

I = 95% confidence interval.

SOURCE: National Program of Cancer Registries (NPCR), CDC/NCCDPHP; Surveillance, Epidemiology, and End Results (SEER) Program, NIH/NCI.

Obj. C-11
Persons Meeting U.S. Preventive Services Task Force (USPSTF) Guidelines for Colorectal Cancer Screening

NOTES: Data are for the proportion of persons aged 50–75 who stated they had a blood stool test in the past year, sigmoidoscopy in the past 5 years with blood stool test in the past 3 years, or a colonoscopy in the past 10 years. Data are age adjusted to the 2000 standard population. Respondents were asked to select one or more races. Data for the single race categories are for persons who reported only one racial group. Data for the Native Hawaiian or Other Pacific Islander population do not meet the criteria for statistical reliability, data quality, or confidentiality. Persons of Hispanic origin may be any race.

I = 95% confidence interval.

SOURCE: National Health Interview Survey (NHIS), CDC/NCHS.
NOTES: Data are for the proportion of women aged 50–74 (2008 and 2010) who stated they had a mammogram in the past 2 years. Data are age adjusted to the 2000 standard population. Respondents were asked to select one or more races. Data for the single race categories are for persons who reported only one racial group. Data for the American Indian or Alaska Native and Native Hawaiian or Other Pacific Islander populations do not meet the criteria for statistical reliability, data quality, or confidentiality. Persons of Hispanic origin may be any race.

I = 95% confidence interval.

SOURCE: National Health Interview Survey (NHIS), CDC/NCHS.

Obj. C-17
Women Aged 18 Years and Older with a Family History of Breast or Ovarian Cancer, 2010

- **5.3%** of women aged 18 years and older had a family history of breast or ovarian cancer.
- **94.7%** of women aged 18 years and older did not have a family history of breast or ovarian cancer.

**NOTES:** Data are for women aged 18 years and older who met the United States Preventive Services Task Force (USPSTF) criteria, based on first-degree relatives only, for BRCA1/2 genetic counseling referral, and who do not have a personal history of breast or ovarian cancer. Data are age adjusted to the 2000 standard population.

**SOURCE:** National Health Interview Survey (NHIS), CDC/NCHS.
Women Aged 18 Years and Older with a Family History of Breast or Ovarian Cancer Who Have Discussed Genetic Testing, 2005 and 2010

Percent
(age adjusted)

2005 2010

NOTES: Data are for women aged 18 years and older who have ever discussed the possibility of getting a genetic test for cancer risk with a health care provider, who met the United States Preventive Services Task Force (USPSTF) criteria, based on first-degree relatives only, for BRCA1/2 genetic counseling referral, and who do not have a personal history of breast or ovarian cancer. Data are age adjusted to the 2000 standard population.

I = 95% confidence interval.

SOURCE: National Health Interview Survey (NHIS), CDC/NCHS.
Current HP2020 Objective Status: Cancer

- C-1 Overall cancer deaths
- C-2 Lung cancer deaths
- C-3 Female breast cancer deaths
- C-4 Uterine cervix cancer deaths
- C-5 Colorectal cancer deaths
- C-6 Oropharyngeal cancer deaths
- C-7 Prostate cancer deaths
- C-8 Melanoma deaths
- C-9 Invasive colorectal cancer
- C-10 Invasive uterine cervical cancer
- C-11 Late-stage female breast cancer
- C-12 Statewide cancer registries
- C-13 Cancer survival
- C-14 (Developmental) Mental and physical health-related quality of life of cancer survivors
- C-15 Cervical cancer screening
- C-16 Colorectal cancer screening

- C-17 Breast cancer screening
  - C-18.1 Receipt of counseling about mammograms
  - C-18.2 Receipt of counseling about Pap tests
  - C-18.3 (Developmental) Receipt of counseling about colorectal cancer screening
  - C-19 (Developmental) Prostate-specific antigen (PSA) test
  - C-20.1 (Developmental) Adolescent sunburn
  - C-20.2 Adult sunburn
  - C-20.3 Adolescent artificial UV light for tanning
  - C-20.4 Adult artificial UV light for tanning
  - C-20.5 Adolescent measures to reduce risk of skin cancer
  - C-20.6 Adult measures to reduce risk of skin cancer

Legend:
- Target met
- Improving
- Little/No change
- Getting worse
- Baseline only
- Developmental
Current HP2020 Objective Status Summary: Cancer

- 7% (n=2) Target met
- 15% (n=4) Improving
- 15% (n=4) Little/No change
- 15% (n=4) Getting worse
- 7% (n=2) Baseline only
- 41% (n=11) Developmental

Total number of objectives: 27
Current HP2020 Objective Status: Genomics

- G-1 Genetic counseling for women with a family history of breast and/or ovarian cancer
- G-2 (Developmental) Genetic testing for persons with colorectal cancer to detect Lynch syndrome
Progress over the past decade in reducing death and incidence rates for the major cancers is encouraging.

