108TH CONGRESS
2D SESSION

S. 2771

To amend the Public Health Service Act to improve the quality of care for cancer, and for other purposes.

IN THE SENATE OF THE UNITED STATES

JULY 22, 2004

Mr. FRIST (for himself and Mr. KENNEDY) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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A BILL

To amend the Public Health Service Act to improve the quality of care for cancer, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''Quality of Care for Individuals With Cancer Act''.

SEC. 2. TABLE OF CONTENTS.

TITLE I—MEASURING THE QUALITY OF CANCER CARE

SEC. 101. DEVELOPMENT OF CORE SETS OF QUALITY OF CANCER CARE MEASURES.

(a) DEVELOPMENT OF CORE SETS OF QUALITY OF CANCER CARE MEASURES.—Subpart 1 of part C of title IV of the Public Health Service Act (42 U.S.C. 285 et seq.) is amended by adding at the end the following:

"SEC. 417E. DEVELOPMENT OF CORE SETS OF QUALITY OF CANCER CARE MEASURES.

''(a) IN GENERAL.—The Secretary shall award a contract to a national voluntary consensus organization to identify core sets of quality of cancer care measures.

''(b) QUALITY OF CANCER CARE MEASURES.—An entity that receives a contract under this section shall identify core sets of quality of cancer care measures in consultation with a panel or advisory group of interested parties, including significant participation from consumer representatives (which shall include survivors of cancer and their families and members of organizations representing such survivors and their families), health care providers, cancer researchers, payers and purchasers of cancer care services and insurance, and public and private organizations that monitor, accredit, or seek to improve the quality of cancer care.

''(c) REPORT BY ENTITY.—Not later than 24 months after the date of enactment of this section, an eligible entity that receives a contract under this section shall submit to the Secretary a report that—

''(1) lists existing measures used to assess and improve the quality of cancer care;

''(2) identifies those measures that have been scientifically validated, those measures that still require validation, and those aspects of cancer care for which additional measures need to be developed or validated;

''(3) recommends a core set of validated quality of cancer care measures, reflecting a voluntary consensus of interested parties, for measuring and improving the quality of cancer care;

''(4) summarizes the process used to develop the consensus recommendations in paragraph (3), including a statement of any minority views; and

''(5) develops a process for updating the core sets of validated quality of cancer care measures as new scientific evidence becomes available.

''(d) RECOMMENDATIONS BY SECRETARY.—Not later than 6 months after the date the Secretary receives the report described in subsection (c), the Secretary shall issue recommendations on the areas described in paragraphs (1)

through (5) of such subsection and shall transmit such recommendations to the President.

''(e) REPORT BY PRESIDENT.—Not later than 6 months after receipt of the report described in subsection (d), the President shall, in consultation with the Quality Interagency Coordination Task Force (established by a Presidential Directive in 1998)—

''(1) provide to the appropriate committees of Congress a report that describes a plan to use the core sets of quality of cancer care measures in programs administered by the Federal Government, including outlining activities to support the widespread dissemination of the report, and provide any other recommendations the President determines to be appropriate; and

''(2) provide updated reports, in accordance with subsection (c)(5), if new quality measures or scientific evidence on quality of cancer care develops.

''(f) TECHNICAL SUPPORT.—The Secretary may provide scientific and technical support to ensure that the scientific evaluation requirements in this section are met.

''(g) AHRQ.—

''(1) ANNUAL REPORT.—The Agency for Healthcare Research and Quality shall include in the annual report required under section 913(b)(2) the

core set of quality of cancer care measures developed under this section that are suitable for quality monitoring.

''(2) REQUIREMENT.—The Secretary shall ensure that all agencies within the Department of Health and Human Services shall provide the information necessary for the report described in paragraph (1) regarding quality of cancer care measures.

''(h) SUPPORT.—The Director of the Agency for Healthcare Research and Quality, acting in collaboration with the Director of the National Cancer Institute and the Director of the Centers for Disease Control and Prevention, shall support the development and validation of measures identified by the report in subsection (d).

