



THE GW CANCER INSTITUTE'S
CENTER FOR THE ADVANCEMENT OF CANCER SURVIVORSHIP,
NAVIGATION AND POLICY (CASNP)

CANCER HEALTH POLICY SCHOLARS PROGRAM

November 7–9, 2011
Washington, DC

Presented by

THE GW
CANCER INSTITUTE
THE GEORGE WASHINGTON UNIVERSITY

CENTER FOR THE ADVANCEMENT OF
CANCER SURVIVORSHIP, NAVIGATION AND POLICY

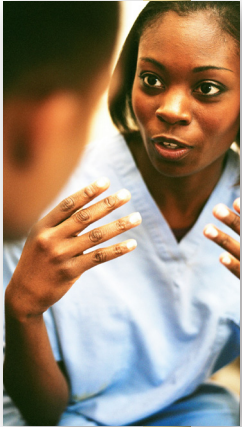
THE GEORGE WASHINGTON UNIVERSITY
SCHOOL OF PUBLIC HEALTH
AND HEALTH SERVICES

DEPARTMENT OF HEALTH POLICY

*This program is generously supported by the Pfizer Foundation and Pfizer Inc.'s
Global Health Partnership Program.*

 The Pfizer Foundation

 Oncology



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CENTER FOR THE ADVANCEMENT OF
CANCER SURVIVORSHIP, NAVIGATION AND POLICY

Dear Scholar,

On behalf of the GW Cancer Institute's Center for the Advancement of Cancer Survivorship, Navigation and Policy (caSNP) we welcome you to the second annual Cancer Health Policy Scholars Program. As you are aware, the program has been developed through a partnership between caSNP and the Department of Health Policy within the School of Public Health and Health Services.

Our 2011 Scholars program focuses on the implications of health reform for cancer prevention and care by providing a comprehensive orientation to cancer health policy, the federal policymaking process, major provisions of the Patient Protection and Affordable Health Care Act and emerging health reform implementation issues. Special attention will be devoted to the implications of health reform for cancer patient navigation and survivorship.

We are honored to be bringing our cancer health policy program to such an outstanding and diverse group of cancer health professionals. Each of you brings a unique set of experiences that will enrich our discussions about the challenging opportunities that health reform presents to the cancer community for advancing the accessibility and quality of all phases of cancer care.

Sincerely,



Steven R. Patierno, PhD
Executive Director
GW Cancer Institute



Paula Lantz, PhD
Professor and Chair
GW Department of Health Policy



Anne Willis, MA
Director, Division of Cancer Survivorship,
co-Director
Center for the Advancement of Cancer
Survivorship, Navigation and Policy



Becky Beauregard
Senior Research Scientist, Department of
Health Policy,
co-Director
Center for the Advancement of Cancer
Survivorship, Navigation and Policy

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Acknowledgements

Steven R. Patierno, PhD	Executive Director, GW Cancer Institute
Paula Lantz, PhD	Professor and Chair, Department of Health Policy
Mandi Pratt Chapman, MA	Associate Director, GWCI, Community Programs
Becky Beauregard	co-Director, caSNP, Senior Research Scientist, Department of Health Policy
Anne Willis, MA	Director, Division of Cancer Survivorship, co-Director, caSNP
Elisabeth Reed	Program Coordinator, caSNP, NCSRC

About GWCI

The GW Cancer Institute takes a comprehensive approach to this complex disease. GWCI combines the myriad of cancer resources at The George Washington University into a unified force in the prevention, diagnosis and treatment of cancer, as well as life after cancer. High technology clinical care is delivered with a compassionate, personal touch. Leading edge research programs span from molecular genomics and drug discovery, to survivorship and cancer health policy, and advanced clinical trials. Innovative educational programs are both professional and community based and our community outreach programs are effectively impacting the cancer health of our Nation's Capital.

About the Department of Health Policy

The Department of Health Policy is the home for health policy studies and research at The George Washington University and its School of Public Health and Health Services. The Department focuses on virtually all phases of U.S. health policy and prepares students to analyze health policy matters in the real world, taking maximum advantage of our location in Washington, D.C., the nation's health policy epicenter.

About caSNP

The Center for the Advancement of Cancer Survivorship, Navigation and Policy (caSNP) focuses broadly on the interrelated scientific, clinical, public health and health policy dimensions of cancer care with a special emphasis on patient navigation and survivorship. The Center was created in 2009 by the GW Cancer Institute, in partnership with the Department of Health Policy within the School of Public Health and Health Services (SPHHS) and is supported by the Pfizer Foundation and Pfizer Inc.'s Global Health Partnerships Program. For more information, visit www.gwumc.edu/caSNP.

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- Learning Objectives -

- To expand awareness of U.S. cancer health policy history
- To increase understanding of the policymaking roles of the federal legislative, executive and judicial branches of government
- To gain familiarity with the roles of advocacy organizations and interest groups in the development and implementation of cancer health policy
- To increase awareness of the key issues in health reform affecting cancer prevention and care
- To gain familiarity with emerging health reform implementation issues affecting cancer prevention and care
- To increase understanding of the implications of health reform for cancer patient navigation and survivorship
- To interact with key policy analysts and policymakers

2011 CANCER HEALTH POLICY SCHOLARS PROGRAM

AGENDA

NOVEMBER 7-9, 2011

BOARD ROOM

HOTEL LOMBARDY, WASHINGTON DC

November 7, 2011

- | | |
|--------------------------------|--|
| 8:30 a.m. – 9:00 a.m. | Continental Breakfast (Fortuny Room) |
| 9:00 a.m. – 9:30 a.m. | Welcome and Introductions
Steven R. Patierno, PhD, Executive Director, George Washington Cancer Institute |
| 9:30 a.m. – 10:30 a.m. | Understanding the Cancer Health Policymaking Process
Speaker: Jennifer Leonard, JD, MPH, GW Department of Health Policy
<i>This session will provide a brief history of U.S. cancer health policies and an overview of the cancer health policymaking process and players including state and federal government and interest groups.</i> |
| 10:30 a.m. – 10:45 a.m. | Morning Break (Fortuny Room) |
| 10:45 a.m. – 12:30 p.m. | Cancer and Health Reform: An Overview
Speakers: Jane Thorpe, JD, Katherine Hayes, JD, and Nancy Lopez, JD, GW Department of Health Policy
<i>This session will outline major provisions of the Affordable Care Act (ACA) and their implications for the delivery of cancer care.</i> |
| 12:30 p.m. – 2 p.m. | Lunch Discussion on the Breast and Cervical Center Control Program
Guest Speakers: Paula M. Lantz, PhD, Professor and Chair, GW Department of Health Policy, Leighton Ku, PhD, Professor, GW Department of Health Policy
<i>Dr. Lantz will present her Breast and Cervical Cancer Prevention and Treatment Act of 2000 (BCCPTA) case study and facilitate a discussion on the program, health disparities and health reform with Leighton Ku, PhD, Department of Health Policy. Dr. Ku will present recent work on the impact of health reform on the Breast and Cervical Cancer Control Program (BCCCP).</i> |
| 2:00 p.m. – 2:15 p.m. | Afternoon Break (Fortuny Room) |
| 2:30 p.m. – 4:00 p.m. | Implementing Health Reform: Emerging Issues for Cancer Prevention and Care |

Speakers: Erin Reidy, American Cancer Society Cancer Action Network, Christine Ferguson, JD, GW Department of Health Policy
This session will delve into health reform implementation issues with an emphasis on coverage and access (health disparities), survivorship and navigation.

November 8, 2011

8:30 a.m. – 9:00 a.m.

Continental Breakfast (Fortuny Room)

9:00 a.m. – 10:15 a.m.

Advocacy in the Era of Health Reform

Speakers: Loyce Pace Bass, MPH, LIVESTRONG, Nancy Davenport-Ennis, National Patient Advocate Foundation, Nicole Tapay, JD, National Coalition for Cancer Survivorship; moderated by Mandi Pratt-Chapman, MA, GWCI

Representatives from national advocacy groups will talk about their health reform implementation priorities, influencing the cancer policy agenda, and how to specifically educate the public on important health issues and policies with a focus on survivorship and navigation

10:15 a.m. – 10:30 a.m.

Morning Break (Fortuny Room)

10:30 a.m. – 11:45 a.m.

Making the Connection: How Research Informs Policy

Speakers: Jeff Allen, PhD, Friends of Cancer Research, Joanne Buzaglo, PhD, Cancer Support Community, Robin Yabroff, PhD, National Cancer Institute

The session will focus on how research impacts the public health agenda and ways advocacy groups and other catalyst organizations use research to inform and promote health policy initiatives.

11:45 a.m. – 12:30 p.m.

Lunch (Fortuny Room)

12:30 p.m. – 1:30 p.m.

Travel to Capitol Hill

1:30 p.m. – 4:00 p.m.

Congressional Meetings

6:00 p.m. – 8:00 p.m.

Scholars Dinner at RIS Restaurant

(2275 L Street NW, Washington, DC , 202-730-2500)

November 9, 2011

8:15 a.m. – 9:30 a.m.

Continental Breakfast & Discussion

Defining Quality Cancer Care: Treatment and Beyond

Speakers: Kristen McNiff, MPH, American Society of Clinical Oncology, Stephen Edge, MD, FACS, Roswell Park Cancer Institute/University at Buffalo, Claire F. Snyder, PhD, John Hopkins Bloomberg School of Public Health

A panel will discuss what is meant by the term “quality cancer care” focusing on survivorship and navigation as part of the cancer continuum of care.

9:30 a.m. – 10:45 a.m.

“Health Reform, Cancer and You”

Speaker: Christina Cianflone, JD, GWCI

10:45 a.m. – 11 a.m.

Morning Break (Fortuny Room)

11:00 a.m. – 12:15 p.m.

Ask the Experts

Speakers: Janice Phillips, PhD, RN, FAAN, Robert Wood Johnson Foundation Health Policy Fellow, Office of Senator John D Rockefeller IV, Joan T. Panke, MA, RN, ACHPN, Consultant, Adam Clark, PhD, Scientific and Healthcare Consultant, Steven R. Patierno, PhD, GWCI, Katherine Sharpe, American Cancer Society; Moderated by Anne Willis, MA, GWCI

A panel of experts will share their insight and answer questions on quality cancer care issues such as palliative care, health care workforce, health information technology and navigation and survivorship.

12:15 p.m. – 1:15 p.m.

Lunch (Fortuny Room)

1:15 p.m. – 2:00 p.m.

Closing Remarks, Certificate Presentation, and Adjourn

2011 CANCER HEALTH POLICY SCHOLARS PROGRAM

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NOVEMBER 7, 2011

BOARD ROOM

HOTEL LOMBARDY, WASHINGTON DC

- 8:30 a.m. – 9:00 a.m.** **Continental Breakfast (Fortuny Room)**
- 9:00 a.m. – 9:30 a.m.** **Welcome and Introductions**
Steven R. Patierno, PhD, Executive Director, George Washington Cancer Institute
- 9:30 a.m. – 10:30 a.m.** **Understanding the Cancer Health Policymaking Process**
Speaker: Jennifer Leonard, JD, MPH, GW Department of Health Policy
This session will provide a brief history of U.S. cancer health policies and an overview of the cancer health policymaking process and players including state and federal government and interest groups.
- 10:30 a.m. – 10:45 a.m.** **Morning Break (Fortuny Room)**
- 10:45 a.m. – 12:30 p.m.** **Cancer and Health Reform: An Overview**
Speakers: Jane Thorpe, JD, Katherine Hayes, JD, and Nancy Lopez, JD, GW Department of Health Policy
This session will outline major provisions of the Affordable Care Act (ACA) and their implications for the delivery of cancer care.
- 12:30 p.m. – 2 p.m.** **Lunch Discussion on the Breast and Cervical Center Control Program**
Guest Speakers: Paula M. Lantz, PhD, Professor and Chair, GW Department of Health Policy, Leighton Ku, PhD, Professor, GW Department of Health Policy
Dr. Lantz will present her Breast and Cervical Cancer Prevention and Treatment Act of 2000 (BCCPTA) case study and facilitate a discussion on the program, health disparities and health reform with Leighton Ku, PhD, Department of Health Policy. Dr. Ku will present recent work on the impact of health reform on the Breast and Cervical Cancer Control Program (BCCCP).
- 2:00 p.m. – 2:15 p.m.** **Afternoon Break (Fortuny Room)**
- 2:30 p.m. – 4:00 p.m.** **Implementing Health Reform: Emerging Issues for Cancer Prevention and Care**
Speakers: Erin Reidy, American Cancer Society Cancer Action Network, Christine Ferguson, JD, GW Department of Health Policy
This session will delve into health reform implementation issues with an emphasis on coverage and access (health disparities), survivorship and navigation.

**The Center for the Advancement of
Cancer Survivorship, Navigation and Policy's**
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- SPEAKER BIOGRAPHIES -

November 7, 2011

Understanding the Cancer Health Policymaking Process



Jennifer Leonard, JD, MPH

Associate Professor
The George Washington
University Department of
Health Policy

Dr. Leonard specializes in the legal and policy issues associated with the areas of Medicaid, health care delivery systems, including community health centers and Medicaid managed care organizations, privacy of health information, and fraud and abuse. Ms. Leonard is the lead in the legal aspects of a large project with the District of Columbia, Department of Health Care Finance. In this role she provided legal and policy assistance in the drafting of the District of Columbia's Medicaid and Alliance Managed Care Program Request for Proposal, participated in the evaluation, award, and transition of the new contractors, analyzed of options for restructuring the District of Columbia government to include creation of the Department of Health Care Finance. Ms Leonard continues to assist with various other aspects of the Medicaid, Alliance, and health policy operations of the Department of Health Care Finance. Ms. Leonard teaches Health Services and the Law, Health Law for Managers, Policy Approaches to Public Health, and the Policy of Cancer.

Prior to joining the faculty, Ms. Leonard practiced law at the Washington, D.C. law firm of Feldesman Tucker Leifer Fidell LLP where she specialized in health law, counseling clients on risk management issues, employment-related matters, provider affiliations, and corporate compliance programs. Specifically, Ms. Leonard advised clients on a wide variety of matters including compliance with Medicaid and Medicare requirements, the Health Insurance Portability and Accountability Act, compliance with grant or government contract-related requirements, and various other Federal and State laws and regulations.

Cancer and Health Reform: An Overview



Jane Hyatt Thorpe, JD

*Associate Research
Professor*
The George Washington
University Department of
Health Policy

Jane Hyatt Thorpe, J.D. is an Associate Research Professor in the Department of Health Policy in the School of Public Health and Health Services at the George Washington University. She specializes in health care law and policy in the areas of Medicare, Medicaid, health care delivery systems and financing, health information technology, and corporate compliance. She is currently focusing her research and writing on legal and policy issues related to health reform implementation particularly related to health care quality, delivery, and payment. Professor Thorpe also serves as the program director

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for the Healthcare Corporate Compliance Graduate Certificate Program.

Prior to joining the Department in February 2009, Professor Thorpe served as the Deputy Director of the Office of Policy for the Centers for Medicare and Medicaid Services (CMS) within the U.S. Department of Health and Human Services. In that role, she was responsible for matters related to the Agency's crosscutting policy and strategic planning particularly focusing on emerging issues in healthcare delivery and financing. Professor Thorpe's previous experience includes policy development and serving as a regulatory liaison to CMS in her role as Associate Vice President for Payment and Policy at the Advanced Medical Technology Association (AdvaMed). Prior to joining AdvaMed, Professor Thorpe practiced health care law.

Professor Thorpe has an A.B. *magna cum laude* in History and a Certificate in American Studies from Princeton University and a J.D. from Vanderbilt University School of Law. She is a member of the American Health Lawyers Association and the D.C. Bar Association.

Katherine Hayes, JD

*Associate Research
Professor*

The George Washington
University Department of
Health Policy

Katherine Hayes is an Associate Research Professor in the Department of Health Policy at the George Washington University School of Public Health and Health Services. As a member of the Hirsh Health Law and Policy Program, she specializes in legal and policy matters related to Medicaid, the Children's Health Insurance Program, private health insurance, long-term care, and health reform implementation. She is co-director for Health Reform: GPS a website dedicated to policy analysis related to the implementation of the Affordable Care Act.