Cancer
- Disparities by race and ethnicity and by income persist in the risks of developing and dying from cancer.
- Collecting data from the smaller population groups is a continuing challenge.
- Screening guidelines are subject to change, which affects trends.

Genomics
- Monitoring progress is challenged by the relatively small target populations.
Robert T. Croyle, PhD
Director, Division of Cancer Control and Population Sciences
National Cancer Institute
National Cancer Institute
Division of Cancer Control and Population Sciences

- Science and research to promote the use of effective cancer screening and to inform policy
  - Understanding current screening practices and outcomes
  - Identifying high risk populations
  - Evaluating screening strategies and new technologies

- Related research areas
  - Health disparities and underserved populations
  - Health care research
  - Health communication and health literacy
  - Decision making
  - Common measures in behavior and social science research
  - Implementation science
Screening as a Process Rather than an Isolated Event

Processes of Care across the Cancer Care Continuum

- Risk assessment
- Primary prevention
- Screening
  - Detection
    - Screening or Symptomatic
  - Diagnosis
  - Cancer or precursor RX
    - Post-treatment survivorship
    - End-of-life care

Patient Outcomes

- Risk status
- Biologic outcomes
- Health related quality of life & well-being
- End-of-life experience
- Financial burden
- Patient engagement

Population Outcomes

- Mortality
- Morbidity
- Cost-effectiveness
Population-based Research Optimizing Screening through Personalized Regimens (PROSPR)

- **Goal**: Develop multi-site, coordinated, transdisciplinary research to document, evaluate and improve the entire screening process.

- Research to understand recruitment, screening, diagnosis, and referral for treatment of breast, colon and cervical cancer.

- **Objectives**:
  - Comparative effectiveness of existing and emerging screening processes in community practice.
  - Balance of benefits and harms across recognized cancer risk profiles.
  - Preliminary studies to inform future research.

Objectives C-15, C-16, C-17, C-18: Increase the proportion of adults who received screening based on most recent guidelines and increase the proportion of adults who were counseled about cancer screening consistent with guidelines.
Goal: Strengthen the national capacity to implement cost-effective large-scale research studies that engage health care delivery organizations as research partners.
Goal: Establish partnership between research institutions and federally qualified health centers (FQHCs) to achieve sustainable and large-scale impacts on colorectal cancer (CRC) screening rates.

Assess effectiveness of:

- Automated data-driven, EHR-linked program for mailing Fecal Immunochemical Test (FIT) kits to patients due for CRC screening.
- Higher-intensity program consisting of a mailed FIT kit plus additional interventions selected by clinics.

Objective C-16 Increase the proportion of adults who received colorectal cancer screening based on most recent guidelines.
Cancer Intervention and Surveillance Modeling Network (CISNET)

- **Goal**: Model the relationship between upstream (screening rates and risk factors) and downstream (incidence and mortality) goals to evaluate public health interventions

- Support modeling consortiums for breast, colorectal, esophagus, lung and prostate cancer

- **Objectives**:
  - Translating scientific evidence to the population setting
  - Identifying key factors influencing outcomes
  - Identifying efficient cancer control strategies
  - Informing clinical practice and recommended guidelines

Objectives C-2, C-3, C-5, C-7, C-11, C-13 Reduce cancer death rate for lung, breast, colorectal and prostate cancer, reduce incidence of colorectal cancer and late stage breast cancer
Goal: Use HMO delivery systems to conduct research in the community setting
- Cancer prevention
- Early detection
- Cancer communication
- Dissemination and implementation

Includes information from 14 HMOs nationwide that collectively provide care to nearly 10 million individuals

Multidisciplinary approach includes expertise in epidemiology, health services, behavioral medicine, biostatistics, and specialty care