''(i) DEFINITIONS OF HOSPICE CARE; PALLIATIVE CARE; QUALITY OF CANCER CARE; HEALTH DISPARITY POPULATIONS; HEALTH DISPARITIES RESEARCH.—In this section the terms 'hospice care', 'palliative care', 'quality of cancer care', 'health disparity populations', and 'minority health disparities research' have the meanings given such terms in section 399AA.

''(j) AUTHORIZATION OF APPROPRIATIONS.—There is authorized to be appropriated to carry out this section, such sums as may be necessary for each of fiscal years 2006 through 2010.''.

(b) MONITORING.—Not later than 4 years after the date of the transmission of the report required under section 417E(e) of the Public Health Service Act, the Comptroller of the General Accounting Office shall submit to the appropriate committees of Congress a report that evaluates the extent to which Federal and private sector health care delivery programs, States, and State cancer plans are utilizing the core sets of quality of cancer care measures (developed under section 417E of the Public Health Service Act) and the extent to which its adoption is affecting the quality of cancer care.

TITLE II—ENHANCING DATA COLLECTION

SEC. 201. EXPANSION OF NATIONAL PROGRAM OF CANCER REGISTRIES.

Part M of title III of the Public Health Service Act (42 U.S.C. 280e et seq.) is amended by inserting after section 399E, the following:

"SEC. 399E–1. MONITORING AND EVALUATING THE QUALITY OF CANCER CARE.

''(a) DEMONSTRATION PROJECTS.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, and in coordination with the Director of the National Cancer Institute, shall award competitive grants to State cancer registries that receive funds

under this part to enable such registries to expand their ability to monitor and evaluate the quality of cancer care, to develop information concerning the quality of cancer care, and to monitor cancer survivorship.

''(b) ELIGIBILITY.—To be eligible to receive a grant under subsection (a), a State cancer registry shall be certified by the North American Association of Central Cancer Registries or other similar certification organization.

''(c) APPLICATION.—A State cancer registry desiring a grant under this section shall submit an application to the Secretary at such time, in such manner, and containing such information as the Secretary may require.

''(d) CONTRACTING AUTHORITY.—A State cancer registry receiving a grant under this section may enter into contracts with academic institutions, cancer centers, and other entities determined to be appropriate by the Secretary, to carry out the activities authorized under this section.

''(e) USE OF FUNDS.—A State cancer registry receiving a grant under this section shall use amounts received under such grant to—

''(1) collect information for public health surveillance and quality improvement activities using the quality of cancer care measures developed under section 417E (where appropriate), including data

concerning racial, ethnic, and other health disparity populations within the State that may have a disparity in incidence or survival from cancer;

''(2) develop linkages between State cancer registry data and other databases, including those that collect outpatient data, to gather information concerning the quality of cancer care;

''(3) identify, develop, and disseminate evidence-based best practices relating to cancer care regarding how States use registry data and how to better link and coordinate the sharing of such data;

''(4) identify geographic areas and populations within the State that have an increased need for awareness regarding cancer risk reduction, screening, prevention, and treatment activities;

''(5) increase coordination between State cancer registries and other entities, including academic institutions, hospitals, health centers, researchers, health care providers, cancer centers, or nonprofit organizations;

''(6) incorporate the collection of data on cancer survivors for the purpose of improving the quality of cancer care;

''(7) identify the impact of co-morbidity of other diseases on survival from cancer; or

''(8) develop methods of determining whether cancer survivors are at an increased risk for other chronic or disabling conditions.

''(f) PRIVACY.—A State cancer registry receiving a grant or an entity receiving a contract under this section shall comply with appropriate security and privacy protocols (including protocols required under the regulations promulgated under section 264(c) of the Health Insurance Portability and Accountability Act of 1996 (42 U.S.C. 1320d–2 note)), if applicable, with respect to information collected under this title. Nothing in this section shall be construed to supersede applicable Federal or State privacy laws.

''(g) DATABASES.—

''(1) IN GENERAL.—In carrying out this section, a State cancer registry may utilize appropriate databases, including—

''(A) the National Death Index;

''(B) databases related to claims under the medicare and medicaid programs under titles XVIII and XIX of the Social Security Act; and

''(C) other databases maintained by the Department of Health and Human Services (including those maintained at the Agency for Healthcare Research and Quality, the Centers

for Disease Control and Prevention, the Centers for Medicare & Medicaid Services, and the National Institutes of Health).