She has over twenty-five years experience in health policy, serving two U.S. Senators, a Member of the House of Representatives and two governors. Prior to joining GW, she served vice president for health policy at Jennings Policy Strategies, Inc.

Other private sector experience includes legal practice with a large Washington, DC – based law firm, policy director for two Catholic health systems, and a children's hospital. She also served as a program consultant for a state Medicaid agency and as a senior health policy advisor to a major presidential campaign.

At GW she teaches courses on federal advocacy and policymaking and the federal budget process. She has a B.A. from University of North Carolina at Chapel Hill, and a J.D. from the American University, Washington College of Law.

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Nancy Lopez, JD

Senior Research Scientist
The George Washington
University Department of
Health Policy

Nancy Lopez is a senior research scientist and professorial lecturer in the Department of Health Policy at the George Washington University School of Public Health and Health Services. Ms. Lopez specializes in legal and policy matters related to Medicaid, private health insurance, health reform implementation, specifically health insurance Exchanges, and health care fraud. Her research has been used to produce analyses and papers regarding various aspects of Medicaid financing for comprehensive integrated service systems for children; development of

Medicaid and Medicare special managed systems of care for people with serious disabilities; Medicare Coverage Determination; case law interpreting “efficiency” clauses within Medicaid; legal analysis of case law of intermediate sanctions under Medicaid; coverage and reimbursement policies of state Medicaid programs and private insurance issuers for obesity treatment or prevention; and health care fraud in public and private insurance programs. She is also part of a research team tasked with analyzing policy implications of various provisions of the Affordable Care Act of 2011 and in addition, reviews and analyzes CCIIO regulations regarding health insurance Exchanges. Prior to joining SPHHS, she practiced law in a bankruptcy firm where she specialized in litigation for debtors and creditors.

Lunch Discussion on the Breast and Cervical Center Control Program



Paula M. Lantz, PhD

Professor and Chair
The George Washington
University Department of
Health Policy

Paula M. Lantz, PhD, is Professor and Chair of the Department of Health Policy at the George Washington University School of Public Health and Health Services. Before joining the GWU faculty, she was a faculty member at the University of Michigan, School of Public Health and the Gerald R. Ford School of Public Policy, including serving for six years as the chair of the Department of Health Management and Policy. Dr. Lantz's main research interests include the role of public health in health care reform, clinical preventive services (such as cancer screening and prenatal care), and social inequalities in health. She has led several research projects related to the National Breast and Cervical Cancer Early Detection Program, and conducted other studies on breast/cervical cancer screening and treatment in low-income populations. In addition, she has served as a lead investigator on the *Americans' Changing Lives Study*, which is an ongoing, longitudinal research study of social disparities in health status and aging in the United States.

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- SPEAKER BIOGRAPHIES -



Leighton Ku, PhD, MPH
Professor

The George Washington
University Department of
Health Policy

As a health policy researcher, a public policy analyst, and an advocate, Dr. Ku's career has been built around the effort to understand and improve access to affordable health care for vulnerable populations. Among his areas of expertise are Medicaid, the State Children's Health Insurance Program (SCHIP), immigrant health, state health reform, and health care financing and budgets, with an emphasis on strengthening the health care safety net. "I am interested in applying the lessons of research to policies and programs at the federal and state levels, and working with governmental officials, community groups and advocacy organizations to do it," he says. Professor Ku joined SPHHS as a full-time faculty member in 2008, but he has held adjunct positions at GW's School of Public Policy and Public Administration since the early 1990s. During that time, he also served as a senior fellow at the Washington-based Center on Budget and Policy Priorities, which focuses on improving policies for low- and moderate-income Americans; as principal researcher at the Urban Institute; and as a policy and budget analyst for the federal Women, Infants and Children (WIC) nutrition program.

Implementing Health Reform: Emerging Issues for Cancer Prevention and Care



Erin Reidy
Associate Director of Policy
American Cancer Society
Cancer Action Network

Erin Reidy is Associate Director of Policy at the American Cancer Society Cancer Action Network (ACS CAN). She leads efforts to identify and analyze state, local, and national policies on the implementation of the Affordable Care Act, private health insurance and Medicaid. Prior to ACS CAN, she was a statistician at the National Center for Health Statistics, working on Healthy People 2010. Erin received her undergraduate degree in sociology from Syracuse University and completed the course work toward her doctoral in sociology/demography at the University of Michigan as a National Institutes of Aging predoctoral fellow.

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Christine Ferguson, JD
Professor of Health Policy
The George Washington
University Department of
Health Policy

Prior to joining SPHHS in 2006, Ms. Ferguson had spent most of her professional life in the public sector, most recently as Commissioner of the Department of Public Health in Massachusetts, where she served under Governor Mitt Romney. In that capacity, she led initiatives addressing public health emergencies, including SARS and influenza vaccine shortages, and created regional health coalitions for emergency preparedness. She was also very involved in initiatives to enhance patient safety, restructure substance abuse services, and strengthen early childhood programs. In an earlier post, she ran the Rhode Island Department of Human Services, providing critical programs for low-income families, children, senior citizens, veterans and the disabled. Rhode Island's innovative achievements in health care, Medicaid managed care, early education and child care and welfare reforms were widely recognized during her tenure. Of particular note, Rhode Island had the nation's highest percentage of children with health care coverage. Ms. Ferguson also served as counsel and deputy chief of staff

to the late U.S. Senator John H. Chafee and was instrumental in developing a bipartisan health reform proposal in the 1990s. Her accomplishments have been recognized by Faulkner & Gray's Healthcare, which called her "one of the most influential health policymakers," and by National Law Journal, which named her one of the nation's 100 most influential lawyers. Ms. Ferguson was also named one of the top 25 "most influential working mothers" by Working Mothers magazine.

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AGENDA

NOVEMBER 8, 2011

BOARD ROOM

HOTEL LOMBARDY, WASHINGTON DC

- 8:30 a.m. – 9:00 a.m.** **Continental Breakfast (Fortuny Room)**
- 9:00 a.m. – 10:15 a.m.** **Advocacy in the Era of Health Reform**
Speakers: Loyce Pace Bass, MPH, **LIVESTRONG**, Nancy Davenport-Ennis, National Patient Advocate Foundation, Nicole Tapay, JD, National Coalition for Cancer Survivorship; moderated by Mandi Pratt-Chapman, MA, GWCI
Representatives from national advocacy groups will talk about their health reform implementation priorities, influencing the cancer policy agenda, and how to specifically educate the public on important health issues and policies with a focus on survivorship and navigation
- 10:15 a.m. – 10:30 a.m.** **Morning Break (Fortuny Room)**
- 10:30 a.m. – 11:45 a.m.** **Making the Connection: How Research Informs Policy**
Speakers: Jeff Allen, PhD, Friends of Cancer Research, Joanne Buzaglo, PhD, Cancer Support Community, Robin Yabroff, PhD, National Cancer Institute
The session will focus on how research impacts the public health agenda and ways advocacy groups and other catalyst organizations use research to inform and promote health policy initiatives.
- 11:45 a.m. – 12:30 p.m.** **Lunch (Fortuny Room)**
- 12:30 p.m. – 1:30 p.m.** **Travel to Capitol Hill**
- 1:30 p.m. – 4:00 p.m.** **Congressional Meetings**
- 6:00 p.m. – 8:00 p.m.** **Scholars Dinner at RIS Restaurant**
(2275 L Street NW, Washington, DC, 202-730-2500)

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Advocacy in the Era of Health Reform



Loyce Pace Bass, MPH
Director of Health Policy
LIVESTRONG

Loyce Pace Bass is Director of Health Policy for LIVESTRONG and is responsible for the development and pursuit of their global policy agenda to ensure protections for people affected by and at risk for cancer worldwide. In her current position, she effectively promotes and communicates the link between research, practice and legislation across diverse sectors within the US and abroad.

Previously, Loyce was the Director of Regional Programs for the American Cancer Society's Department of Global Health, expanding their capacity-building and advocacy programs across Asia and sub-Saharan Africa. Loyce holds a Bachelor's degree with Honors in Human Biology from Stanford University and a Master's degree in Public Health from Johns Hopkins Bloomberg School of Public Health, where she was inducted into the Delta Omega Society. She has lived in East Asia, Europe, and West Africa. She currently resides in the Washington, DC area.



Nancy Davenport-Ennis
Chief Executive Officer
National Patient Advocate
Foundation

Nancy Davenport-Ennis is one of the nation's leading patient advocacy experts on issues related to patients' healthcare access challenges. In 1996, she founded the Patient Advocate Foundation based in Hampton, Virginia, which provides professional case management services to millions of insured, under-insured and uninsured patients facing chronic, debilitating or life-threatening diseases. Last year, PAF managed nearly 83,000 patient cases. PAF offers more than {20} specialized programs, and partners with other leading organizations such as the American Cancer Society, Susan G. Komen and the Lance Armstrong Foundation, among others. Davenport-Ennis also founded the National Patient Advocate Foundation in Washington, DC, which strives to improve access to patient care through federal and state regulatory and public policy efforts.

Davenport-Ennis has served on the National eHealth Collaborative Board and also served on the Agency for Healthcare Research and Quality's Centers for Education and Research on Therapeutics (CERTs) Committee and the National Institutes of Health's Open Ended Working Group (OEWG). She has previously served on national commissions for the Department of Health and Human Services, the National Cancer Institute, the Centers for Medicare and Medicaid Services, C-Change, and One Voice Against Cancer.

Davenport-Ennis has received national awards for her advocacy efforts from Yoplait and the Susan G. Komen Race for the Cure, US Oncology, and the Association of Community Cancer Centers. She is also

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the recipient of the 2005 Women in Business Achievement Award presented by Anthem and Business Week, and was honored with the 1989 Outstanding Young Woman of America Award, the Association of Community Cancer Centers Advocate of the Year Award and the U.S. Oncology Medal of Honor Award. Davenport-Ennis was also appointed to the Governor's Commission on the Uninsured in Virginia and was named as a *Paul Harris Fellow* by the National Rotary Foundation.



Nicole Tapay, JD
Senior Director of Policy
National Coalition for
Cancer Survivorship

Nicole is the Senior Director of Policy for the National Coalition for Cancer Survivorship (NCCS). Ms. Tapay joined NCCS in May 2011 and is responsible for directing and leading NCCS' public policy efforts to shape legislation, regulations, and policies that strengthen access to quality cancer care. Prior to NCCS, Nicole served as Vice President, Government Affairs and Public Policy, Health Care Reform, for Medco Health Services, Inc., representing Medco before Congress and the U.S. government on issues affecting Medco's Medicare Part D and other prescription drug offerings. Previously, Nicole was the Senior Health Policy Advisor for U.S. Senator Ron Wyden (D-OR), with responsibility for health care related legislation and policy, including issues before the Senate Finance, Budget and Aging Committees. She has been an Associate Research Professor at the Georgetown University Health Policy Institute; the Director of the Division of Benefits, Coverage and Payment for the U.S.

Centers for Medicare and Medicaid Services (CMS), with responsibility for key aspects of the SCHIP and Medicaid programs; Senior Legislative Counsel for Health Policy for the National Association of Insurance Commissioners (NAIC); and an Associate in the health care practice of the law firm Epstein, Becker and Green. She also has worked in international health policy for the Organization for Economic Cooperation and Development (OECD), Novartis AG and the World Bank.

Nicole has authored and co-authored a number of books and articles on health care financing and coverage in the U.S. and abroad. She received a J.D. from Georgetown University Law Center and an A.B. from Princeton University, magna cum laude.



**Mandi Pratt-Chapman,
MA**
Associate Director,
Community Programs
George Washington
University Cancer Institute

Mandi Pratt-Chapman is Associate Director of the George Washington University Cancer Institute's (GWCI) Community Programs and Project Director for the National Cancer Survivorship Resource Center (NCSRC), a collaboration between the American Cancer Society (ACS) and GWCI funded by a five year cooperative agreement between ACS and the Centers for Disease Control and Prevention. As GWCI Program Director for the NCSRC, she oversees evaluation, policy and training activities for the Center and contributes to core measures and guideline development for survivorship care. The NCSRC aims to reduce health inequities and improve health outcomes of cancer survivors at a national level. As Associate Director for GWCI, She is responsible for creating a vision and strategic plan for GWCI community programs from prevention through

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survivorship. Previously, she was founding director of GWCI's Division of Cancer Survivorship and co-director of the GWCI Center for the Advancement of Cancer Survivorship, Navigation and Policy (caSNP). She provides high level direction and evaluation expertise to GW's Thriving After Cancer Program, which provides comprehensive, multidisciplinary follow-up care for adult survivors of pediatric cancer; GW's Citywide Patient Navigation Network, which provides navigation services to all cancer patients in the District of Columbia; GW's Healing With Basketball program for breast cancer survivors; and GW Medical Center's Transportation Assistance program. She has worked collaboratively with the GW Department of Health Policy and advocacy stakeholders to improve access and delivery of care to cancer patients and survivors locally and nationally.

Making the Connection: How Research Informs Policy



Jeff Allen, PhD
Executive Director
Friends of Cancer Research

Jeff Allen, Ph.D. serves as the Executive Director of Friends of Cancer Research (Friends), a cancer research think tank and advocacy organization based in the Washington, D.C. area. Friends pioneers innovative public-private partnerships, organizes critical policy forums, and brings together key stakeholders to overcome the barriers standing between patients and the most promising cancer treatments. Prior to joining Friends, Dr. Allen was an endocrinology fellow in the Laboratory of Clinical Investigation of the National Center for Complementary and Alternative Medicine at the National Institutes of Health. Dr. Allen serves on C-Change's Chemoprevention Advisory Committee, Patent Law Advisory Subcommittee and the Clinical Trials and Biomarker Workgroup. Jeff recently served as the organizing author of a 2009 report, "Improving Medical Decisions Through Comparative Effectiveness Research: Cancer as a Case Study" co-authored by a 25 member academic committee.



Joanne Buzaglo, PhD
*Senior Director of Research
of the Research Training
Institute*
Cancer Support
Community

Joanne S. Buzaglo, Ph.D. is a behavioral health researcher and clinical psychologist with extensive experience in the development and evaluation of interventions designed to help patients cope with the complex challenges associated with cancer. Dr. Buzaglo joined the Cancer Support Community (CSC) in August 2008 as Senior Director of Research of the Research and Training Institute with the charge: 1) to build the Cancer Survivor Registry: Breast Cancer M.A.P. (Mind Affects the Physical) Project and 2) to validate and implement a community-based screening tool that is designed to link patients to resources in the community and facilitate integration of comprehensive cancer care across healthcare systems.

Before arriving at CSC, she was the Deputy Director of the Fox Chase Cancer Center's National Cancer Institute-funded Behavioral Research

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Core Facility. She has been a co-investigator on a number of NCI- and Department of Defense-funded cancer-related studies focused on decision-making, tailored health communications and survivorship with a special focus on enhancing doctor-patient communication, clinical trial participation, and patient adherence. Further, Dr. Buzaglo is a licensed clinical psychologist in Pennsylvania and has clinical experience in providing care to individuals coping with cancer and other chronic illnesses.

Dr. Buzaglo received her doctorate at Temple University and completed a post-graduate fellowship in Health Services, Research & Development at the VA Medical Center in Philadelphia, PA. In addition, she trained at the Center for Cognitive Therapy at the University of Pennsylvania, and at Friends Hospital of Philadelphia.



**K. Robin Yabroff, PhD,
MBA**

Epidemiologist
Health Services and
Economics Branch of
Applied Research Program,
Division of Control and
Population Sciences,
National Cancer Institute

K. Robin Yabroff, PhD, MBA, is an Epidemiologist in the Health Services and Economics Branch of the Applied Research Program. She received her doctorate in epidemiology from The Johns Hopkins University School of Hygiene and Public Health. She also received an MBA in finance from the University of Rochester. Before joining NCI in 2002, she was a research Assistant Professor in the Lombardi Cancer Center at Georgetown University.