Objectives C-15, C-16, C-17, C-18 Increase the proportion of adults who received screening based on most recent guidelines and increase the proportion of adults who were counseled about cancer screening consistent with guidelines
National Surveys that Measure Progress for HP2020 Objectives

**Goal**: Estimate screening utilization, knowledge, perceptions, patient-provider communications and provider attitudes

- **National Health Interview Survey (NHIS)**
  - Serves as a main source of patterns and trends in individual screening behaviors

- **Health Information National Trends Survey (HINTS)**
  - Uniquely dedicated to learning how people find, use and understand health information

- **Behavioral Risk Factor Surveillance System (BRFSS)**
  - Tracks health conditions and risk behaviors at the state level

Objectives C-14, C-15, C-16, C17, C-18, C-19, C-20 Measure mental and physical health-related quality of life, screening rates, counseling on screening, sun exposure activities
Cancer Control P.L.A.N.E.T.
Plan, Link, Act Network with Evidence-based Tools

- Research Synthesis
  - Guide to community preventive services
  - Evaluation of genomic applications in practice and prevention (EGAPP)
- Research-tested intervention programs
- Evaluation – Research effectiveness adoption implementation maintenance (Re-AIM)
- Comprehensive cancer control plans and budgets
Marcus Plescia, MD, MPH
Director, Division of Cancer Prevention and Control
Centers for Disease Control and Prevention
Mission
– Build and support public health capacity for cancer prevention and control across the nation
– Translate research into public health programs, practices, and services

National Programs
– Colorectal Cancer Control Program
– National Breast and Cervical Cancer Early Detection Program
– National Program of Cancer Registries
Division of Cancer Prevention and Control
Programs, Initiatives, and Campaigns

Comprehensive Cancer Control
Collaborating to Conquer Cancer

National Breast and Cervical Cancer Early Detection Program

Screen for life
National Colorectal Cancer Action Campaign

PROSTATE CANCER AWARENESS

Skin Cancer

NPCR NATIONAL PROGRAM OF CANCER REGISTRIES

Healthy People 2020
National Breast and Cervical Cancer Early Detection Program (NBCCEDP)

**Goal:** Increase breast and cervical cancer screening among underinsured and uninsured women

- **Clinical services:** Access to timely cancer screening and diagnostic services across the nation

- **Treatment services:** Medicaid eligibility for cancer treatment (Breast & Cervical Cancer Prevention and Treatment Act)

**Objective C-17:** Increase the proportion of women who receive a breast cancer screening based on the most recent guidelines
Realizing HP 2020 Objectives: 
Future Approaches to Cancer Screening

**Goal:** Build on the existing capacity and extensive clinical network of the National Breast and Cervical Cancer Early Detection Program

- Public education and outreach
- Screening services and care coordination
- Quality assurance, surveillance, and monitoring
- Organized systems to provide screening
Goal: Increase colorectal cancer (CRC) screening among underinsured and uninsured adults

- Screening promotion (population-based)
  - Emphasis on policy and systems change
  - Implement evidence-based strategies (*Community Guide*)
  - Ensure adequate diagnostic and treatment follow-up

- Screening provision (clinical services)
  - Screening for eligible low income, under- and uninsured men and women

Objective C-16: Increase the proportion of adults who receive a CRC screening based on the most recent guidelines
Realizing HP 2020 Objectives: Innovative Public Health Approaches

- **Minnesota Department of Health**
  - Collaboration with state Medicaid program
  - Direct mail reminders about cancer screening to unscreened beneficiaries

- **New York State Health Department**
  - Collaboration with Federally Qualified Health Centers
  - Registry to track screening rates and quality among providers
Federal Partnerships: Cancer Prevention and Control Research Network

Goal: Provide an infrastructure for applying relevant research to local cancer prevention and control needs

- Increases expertise in community-based intervention research in cancer prevention and control
- Facilitates translation of interventions into practice
- Aims to provide expertise for research that meets Community Guide standards
Cancer Prevention and Control Research Network Example

Washington University in St. Louis and United Way 2-1-1 Missouri

- Callers to 2-1-1 have greater need for cancer control services

- Three randomized study arms: verbal referral only, verbal referral plus mailed reminder and verbal referral plus a telephone coach/navigator

- Callers in the verbal referral plus telephone coach/navigator group were more likely to seek referrals for mammograms and Pap tests
Federal Partnerships
Cancer Surveillance Data