''(2) ADDITIONAL DATA.—A State cancer registry may utilize data in addition to the databases described in paragraph (1), including data maintained by private insurance plans and health care delivery organizations.

''(h) RULE OF CONSTRUCTION.—Nothing in this section shall be construed to require an individual or entity to submit information to a State cancer registry under this section.

''(i) DEFINITIONS.—In this section:

''(1) HEALTH CENTER.—The term 'health center' has the meaning given the term 'federally qualified health center' in section 1861(aa)(4) of the Social Security Act (12 U.S.C. 1395x(aa)(4)).

''(2) QUALITY OF CANCER CARE.—The term 'quality of cancer care' has the meaning given such term in section 399AA.

''(j) AUTHORIZATION OF APPROPRIATIONS.—There is authorized to be appropriated to carry out this section, such sums as may be necessary for each of fiscal years 2006 through 2010.

"SEC. 399E–2. CANCER SURVEILLANCE SYSTEM.

''(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, and in coordination with the Director of the National Cancer Institute, shall—

''(1) establish the Cancer Surveillance System (referred to in this section as the 'System') to monitor State cancer registries funded under section 399B; and

''(2) provide for the development, expansion, and evaluation of such registries.

''(b) DUTIES.—The System shall—

''(1) facilitate timely access to and exchange of accurate quality of cancer care information among State cancer registries including the use of the quality of cancer care measures developed under section 417E, where appropriate;

''(2) develop guidelines permitting State cancer registries to access the national registry clearinghouse established under paragraph (3);

''(3) establish and maintain a registry information clearinghouse to collect, synthesize, and disseminate information concerning evidence-based best practices for the creative use of State cancer registries, including maintaining an Internet website where such information may be accessed;

''(4) determine the feasibility of monitoring the quality of palliative care by State cancer registries;

''(5) identify and develop evidence-based best practices for coordination between cancer registries and other entities;

''(6) update information collected or made available under this section as determined to be necessary by the Secretary; and

''(7)(A) review pediatric cancer data collected by State cancer registries and evaluate—

''(i) such data for adequacy, completeness, timeliness, and quality; and

''(ii) current efforts to aggregate and disseminate such data; and

''(B) not later than January 1, 2006, submit to Congress a report on the findings made under subparagraph (A).

''(c) PRIVACY.—The System shall comply with appropriate security and privacy protocols (including protocols required under the regulations promulgated under section 264(c) of the Health Insurance Portability and Accountability Act of 1996 (42 U.S.C. 1320d–2 note)), if applicable, with respect to information collected by the System. Nothing in this section shall be construed to supersede applicable Federal or State privacy laws.

''(d) DEFINITIONS.—In this section, the terms 'palliative care' and 'quality of cancer care' have the meanings given such terms in section 399AA.

''(e) AUTHORIZATION OF APPROPRIATIONS.—There is authorized to be appropriated to carry out this section, such sums as may be necessary for each of fiscal years 2006 through 2010.''.

SEC. 202. REAUTHORIZATION OF NATIONAL PROGRAM OF CANCER REGISTRIES.

Section 399F(a) of the Public Health Service Act (42 U.S.C. 280e–4(a)) is amended—

(1) by striking ''this part,'' and inserting ''this part, other than sections 399E–1 and 399E–2),''; and

(2) by striking ''2003'' and inserting ''2010''.

SEC. 203. MATCHING FUNDS; RELATIONSHIP TO CERTIFICATION.

(a) MATCHING FUNDS.—Section 399B(b)(1) of the Public Health Service Act (42 U.S.C. 280e(B)(1)) is amended by striking ''$3'' and inserting ''$5''.