Dr. Yabroff's research interests include developing methods to estimate the economic and quality-of-life burden of cancer and understanding the determinants of population trends, care, and disparities in the receipt of cancer screening, follow-up services, and cancer treatment. She is author or co-author of over 80 peer-reviewed journal articles on clinical epidemiology and health services research related to cancer. She serves as a reviewer for numerous clinical, health services research, and epidemiology journals, and is currently an associate editor for the *Journal of the National Cancer Institute* and on the editorial board of the *Journal of Cancer Survivorship*. She was a guest editor for a recent *Medical Care* journal supplement, Health Care Costing: Data, Methods, Future Directions. Dr. Yabroff has received several NIH Merit Awards, including one for Economic Studies Related to Cancer Burden and Control and another for The Development and Dissemination of Innovative Statistical and Economic Methods Resulting in the Ability to Estimate the National Burden of Cancer. Dr. Yabroff is currently leading a collaborative effort to improve publicly available data for estimating the burden of cancer in the US, the Medical Expenditure Panel Survey (MEPS): Experiences with Cancer Survivorship Supplement.

2011 CANCER HEALTH POLICY SCHOLARS PROGRAM

AGENDA

NOVEMBER 9, 2011

BOARD ROOM

HOTEL LOMBARDY, WASHINGTON DC

8:15 a.m. – 9:30 a.m.

Continental Breakfast & Discussion

Defining Quality Cancer Care: Treatment and Beyond

Speakers: Kristen McNiff, MPH, American Society of Clinical Oncology, Stephen Edge, MD, FACS, Roswell Park Cancer Institute/University at Buffalo, Claire F. Snyder, PhD, John Hopkins School of Medicine and Bloomberg School of Public Health
A panel will discuss what is meant by the term “quality cancer care” focusing on survivorship and navigation as part of the cancer continuum of care.

9:30 a.m. – 10:45 a.m.

“Health Reform, Cancer and You”

Speaker: Christina Cianflone, JD, GWCI

10:45 a.m. – 11 a.m.

Morning Break (Fortuny Room)

11:00 a.m. – 12:15 p.m.

Ask the Experts

Speakers: Janice Phillips, PhD, RN, FAAN, Robert Wood Johnson Foundation Health Policy Fellow, Office of Senator John D Rockefeller IV, Joan T. Panke, MA, RN, ACHPN, Consultant, Adam Clark, PhD, Scientific and Healthcare Consultant, Steven R. Patierno, PhD, GWCI, Katherine Sharpe, American Cancer Society; Moderated by Anne Willis, MA, GWCI

A panel of experts will share their insight and answer questions on quality cancer care issues such as palliative care, health care workforce, health information technology and navigation and survivorship.

12:15 p.m. – 1:15 p.m.

Lunch (Fortuny Room)

1:15 p.m. – 2:00 p.m.

Closing Remarks, Certificate Presentation, and Adjourn

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November 9, 2011

Defining Quality Cancer Care: Treatment and Beyond



**Stephen B. Edge, MD,
FACS**

*Alfiero Foundation
Endowed Chair in Breast
Oncology, Chief, Breast
Surgery, Professor of
Surgery and Oncology,
Roswell Park Cancer
Institute/University at
Buffalo*

Dr. Stephen Edge is a surgical oncologist and the Alfiero Foundation Endowed Chair in Breast Oncology at Roswell Park Cancer Institute in Buffalo, NY. He serves as Chair of the Commission on Cancer of the American College of Surgeons. In addition, he serves on the Executive Committee of the Board of the National Comprehensive Cancer Network. His medical school and residency training were at Case Western Reserve University, and he served a fellowship in the Surgery Branch of the National Cancer Institute. His research focus is in developing methods to monitor and improve community-wide quality of care. He was a leader in the CoC team that developed quality measures approved by the NQF, and currently also represents the Commission on Cancer and serves as Co-Chair of the Technical Evaluation Panel of the NCQA, developing measures for public reporting by the PPS-Exempt Cancer Centers.



Claire Snyder, PhD

*Associate Professor of
Medicine, Division of
General Internal Medicine
John Hopkins School of
Medicine*

Claire Snyder, PhD, is Associate Professor of Medicine, Division of General Internal Medicine, at the Johns Hopkins School of Medicine with joint appointments in Oncology and Health Policy & Management (Bloomberg School of Public Health). Her research focuses on the quality of cancer care, with emphasis in two areas: quality of life for cancer patients undergoing treatment and coordination of care for cancer survivors. She has conducted studies to investigate preventive and comorbid condition care in cancer survivors and has also applied her research to developing survivorship care strategies at Johns Hopkins. In other research, she is investigating whether having cancer patients complete questionnaires about their quality-of-life and supportive care needs, and providing that information to their clinicians, improves care quality. She also collaborated on a project to develop a framework for evaluating the quality of end-of-life care. She has received competitive funding from government and foundation

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sources and has published numerous manuscripts on outcomes assessment and the quality of care.

Previously, Dr. Snyder worked at the National Cancer Institute and edited *Outcomes Assessment in Cancer: Measures, Methods, and Applications* (Cambridge University Press). She began her career in the private sector at Covance Health Economics and Outcomes Services Inc.

Dr. Snyder received a BA *cum laude* in Public Policy Studies with a certificate in Health Policy from Duke University. She received a Master of Health Science in Health Policy in 2000 and a PhD in Health Policy & Management in 2005 from the Johns Hopkins Bloomberg School of Public Health.

Kristen McNiff, MPH

*Senior Advisor for Strategy
and Implementation in the
Quality & Guidelines
Department , American
Society of Clinical Oncology*

Kristen McNiff serves as the Senior Advisor for Strategy and Implementation in the Quality & Guidelines Department at the American Society of Clinical Oncology (ASCO). In her six years at ASCO, Kristen has overseen the development and growth of ASCO's quality measurement and improvement activities, including the Quality Oncology Practice Initiative (QOPI). She has provided staff leadership for the development and implementation of dozens of oncology quality measures, and numerous clinical tools aimed at improving the quality of care. Kristen leads ASCO's health information technology

efforts related to member education and standards development. She regularly contributes to ASCO policy activities related to quality and health IT.

Prior to joining ASCO, Kristen worked primarily in health services research, including end-of-life care quality measurement and improvement. She received her Masters of Public Health from The George Washington University, and completed the Biomedical Informatics 10x10 program at The Oregon Health and Science University.

Health Reform, Cancer, and You



Christina Cianflone, JD

*Director, Division of Cancer
Prevention and Community
Health*

George Washington
University Cancer Institute

Christina Cianflone leads the Division of Cancer Prevention and Community Health of the George Washington University Cancer Institute (GWCI). In this role, she is responsible for creating public health programming for District residents that address the issues of access to care, screening services, and healthy lifestyle choices. Miss Cianflone also works on policy issues related to health reform and cancer, and she co-taught the cancer policy course for the GW School of Public Health and Health Sciences. Prior to her arrival at GWCI, Miss Cianflone spent several years as the Director of Programs for Safe Kids Worldwide, an international non-profit arm of Children's National Medical Center dedicated to injury prevention. She created national public health programming, worked on local, state and national policy initiatives and served as the national spokesperson. She graduated Magna Cum Laude from The Catholic University of America and also

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received her law degree and a certificate in health law from the University of Pittsburgh.

Ask the Experts



**Joan T. Panke, MA, RN,
ACHPN**
Consultant

Joan T. Panke, MA, RN, ACHPN, is board certified as a nurse practitioner in palliative care. She has worked both clinically and on various educational and outreach projects related to palliative care for nearly 20 years. Currently she is working as an independent consultant providing palliative care educational programs and outreach efforts. Joan implemented and grew the inpatient palliative care consult service at The George Washington University Hospital and served as the service's director for five years, served as Executive Director for the DC Partnership, a regional effort to improve palliative care in the metro DC area funded by the Robert Wood Johnson Foundation's Community-State Partnerships program, worked as curriculum consultant, advisory board member, and national faculty on the End-of-Life Nursing Education Consortium (ELNEC) project. She received her nursing diploma from St. Vincent's Hospital School of Nursing, NY,

bachelor's degree from the University of Washington, Seattle/Bothell, WA and her master's degree at New York University in the Advanced Practice Palliative Care Program. She has extensive teaching experience and has authored several publications on various palliative care topics.



Adam Clark, PhD
*Scientific and Health Care
Consultant, Founder,
MedTran Health Strategies,
Inc.*

Adam Clark, Ph.D. is a scientist and policy advisor with a unique background in biomedical technologies, science and health policy, patient advocacy, and federal government relations. Dr. Clark has a background in biomedical sciences with a focus on molecular diagnostics and personalized medicine. He has worked extensively with federal agencies, congressional staff, technology developers, and patient groups to accelerate medical progress and improving innovation, efficiency, and effectiveness of research and clinical care. Currently, Dr. Clark works as a consultant for disease research organizations through MedTran Health Strategies, a company he started in 2011.

Dr. Clark has worked with numerous patient advocacy and disease research organizations including **LIVESTRONG**, where he served as the Director of Science and Health Policy directing the scientific agendas and policy positions of the foundation. Preceding his work with non-profit organizations, he served as a technology development specialist at the National Cancer Institute (NCI) administering programs in cancer biomarker detection technologies. While at the NCI, he also performed policy assignments in the White House Office of Science and Technology Policy and the Office of the Secretary of Health and Human Services (HHS).

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Dr. Clark's speaking engagements focus on medical innovation to improve patient health. He has contributed to several Institute of Medicine workgroups, served on the Cancer Biomarkers Consortium at the Foundation for the NIH, and currently sits on several committees and advisory boards, including the Federal Advisory Committee for Health Information Technology Policy at HHS and the Director's Consumer Liaison Group at the NCI. He earned his Ph.D. from the University of Cincinnati, College of Medicine and was trained in science and health policy through the Emerging Leaders Program at HHS.



Steven R. Patierno, PhD
Executive Director
George Washington
University Cancer Institute

As Director of the GW Cancer Institute (GWCI), Dr. Patierno leads the integration and coordination of a Medical Center-wide and University-wide comprehensive cancer program center dedicated to advancing multi- and trans-disciplinary cancer research, outreach and education, prevention and control, and treatment. GWCI is a matrix cancer center with over 80 diverse clinical and research faculty spanning Medicine, Public Health, Engineering, Arts and Sciences, International Affairs, and Law. Dr. Patierno is the Vivian Gill Distinguished Professor of Oncology, founding Director of the Molecular and Cellular Oncology Program, Professor of Pharmacology, Genetics and Urology in the School of Medicine and Health Science, and Professor of Environmental and Occupational Health in the School of Public Health and Health Services. Dr. Patierno has over two decades of experience managing nearly \$30 million of grants including large, complex biomedical research grants (both laboratory and population sciences). In addition to basic science research grants, he is principal investigator

to patient-centered and community-based grants from the NCI, Avon, Amgen, DC DOH and Pfizer; and he is experienced in development and integration of complex programs across multiple institutions. This portfolio includes research and interventional programs in cancer disparities, prevention and community health, control and epidemiology, health services and policy, genomics and bioinformatics, social and behavioral health, global health and survivorship. Dr. Patierno earned his doctoral degree at the Graduate School of Biomedical Science, University of Texas Health Science Center in Houston, and the MD Anderson Cancer Institute, where he was awarded the Rosalie B. Hite Fellowship in Cancer Research. He conducted postdoctoral research in molecular oncology at the University of Southern California (USC) Norris Comprehensive Cancer Center as an NIH-funded fellow. He is internationally recognized as a leading expert in cancer causation, carcinogenesis, and translational research in lung, prostate, and breast cancer.

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Katherine Sharpe
*Managing Director,
Prevention and Survivorship
American Cancer Society*

Katherine Sharpe has served as the Managing Director, Prevention and Survivorship, at the American Cancer Society's National Home Office since February 2010. In this capacity, Katherine provides leadership on survivor programs, HP research and plays a crucial role in defining, communicating and executing new business strategies for the Health Promotions Department in support of ACS nationwide strategies and policies. Additionally, Katherine provides oversight on major organizational development initiatives and coordinates research initiatives to help define future development opportunities

Katherine started her career at the American Cancer Society in September 1997 at the National Cancer Information Center in Austin, Texas and has since worked in a variety of functions at NHO.

Prior to her tenure with ACS, Katherine worked as a case manager and counselor in a variety of clinical settings, including Children's Medical Center, Dallas, TX, the Scottish Rite Hospital, Dallas, TX and the Austin State Hospital, Austin, TX.

Katherine holds an undergraduate degree in Psychology from St. Mary College and a master's degree from Seabury-Western at Northwestern University, Evanston, Illinois.



**Janice M. Phillips, PhD, MS,
RN, FAAN**
*Robert Wood Johnson
Foundation Health Policy
Fellow, Sen. John D.
Rockefeller IV (D-WV)*

Janice Phillips is an experienced clinician, researcher, educator and public policy advocate in the health care arena who recently completed service as a 2010-2011 Robert Wood Johnson Foundation Health Policy Fellow, working in the office of Sen. John D. Rockefeller IV (D-WV). With specialties spanning oncology, public health, women's health, healthcare disparities and research administration, she has demonstrated her ability to build and maintain strategic relationships and partnerships among academic institutions, scientific investigators, healthcare institutions and advocacy groups.

As part of her RWJ fellowship, Dr. Phillips built support for implementing the Affordable Care Act. She led efforts in support of the Prescription Drug Abuse and Treatment Act of 2011, addressing the nation's fastest growing drug problem, prescription drug abuse.

Previously, Dr. Phillips was the Manager of Nursing Research at the University of Chicago Medical Center where she strategically positioned the Department of Nursing to achieve its first national recognition for excellence in nursing research and evidence based nursing practice. She also served as a Research Associate/Assistant Professor within the Center for Clinical Cancer Genetics and Global Health, conducting health disparities research and establishing partnerships to enhance community outreach activities targeting faith-based institutions, colleges/schools, and cancer advocacy groups.

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As an Executive Board member for the Metropolitan Chicago Breast Cancer Task Force and Chair of Public Policy for the Chicagoland Affiliate of Susan G. Komen for the Cure, Janice collaborated with Illinois lawmakers, numerous professionals and cancer advocates to ensure the successful passage of "The Breast Cancer Reduction Act of 2008."

Dr. Phillips' career as a nurse researcher, visiting scholar, academician, clinician, consultant and author includes service as an Assistant Professor at the University of Maryland School of Nursing, where she was the first African American nurse in the country to receive an American Cancer Society Oncology Nursing Professorship to advance understanding of breast cancer disparities among African American women. She has presented her work nationally and on six continents and her research findings continue to inform initiatives targeting minority, and underserved women.

From 1999-2004, Dr. Phillips served as a Program Director at the National Institute of Nursing Research (NIH), where she successfully implemented numerous initiatives to stimulate health disparities research and develop nurse scientists to conduct health disparities research in 20 majority and minority serving institutions.

Dr. Phillips holds a BSN from North Park College, an MS in Community Health from St. Xavier College, and a PhD in Nursing from the University of Illinois College of Nursing. She is active in numerous professional organizations, including the American Public Health Association, American Nurses' Association, American Academy of Nursing, Oncology Nursing Society and Sigma Theta Tau International.



Anne Willis, MA

*Director, Division of Cancer
Survivorship, Co-Director,
caSNP*

George Washington
University Cancer Institute

A long-term Ewing's Sarcoma survivor, Anne Willis, MA, is the Director of the Division of Cancer Survivorship at the George Washington University Cancer Institute (GWCI) and Co-Director of the GW Center for the Advancement of Cancer Survivorship, Navigation and Policy (caSNP). She co-chairs the GW Cancer Survivorship Task Force and oversees the cancer institute's Thriving After Cancer Program, which includes a survivorship clinic in collaboration with Children's National Medical Center and the GW Medical Faculty Associates that offers comprehensive multi-disciplinary care to adult survivors of pediatric cancer, survivorship patient navigation, educational seminars and workshops on a variety of practical issues. Anne co-directs caSNP efforts, including education and training programs for health care professionals, meetings on navigation and survivorship and health policy initiatives. Previous to GWCI, Anne was the Director of Survivorship Programs for the National Coalition for Cancer

Survivorship where she developed and disseminated evidence-based programs, including the award-winning Cancer Survival Toolbox[®], to empower people with cancer to advocate for themselves across the survivorship continuum.