**Goal**: complete local, state, regional, and national data on cancer incidence

- **100% coverage for the U.S. population**
  - Surveillance, Epidemiology, and End Results program (NCI)
  - National Program of Cancer Registries (CDC)
- **Source for Healthy People cancer incidence objectives**

Objectives C-9, C-10, C-11: Reduce incidence of colorectal cancer (C-9), invasive uterine cervical cancer (C-10), and late stage breast cancer (C-11)
Mission: To integrate advances in genomics effectively and responsibly into public health programs to improve population health

Goals:

• Implement evidence-based genomic testing and family health history applications into public health programs

• Evaluate genomic tests to identify new opportunities to improve health and transform healthcare

• Develop and provide communications publications, training, policy and technical assistance to programs, providers, policymakers, and consumers.
Public Health Genomics

Welcome to Public Health Genomics
The Office of Public Health Genomics (OPHG) promotes the integration of genomics into public health research, policy, and practice to prevent disease and improve the health of all people.


Focus Areas

Weekly Update
Timely information on health impact of genomics....

Implementation
What public health can do now to save lives using genomics...

Genomics and Health

Reports and Publications
CDC reports and publications in genomics...

Genomics and Health

Polio Eradication & Human Genetics

What's the Connection Between Polio Eradication & PIDD?

Learn More »

1988

2012

Countries that have eliminated polio
Countries that have non-polio acute flaccid paralysis

Genomics and Health

Autism
Breast and Ovarian Cancer
Colorectal Cancer
Fragile X Syndrome
Heart Disease
Hemochromatosis/Iron Overload
Mental Health
Tier 1: Recommended for clinical use by evidence-based panels, based on systematic review of evidence of validity and utility.

Tier 2: May be useful for informed decision making, based on demonstrated validity, and promising utility.

Tier 3: Not ready for clinical use, due to validity or utility not demonstrated, or systematic assessment finding harms outweigh benefits.

http://www.cdc.gov/genomics/gtesting/tier.htm
HP 2020 Genomics Objectives

G-1: Increase the proportion of women with a family history of breast and/or ovarian cancer who receive genetic counseling

→ U.S. Preventive Services Task Force Recommendation

G-2: Increase the proportion of persons with newly diagnosed colorectal cancer who receive genetic testing to identify Lynch syndrome

→ Evaluation of Genomic Applications in Practice and Prevention (EGAPP) Working Group Recommendation
OPHG-Sponsored EGAPP Working Group

• Independent, multidisciplinary, non-federal panel established in 2004

• Established a systematic, evidence-based process to assess validity & utility of genomic tests & family health history applications.
  • New methods for evidence synthesis and modeling in 2013, including next generation sequencing and stratified screening

• Six recommendation statements to date:
  • Colorectal cancer, breast cancer, heart disease, clotting disorders, depression

• New recommendations in 2013
  • Prostate cancer, diabetes, and more
Realizing HP 2020 Objectives: State Genomics Programs

Since 2008, CDC has supported state genomics programs in Michigan, Oregon, and more recently Georgia, to implement the evidence-based genomics recommendations underpinning the HP objectives.

States are:

- Identifying people targeted by the HP 2020 genomics objectives using cancer registries and educating health providers about evidence-based recommendations
- Implementing model payer policies to facilitate coverage consistent with the breast/ovarian cancer objective
- Developing and evaluating new data sources to measure progress toward these objectives
Cancer registry bidirectional reporting

- Identify relevant breast, ovarian, colorectal and other cancer cases reported to central cancer registry
- Inform reporting institutions of relevant cancer cases with informational materials about hereditary breast and ovarian cancer and Lynch syndrome
- Michigan reported back over 15,000 cases of cancer relevant to HP 2020 objectives (2007-2008 data).
- Connecticut reported back over 5000 cases of cancer through a Healthy People 2020 Action Award (2008-2009 data).
Model payer policies to promote HP 2020 genomics objectives

- Michigan Department of Community Health partnered with major payers to implement payer policies consistent with the USPSTF recommendation/HP 2020 breast cancer objective.
  - From 2008-2011, insurance coverage consistent with the USPSTF recommendation/HP 2020 breast cancer objective has been extended to over 6.6 million Michigan residents.