(b) RELATIONSHIP TO CERTIFICATION.—Section 399E of the Public Health Service Act (42 U.S.C. 280e–3) is amended—

(1) by redesignating subsections (d) and (e) as subsections (e) and (f), respectively; and

(2) by inserting after subsection (c) the following:

''(d) RELATIONSHIP TO CERTIFICATION.—The Centers for Disease Control and Prevention is encouraged to work with eligible entities through the provision of technical assistance and funding authority under the National Program of Cancer Registries to assist such entities in complying with the certification process of the North American Association of Central Cancer Registries or similar certification organization.''.

TITLE III—MONITORING AND EVALUATING QUALITY OF CANCER CARE AND OUTCOMES

SEC. 301. PARTNERSHIPS TO DEVELOP MODEL SYSTEMS FOR MONITORING AND EVALUATING QUALITY OF CANCER CARE AND OUTCOMES.

(a) QUALITY OF CANCER CARE.—Part A of title IX of the Public Health Service Act (42 U.S.C. 299 et seq.) is amended by adding at the end the following:

''SEC. 904. AREAS OF SPECIAL EMPHASIS.

''(a) QUALITY OF CANCER CARE.—The Secretary, acting through the Director and in collaboration with the Director of the Centers for Disease Control and Prevention and the Director of the National Cancer Institute,

shall conduct and support research pertaining to the measurement, evaluation, and improvement of the quality of cancer care, take steps to enhance the usefulness of such research to improve patient care, and appropriately disseminate such information by—

''(1) expanding the evidence base concerning effective interventions for improving the quality of cancer care;

''(2) ensuring effective analysis of data collected by State cancer registries funded under section 399B by developing evidence-based best practices for—

''(A) the real-time recording of and automated transfer of cancer care data to State cancer care registries; and

''(B) the linkage of registry data with private sector claims data and other existing data systems for purposes of analytic academic research;

''(3) developing and validating quality of cancer care indicators and evaluate their use and usefulness; and

''(4) developing volume-based quality indicators, as appropriate, and evaluate ongoing efforts to integrate volume-based measures into cancer quality im-

provement programs and their impact on patient decisionmaking.

''(b) PARTNERSHIPS TO SPEED THE PACE OF IMPROVEMENTS IN THE QUALITY OF CANCER CARE.—

''(1) IN GENERAL.—The Secretary, acting through the Director and in collaboration with the Director of the Centers for Disease Control and Prevention and the Director of the National Cancer Institute, shall award competitive grants, contracts, or enter into cooperative agreements with eligible entities to—

''(A) foster the development or adoption of model systems of cancer care;

''(B) speed the pace of improvement in the quality of cancer care; or

''(C) when appropriate, carry out the other requirements of this section.

''(2) ELIGIBILITY.—In accordance with the limitations of section 926(c), an applicant eligible to receive a grant, contract, or cooperative agreement under this subsection shall be a consortium consisting of public- and private-sector entities. Each consortium shall include an institution of higher learning or other research entity and 1 or more of the following:

''(A) An entity that delivers or purchases cancer care.

''(B) A professional society or societies that represent health care providers and other cancer caregivers, including hospice programs.

''(C) A consumer or patient organization.

''(D) An entity involved in the monitoring of quality of cancer care or efforts to improve cancer care (including a State or local health department).

''(c) COLLABORATION.—In carrying out this section, the Secretary, acting through the Director, shall ensure coordination with appropriate Federal and State agencies, private quality improvement entities, and accreditation or licensure organizations with an interest in improving the quality of cancer care.

''(d) DEFINITIONS.—In this section, the term 'quality of cancer care' has the meaning given such term in section 399AA.''.

(b) AUTHORIZATION OF APPROPRIATIONS.—Section 927 of the Public Health Service Act (42 U.S.C. 299c–6) is amended by adding at the end the following:

''(e) QUALITY OF CANCER CARE.—For the purpose of carrying out the activities under section 904, such sums

as may be necessary for each of fiscal years 2005 through 2010.''.

TITLE IV—STRENGTHENING COMPREHENSIVE CANCER CONTROL

SEC. 401. COMPREHENSIVE CANCER CONTROL PROGRAM.

Part B of title III of the Public Health Service Act (42 U.S.C. 243 et seq.) is amended by adding at the end the following:

''SEC. 320B. COMPREHENSIVE CANCER CONTROL PROGRAM.