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THE GEORGE WASHINGTON UNIVERSITY

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- Resources -

The following websites provide helpful information about health policy, cancer health policy and health reform.

American Enterprise Institute

<http://www.aei.org/ra/43>

Brookings Institution, Engelberg Center for Health Care Reform

<http://www.brookings.edu/health.aspx>

Cato Institute

www.cato.org

Center for the Advancement of Cancer Survivorship, Navigation and Policy

<http://www.gwumc.edu/caSNP/>

Center for the Advancement of Cancer Survivorship, Navigation and Policy National Health Reform Comparative Analysis Project

<http://www.gwumc.edu/caSNP/healthpolicy.html>

Commonwealth Fund

<http://www.commonwealthfund.org/Health-Reform.aspx>

GW Cancer Institute

<http://www.gwumc.edu/gwci/>

GW School of Public Health and Health Services, Department of Health Policy

<http://www.gwumc.edu/sphhs/departments/healthpolicy/>

GW School of Public Health and Health Services, Department of Health Policy and the Robert Wood Johnson Foundation

<http://www.healthreformgps.org/>

Heritage Foundation

www.heritage.org

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Institute of Medicine, National Cancer Policy Forum

<http://www.iom.edu/Activities/Disease/NCPF.aspx>

Kaiser Family Foundation

<http://healthreform.kff.org/>

Library of Congress, THOMAS

<http://www.thomas.gov/>

LIVESTRONG

http://www.livestrong.org/pdfs/3-0/LIVESTRONG_PolicyPlatform_2011

National Cancer Institute

<http://legislative.cancer.gov/history>

<http://legislative.cancer.gov/topics>

President's Cancer Panel

<http://deainfo.nci.nih.gov/advisory/pcp/pcp.htm>

Robert Wood Johnson Foundation

<http://www.rwjf.org/healthpolicy/>

U.S. Department of Health and Human Services:

<http://www.healthcare.gov/>

U.S. House of Representatives

www.house.gov

U.S. Senate

www.senate.gov

Urban Institute

<http://www.urban.org/health/index.cfm>

Additional Links to Health Policy Resources

<http://www.gwumc.edu/sphhs/departments/healthpolicy/about/links.cfm>

HEALTH REFORM, CANCER AND YOU

The Patient Protection and Affordable Care Act (ACA) is the most significant health law to impact cancer care in decades. Unfortunately, the majority of Americans are still confused about the law and don't understand how it will affect them personally.[1] This site is intended to help those affected by cancer understand how the law might impact them. For some, health reform will have no noticeable effects. For others, it will mean the difference between access to lifesaving cancer treatments or foregoing care. The difference will largely depend on one's insurance status before reform.

For each major insurance category, we have included brief summaries of the most significant changes as a result of health reform. Also, to help illustrate how one's experience with cancer care could vary as a result of health reform, we have included examples of three individuals affected by cancer, and how they fare both before and after health reform. In each case, a scenario under the current system will be described, followed by a portrayal of likely changes after implementation. While these stories are fictional, whenever possible, they have been informed by the experiences of actual cancer patients.[2]

A few of the most meaningful highlights of the ACA include:

- Insurance plans cannot deny coverage because of a pre-existing condition. For cancer patients this is a very important win. No longer can someone be denied insurance based on a previous diagnosis of cancer.
- Insurance plans cannot charge higher premiums for those with health conditions, such as cancer. Currently, people with chronic illnesses or diseases may face higher premiums because of their illness. This added cost can sometimes mean the difference between an affordable policy and one that is just too expensive.
- Insurance plans cannot drop someone's coverage just because they are diagnosed with cancer.
- More insurance options for those with low to moderate income. Low-income cancer patients are often the most vulnerable. By expanding Medicaid and providing tax credits to help purchase insurance, more needy cancer patients will have access to insurance coverage.
- No more lifetime limits on benefits. Annual limits on benefits will end in 2014.
- Placing limits on out-of-pocket costs for care. Even those with insurance often have a hard time paying for expensive cancer treatments. Starting in 2014, there will be new caps on how much someone has to pay out-of-pocket for their care.
- No more co-pays for recommended preventive cancer screening in new health plans and in Medicare.
- Health plans can't deny access to approved clinical trials and must help cover costs for participating in a clinical trial.
- Starting in 2014, US citizens and legal residents will be required to have health insurance or else pay a yearly tax penalty. [3] This is called the individual mandate. The penalty would start at \$95 or up to 1% of income (whichever is greater) in 2014 and would go up to \$695 or 2.5% of income by 2016. For families the limit would be \$2,085 or 2.5% of household income.

[1] Kaiser Health Tracking Poll, March 2011. Available at <http://www.kff.org/kaiserpolls/8166.cfm>

[2] It is important to note that many key policy decisions have yet to be made by federal and state government agencies involved in implementing the law. Details of implementation can also be influenced by the changing economic and political climate. The projections in these case studies are made to the best of our ability based on current understanding of the ACA and how its implementation is likely to unfold in the coming years.

[3] Exemptions will be granted for financial hardship, religious objections, American Indians, those uninsured for less than 3 months, undocumented immigrants, incarcerated individuals, those with incomes below tax filing threshold, and those for whom lowest cost plan is greater than 8% of their income.

Uninsured with Cancer

Those who are uninsured and have a diagnosis of cancer, or a history of cancer, are likely to gain the most from health reform. Lack of health insurance is a major barrier to obtaining cancer care and leads to worse outcomes. The Affordable Care Act makes significant changes that will expand coverage to the uninsured.

Young adults

If a cancer patient or survivor is younger than 26 years, they have the option now of staying on their parent's insurance plan until they turn 26. Young adults do not have to be students, live with a parent, or be claimed as a dependent on their parent's taxes. Young adults who are married can still be eligible, but not their spouse or children.

For those who need coverage now

Most of the major provisions in health reform take effect in 2014. For those cancer patients and survivors who need care now, health reform created the Pre-Existing Condition Insurance Plan, an insurance plan with reduced premiums for people who have medication-dependent conditions. To apply, you have to be a citizen or legal resident and be uninsured for at least 6 months. For more information, go to <http://www.pcip.gov>

Privately Insured with Cancer

Many cancer patients and survivors have private insurance they have purchased on their own or through their jobs. Health reform makes some important changes to insurance requirements. If implemented correctly, these changes should work to protect cancer patients from high out-of-pocket costs and ensure they get the care they need.

- Insurance plans cannot rescind, or drop, coverage because a person is diagnosed with cancer, or deny benefits needed to treat the cancer.
- Insurance plans have to provide more specific, easy-to-understand information on what they will, or won't, cover when you get sick.
- Those who have been denied claims will have the right to appeal.
- Those who carry a diagnosis of cancer can't be charged higher premiums just because of their medical history.
- There will be an annual cap on how much all individuals and families have to pay in out-of-pocket medical expenses.
- Extra assistance to reduce out-of-pocket expenses for those who have low to moderate income (income less than 400% of the federal poverty level [4]).
- Ends lifetime limits on care and benefits. Starting in 2014, annual limits will end.
- For some plans, reform will end co-pays for some recommended preventive services, such as mammograms for women aged 40 years and older, cervical cancer screening for women who are sexually active, and colorectal cancer screening for those aged 50 to 75.
- Beginning in 2014, many health plans will be required to cover certain basic benefits that will include recommended cancer screening, treatment and follow-up care. The specific benefits are still being determined.
- Beginning in 2014, plans cannot deny a cancer patient the ability to participate in an approved clinical trial and must cover routine costs in connection with the trial.

[4] For individuals, 400% FPL is \$43,320. For a family of four, 400% FPL is \$88,200.

Medicare

For cancer patients and survivors with Medicare coverage, health reform makes some important changes to coverage of preventive care and prescription drugs. Beyond this, health reform does not make many drastic changes to Medicare that directly impact cancer care.

Medicare Welcome Visit

When Medicare enrollees first join the program, they can receive a one-time preventive physical exam during their first year of coverage. This is known as the "Welcome to Medicare Visit" and is meant to help keep people on track with recommended health screening and a wellness plan. Health reform made this visit completely free to the patient by getting rid of co-pays.

There is also a new benefit called the "Annual Wellness Visit" for anyone who has been in Medicare for more than one year and if it's been more than one year since their "Welcome Visit." The co-pays are all waived for this visit as well.

Cancer Screening

As of 2011, there are no co-pays and deductibles for all cancer preventive services rated "A" or "B" by the US Preventive Services Task Force. This includes:

- Colorectal cancer screening for adults from age 50 to 75; Also there is no deductible for colorectal cancer screening tests, even when polyps are found and removed
- Mammography for women every 1-2 years for women aged 40 and older;
- Cervical cancer screening for women who are sexually active;
- Breast cancer chemoprevention counseling and BRCA counseling for women at high risk (actual genetic testing may not be included)
- Tobacco use screening and cessation intervention;
- Hepatitis B screening and immunization

Gap in Drug Coverage

Another important improvement for Medicare beneficiaries is the closing of the "doughnut hole" for prescription drug coverage. This is the gap in drug coverage that forces people in Medicare to pay the full cost of their prescriptions out of pocket. Sadly, more than a quarter of Medicare beneficiaries stop taking their prescription drugs when they hit the prescription drug coverage gap.

Beginning in 2010, seniors who enter the coverage gap will receive a \$250 rebate to help pay for medications. Beginning in 2011, drug companies are required to give a 50% discount on brand-name drugs filled by those in the doughnut hole. Eventually, with a combination of drug discounts and federal subsidies, the gap will be closed by 2020.

Medicare Advantage

The government will be reducing its support of Medicare Advantage plans offered by private companies approved by Medicare. Those who are enrolled in Medicare Advantage could eventually lose extra benefits that plans offer, such as hearing aids, eyeglasses, and gym memberships.

Medicaid

For many low-income cancer patients and survivors, Medicaid is not an option today. States run the Medicaid programs and have very strict rules that restrict who can be covered. Every state is different.

Starting in 2014, the rules will become much simpler. No matter what state a person lives in, if they make below a certain income, and meet certain citizenship requirements, they should be able to get Medicaid. **They would need to have an income less than 133% of the [federal poverty level](#).** [5]

Premium Assistance

If a person's income is higher than the Medicaid cutoff, they will have different options for getting coverage. Starting in 2014, they will be able to get financial assistance to purchase insurance. **They would need to have an income less than 400% of the [federal poverty level](#) to get help paying for premiums.** [6] The lower their income, the more financial help they can get.

Drops in coverage

Health reform specified that those currently enrolled in Medicaid could not be dropped from the program as reforms were being implemented. In particular, those women who were referred to Medicaid for breast or cervical cancer treatment after being screened through the National Breast and Cervical Cancer Early Detection Program cannot be dropped from Medicaid.

Because of tight state budgets, some governors and legislators have pushed to change the law and allow Medicaid to drop some enrollees in order to save on costs. These debates are ongoing.

Tobacco Cessation

Beginning in 2014, Medicaid programs will be able to cover FDA-approved drugs to help enrollees quit smoking, including over the counter products. Medicaid programs are now required to provide counseling and medication to pregnant women to help them quit smoking, at no cost to the patient.

Optional Coverage of Preventive Services

Medicaid coverage for cancer screening services varies by state. Unlike Medicare, there is no federal requirement that certain services be covered for those who are otherwise healthy. Health reform gives Medicaid programs the option to cover screening and preventive services recommended with a grade of A or B by the US Preventive Services.

[5] Based on the 2010 FPL, 133% is \$14,404 for individuals and \$29,326 for a family of four.

[6] For individuals, 133%-400% FPL ranges from \$14,404 to \$43,320. For a family of four, it ranges from \$29,326 to \$88,200.

Anne and Mark: Purchasing Health Insurance with a History of Cancer

Anne is a 29 year old pastor at a small church in Maine. She is single and the church's only employee. The church does not offer health benefits. Anne does not smoke and does not have any chronic conditions. As a healthy, young adult she is able to purchase coverage from a private insurance company in the individual market. The benefits are comprehensive with a \$5,000 annual deductible and a 20% coinsurance requirement for the next \$2,000 in covered medical expenses. Her monthly premium is \$140 or about 5.4% of her \$31,000 gross annual income (~285% FPL).

Anne is very active and enjoys hiking and kayaking. But over the last few months, she has become more fatigued than usual and notices she is not able to exercise as much as she used to. She attributes it to the stress of her job and an unhealthy diet. She tries eating healthier and begins to lose weight. But something still does not feel right to her. She is dropping pounds faster than she expected, and many nights of the week, she wakes up in the middle of the night drenched in sweat. One morning, Anne notices a small lump at the base of her neck and decides to see a doctor.

Pre-reform

After blood tests and a chest X ray, the internist informs Anne that she thinks Anne has lymphoma. She schedules a biopsy for a few days later which confirms the diagnosis. Anne is diagnosed with advanced Hodgkin's Lymphoma, a type of immune system cancer. Anne's life is turned completely upside down. She cannot believe that she is only 29 and has cancer.

Treatment

Fortunately, Anne's health insurance coverage enables her to access cancer care at a major medical center in Maine as well as consultations with specialists at a well-known cancer center in the Boston area. Anne undergoes 10 months of grueling chemotherapy and radiation treatments. By the end of her treatment, she has accumulated total out-of-pocket costs of \$14,000. She borrows the money to pay her medical bills and pays the rest from her savings. Anne has some savings and her parents, who live nearby, help support her.

Fortunately, the treatment is successful. By the end of it, her doctors tell her she is in remission and they are optimistic that she had beaten the cancer. Although the chemotherapy and radiation were incredibly difficult, Anne had no serious medical complications during treatment and was able to cope with the support of family, friends and her faith community. She managed to work throughout most of her treatment.

Anne was worried about her insurance coverage but was pleased to find that her monthly premiums did not dramatically increase as a result of her illness. However, because of the \$5,000 deductible, her annual out-of-pocket expenses were around \$2,600 each year for recommended follow-up physician visits and tests. She required blood tests, x-rays and CT scans for regular surveillance. Her insurance premiums, cost-sharing and medical loan payments total more than 20 percent of her gross annual income.

In remission

Four years later her oncologists say there is no longer any reason for Anne to continue seeing them as long as she has an annual check-up with her primary care doctor and follows age-appropriate cancer screening guidelines.

Anne begins looking for a new job. Her job as a pastor was becoming too taxing and she was afraid that the congregation was suffering as a result. She needed to be the one offering guidance and leadership to members of her congregation, but after the brain radiation treatments, she was having difficulty remembering details of what people told her and it was having a deleterious effect on her relationships. She also would get fatigued much more quickly than she had in the past and would experience short bouts of depression. She used to be able to do multiple home visits in one day but now just cannot manage the same schedule.

Through her sister, Anne finds a job in Missouri¹, working as an assistant program administrator at a nonprofit organization that outreaches to needy families and children. In this new role, Anne can support a cause she believes in but keep a lower profile and slower schedule than in her previous job. And after years of dealing with cancer and its effects, Anne is ready for a new life in a new city. She has almost finished paying off the loan she took to cover her medical bills and is ready to put this difficult chapter of her life behind her.

Anne moves to St. Louis near her sister's family. The full-time position at the nonprofit pays ~\$48,000 and does not offer any benefits. Anne assumes she will be able to

¹ Missouri allows elimination riders, no guaranteed issue, rescission allowed, Kaiser Family Foundation State Health Facts

purchase an insurance plan in the individual market as she had in Maine. She has been completely cancer free for four years now and feels she is in good health.

A Preexisting Condition

Anne begins shopping for health insurance in the individual market. This time though, she carries a past diagnosis of lymphoma, and must report her medical history when applying as part of the medical underwriting process. She applies to more than a dozen health plans and is promptly denied coverage by almost all of them because of her preexisting condition. Anne calls and argues with several of the plans stating that she no longer has cancer and has been in remission for years. She even provides a letter from her oncologist stating she is cancer free. But it does not help.

The only plan that offers her coverage quotes her a monthly premium of \$250 but adds an “elimination rider” which states that the plan will not cover any tests or treatment that may be related to her preexisting condition. For Anne, this plan is affordable but useless because the whole purpose of the insurance is to help pay for her periodic cancer surveillance tests and ensure access to care in case she were to have a recurrence. A visit for almost anything simple, like a common cold, could potentially be linked back to her cancer and be denied coverage.