- CDC’s Division of Cancer Prevention and Control examined medical policies related to genetic counseling for hereditary breast and ovarian cancer.
  - Of 348 health plans across 38 states, 58% had written policies
Public Health Genomics
State Programs Clickable Map

Select a State
Alaska

Healthy People 2020
HP 2020 Genomics Objectives
Additional Facilitators

• Affordable Care Act coverage of the USPSTF recommendation for hereditary breast and ovarian cancer as a preventive service

• Meaningful Use of Electronic Health Records— inclusion of family health history

• Public Health Reporting Initiative— inclusion of family health history

• Current Procedural Terminology code revisions— specific codes for genetic tests, including those relevant to HP 2020 objectives, being implemented
Challenges in Implementing Genomic Medicine (HP2020 & Beyond)

• Evidence of clinical validity and utility slow to accumulate
• Provider awareness and education
• Need for genetic/genomic professionals
• Healthcare system limitations (e.g., family history collection and cascade testing in relatives)
• Laboratory issues
• Ethical, legal and social issues
• Coverage and reimbursement
• Potential for increasing health disparities
AHRQ’s role in addressing Healthy People 2020 objectives

- **Mission:** To improve the quality, safety, efficiency, and effectiveness of health care for all Americans
- AHRQ supports research that helps people make more informed decisions and improves the quality of health care services
- AHRQ also works to translate new knowledge into evidence and tools that people can use to improve the safety and quality of health care.
- ~80 percent of AHRQ's budget is invested in grants and contracts focused on improving health care
The U.S. Preventive Services Task Force is an independent group of national experts in prevention and evidence-based medicine.

The Task Force works to improve the health of all Americans by making evidence-based recommendations about clinical preventive services such as:

- Screenings
- Counseling services
- Preventive medications

AHRQ convenes the Task Force and provides ongoing scientific, administrative, and dissemination support for the operations of the Task Force.
U.S. Preventive Services Task Force (continued)

- Systematically reviews evidence for clinical preventive services implemented in a primary care setting
- The Task Force makes recommendations to help primary care clinicians and patients decide together whether a preventive service is right for a patient’s needs
- To learn more about the USPSTF and how you can engage with them, visit: USPreventiveServicesTaskForce.org
Examples of recent USPSTF Cancer-related A and B recommendations

- The USPSTF recommends **screening** for **cervical cancer** in women ages 21 to 65 years with cytology (Pap smear) every 3 years or, for women ages 30 to 65 years who want to lengthen the screening interval, screening with a combination of cytology and human papillomavirus (HPV) testing every 5 years. (A Recommendation)

- The USPSTF recommends **counseling** children, adolescents, and young adults aged 10 to 24 years who have fair skin about minimizing their exposure to ultraviolet radiation to reduce risk for **skin cancer**. (B Recommendation)

Objectives C-4 Reduce the death rate from cancer of the uterine cervix and C-15 Increase the proportion of women who receive a cervical cancer screening based on the most recent guidelines.

Objective C-20 Increase the proportion of persons who participate in behaviors that reduce their exposure to harmful ultraviolet irradiation and avoid sunburn.
Genomics-related USPSTF recommendation

- The USPSTF recommends that women whose family history is associated with an increased risk for deleterious mutations in **BRCA1** or **BRCA2** genes be referred for **genetic counseling** and evaluation for BRCA testing. (B Recommendation)

- Recommendation is currently being updated.

Objectives G-1 Increase the proportion of women with a family history of breast and/or ovarian cancer who receive genetic counseling.
As a result of the Affordable Care Act, HHS utilizes A and B recommendations from the USPSTF along with recommendations of three other groups to guide Medicare, Medicaid and private insurance companies to increase access to clinical preventive services and to ensure that they are affordable for all Americans.

AHRQ’s cancer-related research areas include:
- Multiple chronic conditions
- Delivery of culturally appropriate clinical preventive services
Tools for implementation

- The Guide to Clinical Preventive Services, 2012
- Electronic Preventive Services Selector (ePSS)
- MyHealthfinder
- Consumer fact sheets
AHRQ developed a clinical decision support tool to facilitate shared decision making between clinicians and women at risk of breast or ovarian cancer.

Tool was originally developed to support the USPSTF’s recommendation.