Anne’s sister advises her to apply to Missouri’s high risk pool. The Missouri health insurance pool is a program run by the state to provide coverage for those who are unable to obtain coverage due to a chronic condition. Anne would be eligible for coverage through the program as someone who was denied coverage because of a history of a serious medical condition. But when Anne researches it, she finds that for a plan with a deductible of \$2500 the monthly premium is \$534. She simply cannot afford the premiums.²

Anne is desperate and begins to think she made a big mistake moving to St. Louis. She loves her job and being close to her sister, but no matter how hard she tries she cannot find affordable insurance. Without insurance coverage, Anne skips the recommended tests she knows she should have to monitor for cancer recurrence or side effects of her treatment because she cannot afford them. Anne remains uninsured and hopes and prays that she will stay healthy.

² <http://www.mhip.org/rates>

Post reform scenario

Anne in Maine's Individual Market

Once the ACA is fully implemented, Anne will likely still need to purchase health insurance on her own in Maine. The small church she works for would not be required to provide health insurance; although if they did provide insurance, they might be eligible to claim certain tax benefits. If Anne did not purchase her own insurance coverage, she would be subject to a monetary penalty.

Anne looks for insurance coverage through her state's insurance exchange and decides to go with a "catastrophic plan." She is eligible for this plan because she is under 30 and she prefers it to other plans because it is cheaper, as long as she stays well. The premium is \$140 per month and her deductible is \$5,950. The plan is still required to cover all essential health benefits, only after she reaches the deductible, except she gets 3 primary care visits covered before she reaches the limit. The plan includes an out-of-pocket limit of \$2,975 (one-half of the HSA limit for 200-300% FPL) that does not include the deductible.

Once she is diagnosed with lymphoma, she is still able to access the care she needs, including mental health coverage and follow-up lab and radiology monitoring tests, but the out-of-pocket costs are not insignificant. By the end of her treatment, Anne has accumulated total out-of-pocket costs of about \$9,000 for her medical care (about \$5,000 less than the original scenario). The out-of-pocket limit of \$2,975 above her deductible actually protects Anne from this increased liability.

Anne in the Missouri Market

When Anne moves to St. Louis, she is still not able to keep her current coverage—even though she is satisfied with it. She bought the plan through the Maine state health insurance exchange. The plan is not available in the state of Missouri, because Maine and Missouri do not share a multi-state compact to offer plans in both states.

However, after health reform, Anne has a much easier time finding insurance coverage in St. Louis. Anne goes to the Missouri state health insurance exchange website and searches for plans. The exchange lists three tiers of available plans—bronze, silver, and gold—based on the level of coverage and cost-sharing. Anne decides to go with a silver plan that's been rated highly for good quality and customer service and applies to several to compare quotes.

Anne receives a quote and offer of coverage from every plan to which she applies. Under health reform, the plans are no longer allowed to deny her coverage because of her history of lymphoma. The plans also cannot include elimination riders that exclude

coverage of benefits for conditions that could be related to her cancer history. Each plan is guaranteed to provide essential benefits like emergency services, outpatient visits, lab tests, radiology studies, and drug coverage.

For a silver plan, the average premium Anne gets quoted is \$319 per month. The estimated maximum out of pocket costs she is responsible for is \$6,250, not including the premium.³ Because her income (\$48,000) is over 400% of poverty, she is not eligible for any premium tax credits. She pays about 8% of her income into health insurance (annual premium \$3832).

Anne feels the monthly premium is a little higher than she would like but her income at the new job is higher and the maximum out-of-pocket expenses would not be too different from what she experienced in Maine. Anne feels confident in the quality and level of coverage of her insurance plan. She hopes she will not really need much medical care anymore, except for the routine surveillance. With good coverage, Anne makes sure she gets all her recommended appointments and tests.

Case #3 (continued) Part II

Pre Health Reform: Anne's story, Continued

Anne and Mark

When Anne moves to St. Louis, her sister introduces her to a friend named Mark and soon they begin dating. Mark works as a broker for an investment firm of over 100 employees that offers excellent health insurance benefits. Mark is concerned about Anne being uninsured and skipping her regular health check-ups. Although they planned to marry eventually, Mark and Anne decide to get married sooner, so Anne can join his insurance plan. Finally, through her husband's work, Anne gains access to an affordable, comprehensive family health plan. Because Mark's employer purchases insurance through the small group insurance market, the plan cannot deny Anne coverage because of her cancer history.

For an employee contribution of \$300 a month, Anne and Mark can now be covered by a plan with comprehensive health benefits--a \$750 individual deductible with a maximum family deductible of \$1,500 and a 20% co-pay for outpatient physician visits. However there is one caveat. Because Anne did not have continuous health insurance coverage, when she joins Mark's plan, the health plan informs her that they will not cover any care related to her lymphoma for 12 months after enrollment. This is called a "preexisting condition exclusion period." Anne does not think this is fair and wants to fight it, but

³ (<http://healthreform.kff.org/SubsidyCalculator.aspx>)

Mark talks with an insurance broker, who says the plan is in compliance with federal and state laws and it is unlikely that they will win. They have no choice but to pay out of pocket for Anne's health care for one more year.

COBRA

Several years later, the economy begins to falter and Mark, along with many others in his company, is laid off. Fortunately for the family, Mark's dream had always been to start his own small business. He has been aggressively saving and has enough to support his family for at least two years.

After losing his job, Mark wants to make sure that his family has good health insurance coverage, so he elects to purchase COBRA health benefits coverage for the family. Without his employer paying the majority of the premiums, the family must pay the entire cost which is significantly higher at \$1,150 per month.

As the 18 months of COBRA benefits coverage nears its end, Mark contacts his insurance broker. His broker tells him that the main issue for the family in finding coverage will be Anne's cancer history. In order to purchase a similar set of covered services for the same amount of money he was paying for COBRA continuation, he would need to purchase a plan with substantial out of pocket costs.

After much discussion, Mark and Anne choose a plan. Each member of the family is subject to a \$5,000 deductible with a maximum family deductible of \$10,000. After the deductible is met there is a 20 percent coinsurance requirement for the next \$5,000 in covered services. Unlike Mark's employer-based group plan, neither dental nor vision services are covered. Mental health coverage is minimal. Premiums total \$1000 each month and increase by 7-15 percent each year that Mark and Anne are covered by the policy.

Another cancer

Two years later, ahead of schedule, Mark's business begins to show a profit. The same year, both of their children are diagnosed with asthma. Then, on a screening mammogram, Anne is diagnosed with early breast cancer (Stage I). Anne is stunned to hear that she has cancer again. Memories of the grueling chemotherapy treatments flood back. Her doctor tells her that ironically the treatments for her lymphoma put her at higher risk for subsequent cancers like breast cancer.

Fortunately, the breast cancer was caught early and requires only a lumpectomy and no further treatment. Anne is relieved and thankful that she had the mammogram done. She schedules the surgery and everything goes well. But with the surgery and the children's asthma, family expenses for health insurance premiums and out-of-pocket costs total

\$24,000 that year. The following year, they total \$29,000. The family's savings and initial business profits are rapidly being consumed by medical expenses.

Bankruptcy

When the economy takes a turn for the worse, Mark's business begins to face serious struggles. Meanwhile the health care bills keep coming. They use up all their savings and even sell their home and move into a small rental. Finally, Anne and Mark close their business and are forced to declare bankruptcy. Mark begins looking in earnest for full-time employment. Mark's dreams of owning his own business are over. He concludes that the only way to protect his family is to find a job that provided employer-based group health insurance benefits.

Anne and Mark both feel that the direction of their professional and personal lives has been controlled by their need to find and keep affordable health insurance that meets the basic needs of their family. With current medical treatments, Anne was able to beat back two different cancers, but the health care that enabled her to survive cost her family their home and their financial security.

Case 3B- Post reform

Anne and Mark

Once Anne and Mark get married, Anne and Mark must decide whether Anne should join his plan or stay with her individual plan purchased through the exchange. For Mark, unless the plan offered by his company is unaffordable, he is not allowed to purchase a health plan through the state exchange. They realize it is cheaper and easier anyway for Anne to join Mark on a family plan provided through his employer.

Previously, Anne had to wait 12 months before she could see any benefits through Mark's company plan. Under health reform, the maximum waiting period that any plan can impose is 90 days. Anne is pleased to find that there are no exclusions of coverage for care related to her prior history of cancer. For the family, this means they can use the reproductive health benefits of the plan to help cover some of the costs of in vitro fertilization. After health reform, their coverage--\$300 per month premium with the deductible of \$1500 is about the same as it was before health reform.⁴

Mark gets laid off

The ACA preserves COBRA coverage. After losing his job, Mark signs up for COBRA to maintain their coverage through his former employer for a maximum 18 months. Anne

⁴ CBO letter estimate—add reference here

begins working part-time and Mark does some freelance consulting while he works to get his business off the ground. Their combined household income is \$60,000 (about 250% of poverty). The COBRA monthly premium of \$1,150 takes a sizable bite out of their income. Mark and Anne begin exploring other insurance options through the exchange.

Back in the Individual Market through the state Exchange

Mark and Anne go to the state exchange website and call a navigator to ask for advice on insurance plans for the family through the exchange. The average premium for a family of four for a Silver plan is \$11,384.⁵ Fortunately, they find out they are eligible for a premium subsidy which covers more than half of the premium, so the amount they are responsible for is \$4,937 annually, or about \$411 per month. Because of their lower household income, the total out-of-pocket limit for the family is also reduced at \$6,250 (includes deductible but not premium).

The exchange plan they purchase does not include dental or vision services for Mark and Anne, but provides these services for their two boys. The plan does include mental health coverage. Each year, the premium for their plan increases, but only by about 5%. They receive documents from their plan each year detailing why the premium increase is happening. These premium increases do not significantly impact Mark and Anne however. Because unless their household income increases, the government tax credit ensures that they do not pay more than 8.2% of their income into their insurance premiums.

As Mark's business begins to grow and pull in a profit, their household income increases. The following year, their income has grown to \$75,000 or about 320% of poverty. Because their income is higher, the amount of their government subsidy decreases to cover about 39% of the premium. Their monthly premium rises to about \$593 for the same plan and their maximum out of pocket cost limit increases to \$8,333.⁶

Out-of-pocket spending protections

The year that Anne gets diagnosed with her second cancer and the boys are diagnosed with asthma, the family reaches their out-of-pocket cost limit with the frequent visits to the ER for the boys and Anne's lumpectomy. Together with their total premium, they spend about \$15,500 on health care in one year or more than 20% of their income. While this is still a significant portion of the household income, it is much lower than it would have been without the out-of-pocket limits.

⁵ Add CBO estimate

⁶ KFF subsidy calculator

When the economic recession reaches its worst, Mark's business cannot support the family's current lifestyle. They downsize their home and scale back on nonessential costs. During the next open enrollment season, Mark and Anne decide to change their plan to a platinum-level plan—which has a higher monthly premium of \$750 but lower deductible and co-pays. The plan protects them better and they end up spending about \$10,000 total or about 13% of their income on health insurance. Still, it is a sizable portion of their shrinking household income.

Mark and Anne continue to fall deeper into debt, albeit at a slower pace. They may have postponed bankruptcy for another year or two, but it still seems like the only way they will ever get out of debt.

Issues Summary

Anne and Mark's case was developed to illustrate the complex, long-term challenges that can face cancer survivors and their families as they attempt to purchase and maintain affordable health care coverage in the health insurance marketplace.

Anne's case illustrates the following issues which cancer survivors can face:

- Denials of coverage in the nongroup, private insurance market due to a preexisting condition
- Very high insurance premiums due to a preexisting condition
- Offers of insurance coverage with “elimination riders” that exclude coverage of care related to preexisting condition
- High risk pools with premiums that are unaffordable
- forgoing needed care due to cost, uninsured, underinsurance
- Long-term complications or health problems, including other cancers
- Difficulties in insurance portability
- Look back periods and preexisting condition exclusion periods
- Burden of cancer on small businesses, particularly during the economic downturn
- Medical bankruptcy
-

Cancer patients in the individual market

Currently, the individual insurance market is regulated at the state level. The rules for insurance plans vary a great deal from state to state. For example, in states like New York, insurers are required to offer coverage to people who apply regardless of their prior health history. This is referred to as guaranteed issue. However, the vast majority of states do not require insurers to adhere to guaranteed issue. When Anne resided in Maine, state regulations prohibited her insurance plan from dropping her coverage when she was diagnosed with cancer and from raising her rates because of her health condition. Once she moved out of state and had to look for new coverage, the rules changed. As a

new customer in Missouri searching for insurance, plans were allowed to deny her coverage because of her health history.

This is the reality for many cancer survivors who cannot access employer sponsored coverage and are not eligible for public programs like Medicare or Medicaid. In most states, they are not able to obtain coverage through the individual market. When they are able to obtain coverage, the premiums are often prohibitively high. There are regulations that govern how insurers set their premium rates, but again, these vary from state to state. Some states limit insurers by restricting rate variations to factors like geographic area, age, or sex. Other states have no limits on insurance rate setting at all, and in those states insurers can price premiums much higher for those who have a history of serious health conditions, like cancer.

In Anne's case, the one plan that offered her coverage in Missouri also placed an elimination rider on the plan that effectively barred her from any coverage that was related to her cancer—virtually all the care that she might stand to need. About 37 states do allow elimination riders in the individual insurance market currently.⁷ Many states also allow a similar practice called rescission, in which insurers can look back into an individual's health history for information that suggests a medical condition was present prior to coverage and hence deny a claim associated with that condition.

Cancer survivors like Anne without employer-based or public insurance would likely not be able to obtain affordable, quality insurance in the individual market, and as a result, may forgo recommended care. Health reform stands to have the biggest impact on this group of cancer survivors. The ACA expressly prohibits insurance plans from denying individuals coverage because of a preexisting condition, from setting premiums based on their health history, and from dropping coverage or refusing to cover care that is related to a prior health condition. These measures effectively end insurance practices that discriminated against people, like Anne, with a history of cancer, whether they are in active treatment for the condition or not.

State Exchanges

Each state will set up an insurance exchange where customers can easily compare and purchase insurance. The exchange is designed to increase quality and competition among insurance plans and to be consumer friendly. It is also the way that premium subsidies will be administered. When Anne moves to St. Louis, the state exchange enables her to purchase insurance with the help of a premium subsidy in the form of a tax credit, so that she can access quality health coverage that costs about 8% of her income. This change is

⁷ <http://www.statehealthfacts.org/index.jsp>

critical in that it allows Anne to continue to afford coverage for the care she needs in the post-treatment phase.

When Anne marries Mark she becomes eligible for coverage through his employer in the small group market. Currently, the small group market is much more highly regulated than the individual market, with federal and state laws that protect consumers in the small group market to a greater extent than in the individual market. Insurers in the small group market are already prohibited from denying coverage based on preexisting conditions and from varying rates based on health status⁸. This is why even before health reform, Anne is able to get health insurance coverage through Mark's employer despite her lymphoma history. However, insurers in some states currently can use a look-back period and a preexisting condition exclusion period to deny coverage of care related to a preexisting condition for up to 12 months.⁹ Health reform changes this by shortening any waiting periods for benefits to a maximum of 90 days.

Health reform will make the individual market look more like the small group market. The ground rules that protect consumers in the small group market will be standardized and extended to the individual market. Insurers in either market who wish to sell plans through exchanges will be required to abide by guaranteed issue and renewal, will not be allowed to use health status to determine premiums, and cannot use elimination riders or rescissions to deny coverage. Each plan must cover the essential benefits outlined in the ACA.

COBRA

When Mark loses his job, he is able to keep his coverage through COBRA. Health reform does not change or eliminate COBRA. People will still be eligible for COBRA benefits for up to 18 months after a qualifying event, such as job loss. However, the cost of COBRA coverage, as illustrated through this case, is still likely to be much higher than the employee contribution alone.

Health reform will offer more options to people who have lost their jobs. As this case illustrated, families will be able to purchase insurance through state exchanges where

⁸ The federal law HIPAA, the Health Insurance Portability and Accountability Act, outlined these rules for the small group market in states.

⁹ Look-back period is the period of time before purchase of a policy that an insurer can examine for evidence of a pre-existing condition. A pre-existing exclusion period is the amount of time an insurance plan may require someone to wait before they will begin covering a pre-existing condition. Under current HIPAA rules, the maximum exclusion period is 12 months.

they may be eligible for tax credits and cost-sharing limits that help protect them from the high cost of insurance when it is not employer-sponsored.

Although health reform helped in this case, it did not guard against financial hardship. Once Anne is diagnosed with breast cancer and their children develop problems with asthma, the family medical expenses skyrocket. Even with the out of pocket limit and premium subsidies, Mark and Anne are still exposed to significant financial liability, with anywhere from 13-20% of their income going to medical expenses. In a poor economy, it would not be unrealistic for Anne and Mark to still see bankruptcy as their best option for getting out of debt.

Brenda Williams: Privately Insured with Breast Cancer

Brenda Williams is a 45-year-old human resources assistant manager who lives in Pittsburgh. She has been with her current employer, a large manufacturing company for nearly 10 years. She is a single mother with two children, Matthew, age 12 and Brianna, age 9.

Her annual income is \$45,000. Brenda has only \$1,000 in savings—she spent most of her savings on legal fees from her divorce two years ago—but she also carries no debt. As a single parent, she is very careful with her finances and rarely spends out of her budget. Monthly expenses for the family total about \$3,500, including a modest 2-bedroom rental, food, child care, transportation, taxes and health insurance.¹ Her ex-husband is currently unemployed, not involved with the children, and does not contribute child support.

Pre-reform

Brenda feels that she has always had good health insurance through her job. The comprehensive health benefits are one reason she has tried hard to keep her job at her current company. She pays the employee share of the monthly insurance premium which is about \$280 per month for a PPO with family coverage. The plan is self-funded.²

Her annual deductible is \$1500, which includes what she spends on her children's care for the year. To see a primary care physician, there is a \$20 co-pay. For an office visit with a specialist, there is a \$40 co-pay. If she gets admitted to the hospital, she must first meet a separate hospital deductible of \$700; then she is responsible for 20% of the costs. For outpatient surgeries, she must meet a separate outpatient surgery deductible of \$1,000; then she is responsible for 20% of the costs. The plan has an out-of-pocket limit

¹ epi.org basic family budget calculator http://www.epi.org/content/budget_calculator).

² In self-funded plans, the employer assumes direct financial responsibility for the cost of enrollees' medical claims. The Employee Retirement Income Security Act of 1974 exempts self-funded plans from state insurance laws including reserve requirements, mandated benefits, premium taxes and consumer protection regulations. Covered workers in large firms are more likely to be in self-funded plans.

of \$6,000 per year, which includes the deductible, but does not include office co-pays or prescription drugs (estimates derived from EBRI KFF).

Brenda tries to take good care of herself by exercising regularly and watching her diet. She does not smoke or drink. She has both a family doctor and a gynecologist. She sees her family doctor for high blood pressure for which she is prescribed blood pressure medications. She sees her gynecologist for annual PAP smears and mammograms. Her health plan covers these primary and preventive care office visits before the deductible is met, but she is still responsible for the co-pays and some cost sharing for tests. Her children are both healthy with no chronic conditions, except Brianna has seasonal allergies. Last year, Matthew broke his wrist playing basketball and she had to take him to the ER and to follow-up orthopedic visits.

Since her mother was diagnosed with breast cancer 5 years ago, Brenda has tried to be diligent about getting her annual mammograms. But with all the turmoil around the divorce and the legal fees, she missed her screening mammogram and primary care appointments for the past three years. She had no concerning symptoms, which is why, this year, when she finally has her mammogram, she is stunned to learn that the test revealed abnormalities.

Work-Up and Treatment

Her gynecologist refers her to a breast surgeon who sees her a few days later and orders follow-up mammography, a bilateral sonogram and a core biopsy. The biopsy reveals invasive ductal carcinoma in the left breast, the most common type of breast cancer. Because there is evidence of cancer throughout the breast, the surgeon recommends a total mastectomy with removal and testing of the lymph nodes.

Brenda is devastated. She feels utterly alone, anxious, and helpless. She is scared for her two children. She dreads telling them, especially Matthew, who had a difficult time with the divorce and now will have to cope with this added stress. Brenda also knows she does not have a financial safety net to handle this crisis. She has to keep working as much as she can to maintain her family's income and hope that her insurance plan adequately protects her family from the medical expenses.

Brenda schedules her mastectomy for two weeks later. Waiting for the surgery was difficult for Brenda. Although Brenda did have some family members and friends in the area, she kept most of her anxiety and fears to herself. She did not want to frighten her children or overburden her friends and family.

The surgery proceeds without complications. However, the pathology results reveal that more than a few lymph nodes showed signs of cancer (Stage III). She will have to undergo aggressive chemotherapy and radiation treatments. She plans for a breast

reconstruction but decides to delay it for now.³ She has already exhausted her sick leave and has to minimize her time away from work. She looks into temporary disability but it does not pay her full salary and she needs all her income to support her family. She decides not to take it. She is grateful when her coworkers donate some sick leave and vacation days to her.

Brenda has an indwelling catheter placed and undergoes several cycles of chemotherapy. She battles cycles of nausea, vomiting, and fatigue, and struggles to keep working. Meanwhile the bills begin to mount. Brenda quickly reaches her \$1500 deductible, and with the separate inpatient deductible and hospital charges for her surgery she reaches her \$6,000 out of pocket limit in a little over 2 months. By then, her meager savings are gone and she is already nearly \$8,000 in debt due to medical costs, lost wages, extra child care, and transportation costs. Much of the extra expenses are on her credit card or borrowed. She feels relieved that now that she has reached the out of pocket limit, she can begin to pay off her debts/ the balance.

Denials

Finally, Brenda completes the course of chemotherapy and has follow-up CT and PET scans. Unfortunately, the cancer cells have not responded well to the treatment and there seem to be signs of spread to more lymph nodes. Brenda is crushed. She had so hoped for a good outcome and to be finished with chemotherapy. Her oncologist recommends switching to a different chemotherapeutic agent.

Several weeks into treatment with the new chemotherapy regimen, Brenda receives a notice from her insurer that they have denied coverage for one of the new drugs in the regimen because they do not feel it is medically necessary. Additionally, Brenda finds she is still responsible for out-of-pocket expenses for some anti-nausea medications given with the chemotherapy. The out-of-pocket limit apparently does not include Brenda's share of prescription drug costs. Altogether, these charges total over \$3,000.

Brenda is angry at the insurer yet feels powerless. She cannot afford these extra charges—to pay down her bills with her reduced income she already cut out after-school lessons for her children, canceled expenses like cable and Internet, and can barely cover rent and food. Her son is doing poorly in school and she cannot afford child counseling since it is not covered by her insurance plan. She begins filing an appeal with her insurance company.

³ Coverage of the breast reconstructive surgery is required by federal law, the Women's Health and Cancer Rights Act, which states that group health plans that cover medical and surgical costs for mastectomy must also cover breast reconstruction.

Out of network

She talks to one of her coworkers, a breast cancer survivor who recommends that she see an oncologist at a tertiary care center for a second opinion. The physician is out of her insurance network, which means she will have to pay extra out of pocket (not included in her out of pocket limit) but she decides to go anyway.

The doctor tells her about a clinical trial that could potentially help her, but she is afraid of extra costs if she enrolls. He ensures her the trial would cover the cost of the drug and any extra tests needed. However because her insurance plan would consider the treatment experimental, the plan may not cover the costs of routine care like hospital stays or office visits that they would have covered if she was not in the trial. She just cannot afford to be exposed to the extra cost. She would also have to travel farther and take more time off work to participate in the trial. She decides not to participate in the trial. She returns to her primary oncologist and asks her to help her with the appeal or choose a drug regimen that would definitely be covered by her plan.⁴ Unfortunately, after many months of fighting, Brenda's appeal is denied. She is informed by the insurer that the decision is final and she has no further recourse. Covering these costs will leave her nearly \$12,000 in debt, despite having health insurance. She has already withdrawn funds from her 401(k) to cover expenses. Her savings are exhausted. Friends and family have tried to help her financially but it is not enough. Being a single mother of two makes it especially hard on Brenda. She worries constantly about the cancer, her children and her family's finances. She is referred to a mental health specialist to help her cope with anxiety and depression, but she decides not to go because the additional co-pays are not included in the out of pocket limit. Brenda is engaged in a battle for her life, but she feels as if her hands are tied because of her financial constraints.

After reform

After implementation of the Affordable Care Act, Brenda and her family are still covered under her employer's health insurance plan. As a large company with more than 200 employees, the employer is required to pay a fine if their workers seek coverage outside

⁴ When a health plan decides that the care a patient or their doctor wants is not medically necessary, or limits the care in some way, or denies payment for the care, the potential for a dispute with the plan arises. Consumers have certain rights under state and federal laws that they can exercise if they disagree with a decision their plan makes about medical coverage. These rights apply to both the "internal review" process and "external review." An internal review is an appeals process that stays inside the health plan. An external review is a process outside of the health plan to provide an objective way to resolve disputes between patients and their plans. The rights depend on the type of health plan the person has and which state they live in. Source: A Consumer Guide to Handling Disputes with Your Employer or Private Health Plan, 2005 Update, by Consumers Union and Kaiser Family Foundation.

of work and receive federal aid in the form of premium tax credits. The employer is also required to automatically enroll their employees into an offered health insurance plan. Neither of these new provisions impact Brenda.

Brenda's premium is still \$280 per month for family coverage.⁵ The employee share of her premium (\$3,360 per year) is about 7.5% of her income (assuming her income is still \$45,000). Therefore, according to the new law, she is not eligible for subsidies to help pay her premiums.⁶

One change Brenda notices with her insurance after health reform is that for the first time ever she receives a description of benefits for her plan that she can actually understand.⁷ The description was clear and outlined exactly what she was responsible for paying and what benefits would be covered and what would not be. It helped to have this description to refer to. Brenda learns she does not have to pay anything for her screening mammogram because her plan is not a "grandfathered plan" and is required to comply with other measures in the Affordable Care Act.⁸

She is glad she is not required to pay any out-of-pocket costs for the mammogram. But the main barrier for her to get the test done is the stress of working full-time and being a single parent of two children. She is still not able to make it to her regular doctor for her check-ups and screening mammograms. That is why Brenda is pleasantly surprised to find out about an expansion of her company's annual employee wellness fair to include on-site mammography for the first time.⁹ Because this is a recommended screening test

⁵ According to Congressional Budget Office estimates, in the large group market, which is defined here as consisting of employers with more than 50 workers, the legislation would yield an average premium per person that is zero to 3 percent lower in 2016 (relative to current law). Those overall effects reflect the net impact of many relatively small changes, some of which would tend to increase premiums and some of which would tend to reduce them. Thus, we are assuming the premium stays about the same.

⁶ Employees who are offered insurance through their work but whose share of the premium is more than 9.5% of their income are potentially eligible for premium credits through the exchanges.

⁷ Section 2715 of the PHS Act requires development of a standardized, easy-to-understand format for plan benefits and coverage summary. The language must be understandable by the average plan enrollee and cannot exceed 4 pages in length. The summary must also include a coverage facts label that includes examples for common benefits scenarios and related cost sharing

⁸ Preventive regulations: Interim Final Rules for Group Health Plans and Health Insurance Issuers Relating to Coverage of [Preventive Services](#) under the Patient Protection and [Affordable Care Act](#)

⁹ ACA provides for funding to states for prevention and wellness efforts and expands CDC's ability to assist employers with wellness programs

for Brenda, she pays nothing for the mammogram and is able to have it done conveniently while on her lunch break.

When Brenda receives the devastating news of her cancer diagnosis, one of the first things she does is return to her insurance plan benefit description. She remembers reading in the plan a description of what would be covered for someone diagnosed with cancer. She can hardly believe that she now falls into that category. She would never have predicted when she last looked at her insurance information that cancer is what she would be dealing with now.

The benefits summary states that based on her income, the out-of-pocket limit for her family is \$5,950.¹⁰ She also notes that the plan covers prescription drugs, mental health services, rehabilitative and habilitative services and devices. This includes breast reconstructive surgery and basic prosthetics. It is not clear from the plan description which chemotherapeutic agents her plan will cover.

When Brenda fails to respond to the first chemotherapy treatment and begins the second treatment with the newer more expensive drugs, she encounters the same problem. The plan informs her that one of the new drugs will not be covered. The plan also sends her information on how to appeal the denial of coverage. Brenda's oncologist's office helps her to file the internal appeal with her insurer as an "urgent care" issue so that she receives an answer back within 72 hours.¹¹ The insurance plan upholds the denial but is required to provide detailed information on how to pursue an external appeal. This will involve review by an independent body assigned by the state and expedited review if she qualifies as an urgent claim. Brenda works with her oncologist to pursue the external appeal and is hopeful that she will get the new chemotherapy drug covered.

In the meantime, Brenda's oncologist recognizes the tremendous stress and anxiety Brenda faces and strongly urges her to seek help. She tells Brenda she is at high risk for depression and so are her children. Because this is a covered benefit and she has already reached her out-of-pocket limit, Brenda agrees to begin seeing a mental health specialist.¹² She also arranges for family counseling for her children. Brenda is prescribed antidepressants which help her to cope with her constant anxiety.

¹⁰ Assuming one-half of the maximum out-of-pocket limit for Health Savings Account-qualified health plans \$11,900 for family coverage in 2010

¹¹ PHS 2719; Regulation: Interim Final Rules for Group Health Plans and Health Insurance Issuers Relating to Internal Claims and Appeals and External Review Processes under the Patient Protection and Affordable Care Act

¹² Under Sec 1302 of the ACA, health insurance plans must provide essential health benefits, which include mental health care.

When Brenda's coworker suggests she meet with another oncologist for a second opinion, she learns that she will still have to pay additional co-pays for the out-of-network visit. Brenda wants to enroll in the clinical trial recommended by the second oncologist. Under ACA, her insurance plan cannot prevent her from participating in the trial. Her plan also tells Brenda they will pay for routine patient costs for items and services that they would have paid for her regardless of whether she was enrolled in the trial. They will not pay for the trial drug and any services that are specific to the trial, but those expenses are covered by the trial anyway. Brenda is excited and tells the team she would like to enroll. It is farther and more inconvenient, but she is hopeful that she will do well in the trial.

The next day, the doctors call Brenda to tell her that her insurer is asking her to participate in the trial through an oncologist in her network. She can enroll through the tertiary center but the plan is not guaranteeing they will cover all routine costs because they are out-of-network. Brenda returns to her primary oncologist and asks if she can access the trial through her office. While Brenda's oncologist is not participating in the trial, fortunately, she is able to find a colleague who is in-network and who can help get Brenda into the trial. Although she will have to travel farther to the new oncologist to access this treatment, she is relieved that her plan will cover it at all.

Ultimately, with the benefit of an external review, Brenda's appeal of her insurance denial is returned in her favor. By that time, Brenda has already enrolled in the trial and after discussions with her oncologist decides not to return to the disputed chemotherapeutic plan. However, the decision still helps her since the insurer must now cover more than \$2,000 in drug costs that she would have been otherwise responsible for.

Brenda is still nearly \$10,000 in debt, despite having health insurance. She is feeling better overall because she is in a clinical trial and is receiving mental health treatment, but financially, the cancer has still taken a significant toll. Being a single parent and having breast cancer has made it extremely difficult to make ends meet, even with her employer-sponsored health insurance.

Analysis

Like Brenda, 70% of cancer patients who are under the age of 65 have private health insurance, usually through their employer.¹³ However, having insurance does not guarantee one is protected from the high costs of cancer care. Cancer treatments are

¹³ Thorpe KE and Howard D. "Health insurance spending among cancer patients." *Health Affairs*. 2003;W3-189.

expensive and lengthy, and the cost-sharing that is incurred through deductibles, co-pays, and co-insurance can quickly become burdensome.¹⁴ Insurance plans may not cover recommended treatments or out-of-network providers, leaving the patient to shoulder the bulk of these costs or forgo treatment. Some insurance plans also specify annual or lifetime benefit limits that can be maxed out over years of cancer treatments and surveillance.