It has been adapted for use by the CDC’s Division of Cancer Prevention and Control.

https://www3.orau.gov/BodyTalk
Healthy People and the U.S. Preventive Services Task Force

Cancer

Find evidence-based information and recommendations related to cancer.
Clinical Recommendations
Community Interventions
Consumer Information

Clinical Recommendations
The following clinical recommendations come from the US Preventive Services Task Force (USPSTF).

Behavioral Counseling to Prevent Skin Cancer
The U.S. Preventive Services Task Force (USPSTF) recommends counseling children, adolescents, and young adults aged 10 to 24 years who have fair skin about minimizing their exposure to ultraviolet radiation to reduce risk for skin cancer. Learn more.

Genetic Risk Assessment and BRCA Mutation Testing for Breast and Ovarian Cancer Susceptibility
The U.S. Preventive Services Task Force (USPSTF) recommends that women whose family history is associated with an increased risk for deleterious mutations in BRCA1 or BRCA2 genes be referred for genetic counseling and evaluation for BRCA testing. Learn more.

Screening for Breast Cancer
The U.S. Preventive Services Task Force (USPSTF) recommends biennial screening mammography for women aged 50 to 74 years. Learn more.

Screening for Cervical Cancer
Oregon Genetics Program
Public Health Division / Oregon Health Authority
Summer Lee Cox, MPH
Feb 6, 2013
Oregon Genetics Program

- Center for Prevention & Health Promotion
  - Oregon Public Health Division/Oregon Health Authority

- Mission
  - Promote the health, well-being, and quality of life of Oregonians using up-to-date knowledge of genomics

- Funding
  - CDC Division of Cancer Prevention and Control
Surveillance, Education & Policy

- **Surveillance**
  - Identify use & understanding, current gaps and opportunities for change

- **Education**
  - Health care providers, health insurers and the public

- **Policy**
  - Improve access to genetic services
Cancer Risks: Comparing BRCA+ to the General Population (among Women)

- **Risk of Breast Cancer**
  - Women who are BRCA+: 60%
  - Women in the general population: 12%

- **Risk of Ovarian Cancer**
  - Women who are BRCA+: 40%
  - Women in the general population: 1%

The Adult Oregon Population

Approximately 154,000 candidates for BRCA testing

20,500
133,500

2,822,744

Adult Oregonians with no family history of HBOC
BRCA Carriers
BRCA Testing Candidates minus BRCA Carriers

Oregon BRCA Testing in 2008

Education/Outreach
General Public & Targeted Populations (Ashkenazi Ancestry)

Policy
Healthcare Systems & Providers
Oregon Partnership for Cancer Control (OPCC)

Surveillance
Other Public Health Programs
Oregon State Cancer Registry (OSCaR)

Medicaid
Oregon Medicaid

Cancer Genetic Specialists
Cancer Genetic Specialists

Genetic Specialists
Genetic Specialists
OGP Approach - Surveillance

Surveillance Data

- Oregon cancer genetics clinics
- Oregon State Cancer Registry (OSCaR)
- Oregon Medicaid
- Behavioral Risk Factor Surveillance Study (BRFSS)
- 2010 Healthcare provider survey
- 2011 Insurance Company survey
OGP Approach – Education

- Education Goals
  - Increasing the use of evidence based guidelines (USPSTF & NCCN)
  - Increasing the number of appropriate referrals to genetic services (Tier 1 applications)
  - Increasing the use and awareness of family history

- Populations
  - Ashkenazi Jewish population & general population
  - Healthcare Providers
  - Health Insurance Companies
OGP Approach - Policy

• Policy
  ○ Medicaid coverage guidelines
  ○ Education of stakeholders on genetic counselor licensure

• Future activities
  ◦ Discussion with health insurance companies
    • Evidence based guidelines to decide coverage
  ◦ Discussion with healthcare providers & systems
    • Evidence based guidelines to decide health care
What We Have Learned

- What gets measured gets done
  - baseline data & targets
- Use multiple data sources
  - OSCaR, Oregon Census data, data from literature
- Bring together multiple partners
  - Share resources and brainstorm
- Use multiple and comprehensive approaches
  - Multipronged solutions for complex conditions
Next Steps

- Letter writing campaign
  - Collaboration with the Oregon Cancer Registry
  - Simultaneously educating cancer patients AND their doctors

- Discussion with health insurance companies
  - Evidence based recommendations
  - Cost effectiveness studies
  - Client support

- Continue collaborating with Cancer partners
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Stay Connected

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