Individuals with cancer must also deal with the indirect costs of their illness in terms of lost wages due to loss of employment, lost productivity or reduced hours. Other costs associated with treatment include prosthetics and wigs, transportation to and from treatment sites, lodging, and child care. Regardless of the success or intensity of efforts at federal health reform, these costs are not affected and weigh heavily on patients, greatly affecting the process and, sometimes the outcomes, of care.

Brenda's case illustrates several issues common to cancer patients with employer-based insurance:

- High out-of-pocket costs of treatment that lead to growing medical debt.
- Separate deductibles for different types of treatment.
- Insurance coverage denials or restrictions for therapies or clinical trials.
- Out-of-Pocket costs incurred by seeing out-of-network providers who may be experts in their field for a particular type of cancer or treatment.
- Obligation to keep working through treatment to maintain health insurance and income.
- Lack of psychosocial support and/or mental health evaluation and treatment.
- Stress associated with financial liability.

After health reform, Brenda's situation is not all that different from her situation prior to reform. One reason is that Brenda is already covered by a comprehensive health plan issued by a large employer. Many large employer plans are already in compliance with the insurance reforms contained in the law. Another reason is that one of the provisions of health reform explicitly preserves an individual's right to maintain their existing coverage.¹⁵ If someone like Brenda was covered by a plan in effect on the day the new law passed March 23, 2010, then the plan is considered a "grandfathered plan." The ACA requires many changes to insurance plans, but all of these do not necessarily apply to plans that are grandfathered. If a plan loses their grandfathered status, then they will be subject to the new rules for insurers. The Obama administration has projected that

¹⁴ Kim P. "Cost of cancer care: the patient perspective." *Journal of Clinical Oncology*. 2007;25:228-232.

¹⁵ ACA§1251

between 39-69% of employer groups plans will give up their grandfathered status by 2013.¹⁶

In this case study, Brenda had comprehensive health insurance prior to health reform because it was offered to her as a full-time employee at a large company. We assume that she will keep her coverage post-Reform and that the plan will not have grandfathered status.

The employee share of her premium is not expected to change significantly.¹⁷ Her plan, like most employer plans included an out-of-pocket limit of \$6,000. Under the ACA, Brenda and her family would also have a similar out-of-pocket limit of \$5,950 (based on 2010 tax estimates). This out-of-pocket limit should include deductibles, coinsurance, copayments or similar charges. Whenever there are out-of-pocket expenses that are not counted toward the out-of-pocket limit, the expenses would likely have a significant impact on Brenda's finances.

As far as benefits, the ACA defines an essential benefits package for insurance plans which includes broad categories of services.¹⁸ This package is designed to be equal to the scope of benefits under a typical employer plan. Thus, we would not expect Brenda's covered benefits to be drastically different under ACA. The specific details of what should be covered under each category of service and how to judge whether insurance plans are meeting these requirements is still being decided. However, one category of benefit that is often underinsured in group plans is mental health treatment. In cancer care, mental health evaluation and treatment is critical. No one knows yet how much mental health care will be required to be covered by new health plans.

Another major change in the ACA is the additional right for consumers to appeal insurance plan decisions. Prior to health reform, laws governing appeals rights were primarily at the state level. In 45 states, insurance plans that were subject to state insurance laws had to allow for external review of appeals decisions.¹⁹ However,

¹⁶ Interim Final Rules for Group Health Plans and Health Insurance Coverage Relating to Status as a Grandfathered Health Plan Under the Patient Protection and Affordable Care Act

¹⁷ Congressional Budget Office "An Analysis of Health Insurance Premiums Under the Patient Protection and Affordable Care Act," November 30, 2009

¹⁸ ACA essential benefits reference

¹⁹ AHIP Center for Policy and Research, An Update on State External Review Programs, July 2008; New laws in Idaho and Illinois give patients the right to an independent review of health insurance benefit denials, <http://www.doi.idaho.gov/consumer/ExtReview/welcome.aspx>. Only five states (Mississippi, Nebraska, North Dakota, South Dakota, and Wyoming) have no laws mandating external review of insurance denials.

insurance plans that were self-insured did not necessarily have to comply with state insurance laws about external review. Under the ACA, grandfathered health plans must follow new regulations setting tight standards around internal and external review of decisions. In addition, the ACA establishes a \$30 million grant program to strengthen consumer assistance offices in states. In many states, external review overturns the initial decision in ~45% of cases.²⁰ Under the ACA, Brenda was clearly ensured an external review which ultimately, in this case, did overturn her initial denial of coverage.

Finally, the ACA requires health plans to cover routine patient costs associated with their participation in approved clinical trials. After 2014, plans are prohibited from denying an individual participation in an approved clinical trial and denying or limiting coverage of routine patient costs provided in connection with the trial.²¹ The plan is not required to pay for the investigational drug or service itself, but it will be required to pay for routine costs which include items and services covered for an individual not enrolled in a clinical trial. However, a plan may require the individual to participate in a trial through an in-network provider. Before reform, Brenda is deterred from participating in a trial because of concerns about routine costs. After health reform, Brenda can feel confident knowing that her regular care costs will still be covered by her plan even when she is enrolled in a trial, with the caveat that her plan requires her to enroll through an in-network provider.

The insurance reforms under health reform that apply to new plans (non-grandfathered) do help Brenda gain access to benefits that were difficult prior to health reform. However, fundamentally she still has the same level of financial liability that she did before health reform. For a family that is low to middle income, especially with a single parent, a diagnosis of cancer still means financial struggles even after health reform.

²⁰ Kaiser Family Foundation, *Assessing State External Review Programs and the Effects of Pending Federal Patients' Rights Legislation*, 2002. <http://www.kff.org/insurance/externalreviewpart2rev.pdf>.

²¹ ACA §10103 or PHSA §2709

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Hector Gonzalez: Uninsured with a Diagnosis of Cancer

Hector Gonzalez is a 55 year-old carpenter in a small town in northwest Texas. He has lived in Texas for almost 30 years and is a naturalized US citizen. He takes great pride in his work and in his financial independence. He is married and has two children. His wife, Maria, works part-time, his eldest daughter, Christina, is in college at a state university. His second daughter, Sophia, attends public high school.

Their household income is \$55,000 per year, which is about 250% of the federal poverty level for a family of four.¹ They have \$6,000 in savings. Monthly expenses for the family total \$3,650.² This includes housing, food, utilities, transportation, and other expenses. They have saved money over the years to help pay for their daughters' college education. Tuition and room and board costs for his daughter total \$11,000 per year.

Pre- Reform

Hector's current employer is a small company of about 20 employees that does not offer health benefits. Mr. and Mrs. Gonzalez cannot afford to buy health insurance. Even though the Gonzalez family is in good health, a comprehensive health insurance plan purchased on the individual market would cost the family a minimum of \$782 per month (not including a \$5,000 deductible and 25% coinsurance).³ The Gonzalez family makes too much money to qualify for medical assistance through Medicaid.⁴

Neither Mr. nor Mrs. Gonzalez has a primary care doctor. Mr. Gonzalez has been in good health most of his life and takes no medications. He does not drink, but does smoke.

¹ The 2010 Federal Poverty Line for a family of 4 is \$22,050. <http://aspe.hhs.gov/poverty/10poverty.shtml>

² Estimated using "Family Budget Estimator," Center for Public Policy at Priorities. Accessible at http://www.cppp.org/fbe/ft_3.php

³ Based on estimates provided by www.ehealthinsurance.com

⁴ The Medicaid income threshold for working parents in Texas is 26%. based on *Where Are States Today: Medicaid and State-Funded Coverage Eligibility Levels for Low-Income Adults*, Kaiser Commission on Medicaid and the Uninsured, December 2009. Available at: <http://www.kff.org/medicaid/upload/7993.pdf>.

Although he has cut down on the amount he smokes in recent years, he has been unsuccessful in quitting completely on his own.

New Symptoms

Nearly three months ago, Hector came down with a bad cold and was out of work for almost 1 week—which was very unusual for him. He has since recovered, but has not been able to get rid of an irritating cough. He has also felt more fatigued than usual at work. One day, Hector is at work when his cough becomes particularly severe and he begins coughing up blood. His employer calls 911 and he is taken to a local ER, where doctors find a suspicious mass on his chest X-ray, confirmed by a CT scan. The ER doctor tells him he fears that this may be cancer, but that Mr. Gonzalez needs further studies to confirm the diagnosis. He is given the contact information for the community health center and a local free clinic. Because he is stable, he is discharged home.⁵

At home, Hector is confused and frightened. He tells his wife and children he thinks he has cancer but he is not sure. His family members are anxious and have many questions that no one can answer.

Work-Up and Growing Bills

Hector calls the number he was given on his discharge papers to arrange a follow up visit. The earliest appointment is 3 weeks later with a primary care doctor at the community health center. When he arrives, he does not have his medical records from the ER. The physician he meets with cannot access any test results done at the hospital. She orders a second, more detailed, CT scan and refers him to a pulmonologist (lung specialist).

There is only one pulmonologist in the area that will see uninsured patients, Dr. Brown. The office administrator says Dr. Brown will see Mr. Gonzalez only if he agrees to pay for his office visits at the time of each visit. The first office visit will cost him \$250. It takes Hector another 4 weeks to get the CT scan done and see the specialist.

Meanwhile, he receives several bills from the hospital for his ER visit that total nearly \$3,000. His savings are dwindling fast. Realizing that his medical bills are only going to increase, Mr. Gonzalez tries to apply for insurance in the individual market but is denied coverage by every insurer due to his likely cancer diagnosis.

⁵ The federal law known as the Emergency Medical Treatment and Labor Act requires only that emergency departments provide a medical screening exam and treatment to stabilize patients before discharge. A patient with a new diagnosis of cancer without imminent life-threatening sequelae would not necessarily meet criteria for admission. Similarly admitting a patient to the hospital for a new cancer diagnosis would not guarantee that appropriate workup or treatment for the cancer would be initiated.

Texas has a high risk insurance pool to provide health insurance for those who cannot obtain coverage due to a health condition, but the lowest plan he is eligible for costs almost \$700 each month with a \$7,500 deductible. Hector cannot afford to participate in the high risk pool.

Dr. Brown advises bronchoscopy, a procedure to biopsy the lung mass and to see if it has spread into surrounding tissue—this has to be done at the hospital under sedation. Mr. Gonzalez agrees to the procedure but is concerned about the cost. He meets with the pulmonologist's staff and hospital case worker to see how much it will cost him since he is uninsured. The usual charges for the procedure are about \$4,600 but Hector is able to get a reduced charge of \$2,000, assuming no complications.⁶ He schedules the procedure.

Diagnosis and Treatment

When Hector meets with Dr. Brown after the procedure, he is told that he has non-small cell lung cancer and there is evidence of spread into the surrounding tissue, but not outside the lung (Stage IIB). His doctor refers him to an oncologist and a thoracic surgeon. Because of the location of the cancer, Dr. Brown believes that surgery to remove the right upper lobe of the lung is needed. The problem is that no thoracic surgeons in the community will see Hector because he is uninsured. Hector also needs additional testing before surgery, including MRI, PET scan, bone scan, and pulmonary function tests. Dr. Brown's office recommends that he go to the closest public hospital which is 80 miles away to have the best chance of getting his surgery and tests done. Hector drives to the hospital with his wife and is referred to a financial counselor. The counselor tells him that the hospital cannot provide the treatment for free and even after a discount the procedure will still cost more than \$20,000.

Hector does not know what to do. He wants to have the surgery to remove the cancer, but he simply cannot afford it. His wife is distraught and asks their friends, family, and church community if they can donate money so Hector can have the surgery. Meanwhile, Hector returns to the community health center to see if they can offer any other affordable treatment. They refer Hector to an oncologist working at a free clinic.

The oncologist at the free clinic strongly urges Hector to continue to pursue surgery and asks the free clinic's volunteer social worker to assist him. The social worker helps Hector to get the additional tests done at a discounted rate from the local hospital as charity care. Fortunately, the tests show that Hector is a good candidate for surgery and

⁶ Hospital-Based Ambulatory Surgery, 2007. Statistical Brief #86, February 2010. <http://www.hcup-us.ahrq.gov/reports/statbriefs/sb86.jsp>

that the cancer has not yet spread outside his lungs. With the surgery and additional chemotherapy, Hector has a good prognosis. But, without the surgery, or with a long delay in the surgery, the cancer could progress.

The social worker meets with him and after much effort manages to get most of the chemotherapy drugs supplied at almost no cost, which are then administered by the clinic oncologist for free. Hector is relieved to at least begin chemotherapy. He continues to work under light duty restrictions to support the family.

Months of chemotherapy take their toll. He feels tired all the time and nauseous. He experiences shooting pains in his hand and feet and begins to lose his hair. He develops a terrible gnawing back pain. Eventually, Hector realizes he can no longer work and with the help of the case worker, applies for Medicaid and disability now that he has no income. Meanwhile, Hector's medical bills for the hospitalization and doctor visits are now well over \$20,000.

Hector feels extremely burdened by all the medical bills that he cannot pay. He has never carried this much debt before. The collection agencies have been calling his home and sending him threatening letters. He could have stopped working sooner, but he was always very proud of supporting his family, and knew that with the disability alone it would be difficult for them to meet their expenses and keep Christina in school. Ironically, now that he is too sick to work, he can obtain coverage through Medicaid and try to get the surgical treatment he needs.

Before his Medicaid is processed and he can schedule the surgery, Hector wakes up one night with severe shortness of breath and chest pain. Maria frantically calls 911 and he is taken to the ER. There, a CT scan shows that the cancer has progressed—the lung mass is much larger and a large pleural effusion (fluid around the lungs) has developed. He is admitted to the hospital to drain the fluid. The inpatient team also orders additional studies that unfortunately reveal the source of Hector's back pain--the cancer has metastasized to his spine. Although he is now able to have the surgery and get the follow-up care he needs, it has been many months since his diagnosis and his prognosis is much worse. At this point, the surgery may be too dangerous and is not as beneficial for Hector. After difficult conversations with his care team and with his family, Hector decides that the most important thing to him is to be out of pain. He opts for palliative measures only.

Scenario 2016: Post reform

Before diagnosis

Under the new federal law, Hector and his family are all required to either enroll in a health insurance plan or pay a tax.⁷ The tax for Hector's family to remain uninsured in 2016 is estimated to be about \$2,430.⁸ Rather than pay the tax, Hector explores options for coverage. His employer does not offer health benefits. As a small business employing an average of 20 workers, there is no requirement for his employer to provide health insurance. Hector still makes too much money to qualify for Medicaid (the income limit is ~133% of the poverty line). Hector turns to the new state insurance exchange in hopes of finding affordable insurance for his family.⁹

Hector heard that he can get information about plans offered through the exchange online.¹⁰ His daughter Christina helps him navigate the site. She finds the website easy to understand and available in Spanish.¹¹ After entering information about his income, citizenship, employment, and family status, the website reports that he is eligible for some assistance with his insurance premiums in the form of a tax credit.¹²

It also lists the various plans that he could purchase. Three levels of coverage are offered—bronze, silver, and gold. Each provide essential benefits coverage such as emergency services, outpatient visits, hospitalization, surgery, and prescription drug coverage. Plans differ in the amount of cost-sharing required as well as additional, non-

⁷ Patient Protection and Affordable Care Act, §1501

⁸ The penalty is the lesser of 1) the monthly penalty or 2) the national average premium for qualified bronze level plans. Assuming the monthly penalty is lower than the average bronze-level premium, it is calculated by the greater of either \$695 for each dependent or 2.5% of household income. If a dependent is under 18 years old, their penalty is equal to one-half of \$695. The family's tax penalty would be \$2,432.50.

⁹ In this scenario, Hector is incentivized by the individual mandate to purchase insurance *before* he gets sick. The ACA would also help Hector if he decided to apply for insurance *after* he was diagnosed. He could not be denied by insurance plans or charged higher premiums based on his diagnosis alone. However, in that case, he would have to pay the penalty for remaining uninsured.

¹⁰ ACA § 1311(d)(4)(C) – an Exchange is required to maintain an Internet website through which prospective enrollees can obtain standardized information about plans

¹¹ ACA § 1311(c)(1)(G) – must utilize standard format for presenting health benefits plan options, which references PHS Act 2715 which states that the standards shall ensure that the summary is presented in a culturally and linguistically appropriate manner and uses terminology understandable by the average enrollee

¹² ACA § 1311(d)(4)(G)-an Exchange is required to make available an electronic means of calculating the actual cost of coverage after application of premium and cost-sharing credits

essential services.¹³ For example, the gold plans are the most expensive, but provide additional services with lower out-of-pocket costs.

Because Hector's income is at 250% of the federal poverty line,¹⁴ Hector's family is eligible for premium credits to help pay for the insurance. The credits work so that Hector does not pay more than 8.05% of his income (\$4,427.50) into health insurance premiums. The credits cover the difference in premium price between this cap (8.05% of income) and the cost of the second lowest cost silver plan. The annual premium for the second cheapest silver plan is estimated to cost \$15,361 in 2016.¹⁵

Hector would receive a government subsidy (as a tax credit) of \$10,933.50—the difference between the silver plan cost and his premium cap. Hector decides to apply his premium credit towards the purchase of a bronze plan. On the website, Hector picks the lowest cost bronze plan. He is pleased to see that it still received an above average customer satisfaction rating.¹⁶ The premium for this plan is \$12,500.¹⁷

When the plan materials arrive in the mail, Hector's daughter, Christina, reviews them and finds out that they can save up to \$30 every month if her father quits smoking. She is pleasantly surprised to learn the insurance company also offers intensive smoking cessation programs at no extra cost.¹⁸ At his daughter and wife's urging, Hector enrolls in a comprehensive program to help him quit smoking. The treatment involves a combination of intensive counseling (also available over the phone) and medication. Hector is surprised at how effective the medication is at suppressing his urge to smoke and finally feels hopeful that he can quit for good.

New Symptoms

When Hector's cough does not go away following what seems to be a bad cold, he finally agrees to see the doctor at the insistence of his wife. Together, Mr. and Mrs. Gonzalez go to the nearby community health center that has recently extended weekend and

¹³ ACA§1302(d)

¹⁴ In reality, the federal poverty line would likely have increased by the time the exchanges are operational.

¹⁵ Kaiser Family Foundation, Health Reform Subsidy Calculator, <http://healthreform.kff.org/SubsidyCalculator.aspx>

¹⁶ The Affordable Care Act requires each health plan in the exchange to be rated on the basis of relative quality and price. §1311

¹⁷ Letter from the Congressional Budget Office to Senator Olympia Snowe, January 11, 2010.

¹⁸ PHS 2701(a)(1) states that plans can charge higher premiums for those who smoke and PHS 2713(a)(1) states that USPSTF Grade A or B recommendations be covered--this includes tobacco cessation interventions for those who use tobacco.

evening hours and also takes same-day walk-in visits.¹⁹ Hector pays a small co-pay to be seen but now with his health insurance, is not as worried about the cost of the visit. He sees an internist named Dr. Jackson who is working at the health center as part of her commitment to the National Health Service Corps.

Dr. Jackson orders a chest x-ray which is done on-site at the health center. The x-ray reveals a suspicious-looking mass. She sits down with Hector and his wife to explain the x-ray findings. Given Hector's smoking history, Dr. Jackson is concerned about cancer and recommends a follow-up CT scan. The health center does not have a CT scanner but helps arrange the CT scan for the next day at a diagnostic center nearby. The reports are read by a radiologist and linked back to the health center through an electronic medical record system.²⁰

The following day, Dr. Jackson meets with them to inform them that it is very likely Hector has lung cancer. She refers him to an oncology practice nearby that will help arrange further testing. Dr. Jackson also asks the couple to come in and meet with an assigned care coordinator at the health center. They agree. That night, Hector checks all his insurance plan documents again. He is relieved to read that the testing and treatment should be covered by his insurance, including mental health care.

Diagnosis and Treatment

Through the assistance of the care coordinator, Hector is able to meet with the oncologist and pulmonologist the following week. Although the practice is not one of the well-known comprehensive cancer centers, the group is linked with a major cancer center electronically and has ready access to consultations with specialists via their shared network. Hector has to pay a co-pay to see the doctor but otherwise the visit is covered. Hector is introduced to his cancer care team, including a patient navigator who will do an assessment of his support needs once a diagnosis is made and a treatment plan is developed. The navigator is fluent in both Spanish and English and, together with the care coordinator at the health center, can help Hector arrange for a wide variety of services he may need during and after his course of treatment. They help him to schedule a bronchoscopy (a type of lung biopsy) at a local hospital—one that is reported to have low rates of preventable complications, based on hospital data available through the

¹⁹ ACA§ 5601 authorizes a major investment in community health centers, providing \$11 billion for health center expansion over a five year period. It is expected that new funding will be used to add new health center grantees and service sites as well as enhance the service capacity of existing sites by expanding hours of services and offering a broader range of services. Source: Community health centers: Opportunities and challenges of health reform, Kaiser Commission on Medicaid and the Uninsured.

²⁰ Additional health center funding will likely also go to upgrading IT systems.

Internet. They also arrange an appointment for Hector and his wife to see a therapist at the health center.

The bronchoscopy goes smoothly and after the procedure, Hector meets with his oncologist to decide on a treatment plan that includes surgery, chemotherapy, and radiation. The oncologist refers him to a thoracic surgeon with whom the practice is familiar. Hector, with the help of the navigator, schedules an appointment with the surgeon for the following week and all the additional tests that need to be done. Hector moves forward with his lobectomy the next week. He has no difficulty scheduling the surgery because Hector is insured and the surgeon takes his insurance.

Hector continues to meet with the patient navigator. With all these procedures and treatments, he knows he will rapidly reach his deductible. He confides that he is very worried about the costs of all the extensive treatments. Fortunately, his savings will cover nearly all his out-of-pocket costs, after which the insurance will pay for the remainder of his treatment for the year. However, Hector is still concerned about paying his monthly premiums, the deductible for next year, meeting his family's living expenses and his daughter's tuition. He has been told that he may not be able to work for several months. The patient navigator works with Hector to learn that he might be eligible for short-term disability through his employer. With the help of a social worker, he applies for this benefit.

The patient navigator also works together with the care team to help Hector understand his care plan and what he can expect at each step. She helps him obtain transportation to his appointments when his wife is working and ensures that important information is relayed to all Hector's care providers. She also encourages Hector and his wife to continue seeing the therapist at the health center.

Hector's surgery goes well and Hector recovers without complications. He returns to his oncologist to begin chemotherapy and is referred to a radiation oncologist to begin radiation therapy. After six months, Hector seems to be doing very well and according to his oncologist, is on his way to recovery.

Analysis

Mr. Gonzalez' case illustrates some of the difficult challenges that uninsured cancer patients face in getting the care they need, even when their income places them above the poverty line. An estimated 11% of all cancer patients under age sixty-five were uninsured at the time of initial diagnosis.²¹ Among cancer patients under age sixty-five,

²¹ Thorpe KE and Howard D. "Health insurance spending among cancer patients." *Health Affairs*. 2003;W3-189.

Hispanics were more likely to be uninsured (20%), compared with cancer patients in general (11%).²² Individuals with cancer who do not have private or public insurance have worse outcomes and shorter lifespans than those that are insured. Uninsured individuals are more likely to be diagnosed with late-stage cancers and face difficulty in accessing all aspects of cancer care.

One of the ACA's biggest impacts on health care is reforming the system of private insurance so that people like Hector can access affordable coverage. Insurers will be required to abide by new rules—they can no longer refuse to cover someone based on their health status, and cannot charge them a higher premium because of a health condition. The ACA also includes what is referred to as the “individual mandate”—the requirement that most individuals must carry health insurance coverage or pay a tax penalty. Interestingly, this is one of the provisions in health reform that has been most fiercely attacked by its opponents.

For people like Hector, who are not offered insurance through their employer, the new law makes available state-based “insurance exchanges” through which customers can compare and purchase various insurance plans. All plans sold through the exchanges will be required to cover certain essential benefits that are understood to include treatments for serious illnesses like cancer. For Hector, these changes mean that 1) he is incentivized to purchase insurance; 2) he will not be denied a plan because of his illness and can actually afford coverage; 3) he will be able to easily shop for and purchase a plan on his own; and 4) the plan benefits should cover his cancer care.

The ACA ensures that insurance premiums are affordable for low-income households (defined as up to 400% of poverty). Because of his income, Hector becomes eligible for premium subsidies after health reform. Based on estimates published by the CBO, we estimate that for a low-cost plan, after subsidies, Hector will pay about \$130 per month in premiums for his family. The law also creates a limit on total out-of-pocket spending of about \$6,000. With insurance coverage that is affordable and limits out-of-pocket costs, Hector gains some protection from financial liability as a result of his cancer that he would otherwise be entirely exposed to in the pre-reform system. For many households with inadequate or no coverage at all, a diagnosis of cancer can lead to bankruptcy.

It should be noted that unless Hector can obtain temporary disability benefits or other additional support to help replace his wages, the family will still struggle. Medical bills

²² Most uninsured individuals are in low- to moderate-income working families. Incidentally, Texas has the highest percentage of uninsured residents under age 65. Among Texas residents, 40.5% of Hispanics under age 65 were uninsured. (US Census Bureau). This is likely attributable to the types of jobs that a large number of Hispanics work in—construction, service, and food industries.

will not bankrupt this family, but with the primary breadwinner unable to work full-time, the household will still face financial hardship.

Hector's case illustrates how insurance coverage is not just about financial liability, but it also means the difference between life and death for someone with a serious chronic illness. While Hector may have been able to afford routine primary care out of pocket before he became ill, the ability to pay for treatments for cancer out of pocket is entirely out of reach for all but very few Americans. Without insurance and the ability to pay out-of-pocket for his care, Hector's only real hope in battling cancer is to rely on the charity of providers, pharmaceuticals and hospitals. Many public hospitals are turning away uninsured cancer patients because they cannot afford to treat all of the indigent patients who need care. Like Hector, uninsured cancer patients often go without care at all, until it is too late. After reform, with comprehensive insurance coverage, the outcome is entirely different--Hector is able to access the recommended surgery and other treatment he needs to have a chance at survival.

The Affordable Care Act will impact all cancer patients, but it is the uninsured cancer patient who stands to benefit the most from implementation of health reform. Hector's case illustrates how insurance coverage can mean the difference between life and death for a patient with cancer, by enabling access to expensive, but curative treatments.

National Cancer Survivorship Resource Center

Executive Summary: Year One Overview

Introduction

The National Cancer Survivorship Resource Center (NCSRC) is a collaborative effort to shape the future of survivorship care and improve the quality of life of cancer survivors post-treatment. The NCSRC is managed by the American Cancer Society and the George Washington Cancer Institute (GWCI), with funding through a cooperative agreement from the Centers for Disease Control and Prevention. In April 2011, the NCSRC convened Operational Workgroups and an Expert Panel composed of 113 survivorship experts representing 52 diverse organizations to help shape the NCSRC's strategic plan and direction for the future. These experts divided into topic-focused workgroups with specific objectives and deliverables. This summary provides an overview of the accomplishments thus far and strategic recommendations of the Expert Panel.

Quality of Life: Information Delivery Workgroup

This workgroup identified the informational needs of survivors, gaps in resources and the various channels available for survivors to access information and resources. The workgroup recommends the adaptation of existing health promotion materials and programs to meet the post-treatment needs of cancer survivors. The workgroup also recommends that health care professionals (HCP) should be aware of the various types of information and resources and communicate these resource options to survivors. To assist in survivor-HCP communication, the workgroup created three resources: a resource "prescription" pad for HCPs to give to survivors with referrals to provider, community, phone and Web based information resources; an information tip sheet for survivors to increase their awareness of cancer survivorship, possible late effects, links to resources and a checklist for finding trusted online resources; and an information resource inventory. The information resource inventory can assist both HCPs and survivors in finding a specific type of resource on a specific topic (ex: a video on physical activity or a book on late effects).

Quality of Life: Programs and Navigation Workgroup

This workgroup discussed the post-treatment needs of cancer survivors, available resources and the process of developing, evaluating and sustaining survivorship programs. The workgroup identified a gap in research and survivorship programs directed towards medically underserved populations of survivors. The workgroup recommends that programs be evaluated to demonstrate effectiveness within specific populations and those effective programs are further disseminated. The workgroup also suggests that existing Chronic Disease Self-Management models be adapted to help cancer survivors' transition out of treatment and empower survivors to facilitate post-treatment follow-up care. The workgroup also recognizes the diverse group of HCPs assisting survivors in their recovery and recommends the inclusion of patient navigators in survivorship programs. To assist in the development of culturally tailored resources, the workgroup developed a survey to capture information on existing survivorship programs. The survey will be distributed fall 2011 to a variety of community cancer centers and incorporated into the Society's community resource connection (CRN). The CRN is a Web based tool that allows survivors, caregivers and providers to identify local resources. The workgroup also developed a survivorship program evaluation guide. This resource provides guidance for program evaluation and recommends evidence-based measurement tools to assist survivorship programs in evaluating the program's impact on survivorship. GWCI developed and launched the first in a Patient Navigator Survivorship Training series. This web-based training addresses the workgroup's recommendation to include Patient Navigators as a resource for Survivorship care. Systems Policy and Practice: Clinical Survivorship Care Workgroup



National Cancer Survivorship Resource Center Executive Summary: Year One Overview

This workgroup explored the role of HCPs in providing timely, quality care to cancer survivors and identified the clinical and educational opportunities to enhance HCP capacity. The workgroup recommends the creation of clinical survivorship care guidelines addressing the physical and psychosocial needs of cancer survivors post-treatment. They recommend the utilization of survivorship care plans to facilitate communication between HCPs and between HCPs and cancer survivors. Finally, the workgroup recognizes the need to incorporate survivorship into clinical training and continuing education programs for HCPs. Actionable steps by the group to advance these recommendations include the creation of site and symptom specific guidance grids on the follow-up care of survivors, an overview of the history and current status of clinical survivorship care guidelines and development of an inventory of available HCP trainings on survivor needs and survivorship care.

Policy/Advocacy Workgroup

This workgroup focused on identifying the steps and tools necessary to educate policy makers, employers and payors on cancer survivors' medical, physical and psychosocial needs as well as corollary public health implications. The workgroup recommends educating key stakeholders on the importance of funding for research, consistent reimbursement for clinical care and the need for survivorship education and training for HCPs. To facilitate the education of key stakeholders, the workgroup will develop a series of white papers focusing on the aforementioned topics.

Operational Workgroups

There are four NCSRC operational workgroups aimed at monitoring the project's progress and disseminating the findings and work of the Expert Panel. The four workgroups are: Evaluation, Outcomes and Surveillance, the Division Advisory Council and the Comprehensive Cancer Control (CCC) Partnership Advisory Council. The Evaluation workgroup provides guidance on the development and implementation of the NCSRC evaluation plan. The Outcomes Surveillance workgroup provides input on measurement resources to monitor key performance indicators outlined by each of the Expert Panel workgroups. To inform this work, the workgroup developed a landscape analysis of the current surveillance environment in cancer survivorship. The CCC and Division Advisory Councils are composed of CCC and Society staff nationwide. These councils offer a system of checks and balances as they provide input on how to leverage the work of the Expert Panel to meet the need to provide high quality survivorship care. Ultimately, these workgroups will play a significant role in disseminating the work of the Expert Panel.

Expert Panel Summit

The work of the Expert Panel culminated with a meeting of the Expert Panel Steering Committee and workgroup staff leads in Atlanta, GA on August 31, 2011. The Expert Panel Summit offered an opportunity for the participants to view the products of the Expert Panel workgroups and discuss the steps necessary to develop clinical care guidance to facilitate HCPs in providing quality follow-up care to survivors. The Expert Panel recognizes that the development of clinical care guidance is a necessary first step to advance many of the strategic recommendations set forth by the Expert Panel workgroups. The Expert Panel also recommends the concurrent development of educational and program resources to empower survivors to manage follow-up care and to train HCPs on survivorship needs. These priorities, combined with the dissemination of the survivorship resources developed in year one, will be the focus of the NCSRC in year two. Materials developed by the Expert Panel will be available on www.cancer.org in fall 2011.



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