''(a) ESTABLISHMENT.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention and in consultation with the Director of the Agency for Healthcare Research and Quality and the Director of the National Cancer Institute, shall establish a National Comprehensive Cancer Control Program (referred to in this section as the 'Program') to improve the quality of cancer care.

''(b) PROGRAM.—In carrying out the Program the Secretary shall—

''(1) establish guidelines regarding the design and implementation of comprehensive cancer control plans; and

''(2) award competitive grants to eligible entities to develop, update, implement, and evaluate comprehensive cancer control plans.

''(c) ELIGIBILITY.—An entity is eligible to receive assistance under the Program if such entity is a State health department, territory, Indian tribe, or tribal organization or its designee.

''(d) APPLICATION.—An eligible entity desiring a grant under this section shall submit an application to the Secretary at such time, in such manner, and containing such information as the Secretary may require, including—

''(1) a description of how assistance under such grant will be used to develop and implement comprehensive cancer control programs, including programs to monitor the quality of cancer care (which may include the use of quality of cancer care measures developed under section 417E);

''(2) a description of how the applicant will integrate its activities with academic institutions, nonprofit organizations, or other appropriate entities in planning and implementing comprehensive cancer control plans; and

''(3) a description of how activities carried out by the applicant will be evaluated.

''(e) USE OF FUNDS.—An entity shall use assistance received under this section to—

''(1) convene stakeholders, including stakeholders from the public, private, and nonprofit sectors, to determine priorities for the State, territory, or tribe involved;

''(2) develop, update, implement, or evaluate comprehensive cancer control plans;

''(3) assess disparities in cancer risk reduction, prevention, diagnosis, or quality of cancer care; and

''(4) develop and disseminate best practices, where appropriate, and evaluate the application of such practices as necessary.

''(f) DEFINITIONS.—In this section:

''(1) COMPREHENSIVE CANCER CONTROL PLAN.—The term 'comprehensive cancer control plan' means a plan developed with assistance provided under this section that provides for an integrated and coordinated approach to reducing the incidence, morbidity, and mortality of cancer, with a particular emphasis on preventing and controlling cancer among populations most at risk and reducing cancer disparities among underserved populations.

''(2) COMPREHENSIVE CANCER CONTROL PROGRAM.—The term 'comprehensive cancer control

program' means a program to fulfill the comprehensive control plan.

''(3) QUALITY OF CANCER CARE.—The term 'quality of cancer care' has the meaning given such term in section 399AA.

''(4) INDIAN TRIBE; TRIBAL ORGANIZATION.—The terms 'Indian tribe' and 'tribal organization' have the meanings given such terms in subsections (b) and (c) of section 4 of the Indian Self-Determination and Education Assistance Act (25 U.S.C. 450b).

''(g) AUTHORIZATION OF APPROPRIATIONS.—There is authorized to be appropriated to carry out this section, such sums as may be necessary for each of fiscal years 2006 through 2010.''.

TITLE V—IMPROVING NAVIGATION AND SYSTEM COORDINATION

SEC. 501. ENHANCING CANCER CARE THROUGH IMPROVED NAVIGATION AND CANCER CARE COORDINATION.

Title III of the Public Health Service Act (42 U.S.C. 241 et seq.) is amended by adding at the end the following:

''PART R—CANCER PREVENTION AND TREATMENT

''SEC. 399AA. DEFINITIONS; AUTHORIZATION OF APPROPRIATIONS.

''(a) DEFINITIONS.—In this part:

''(1) CULTURALLY COMPETENT.—The term 'culturally competent', with respect to the manner in which health-related services, education, and training are provided, means providing the services, education, and training in the language and cultural context that is most appropriate for the individuals for whom the services, education, and training are intended.

''(2) HEALTH CENTER.—The term 'health center' has the meaning given such term in section 399E–1.

''(3) HEALTH DISPARITY POPULATION.—The term 'health disparity population' has the meaning given such term in section 903(d)(1).

''(4) HEALTH DISPARITIES RESEARCH.—The term 'health disparities research' means basic, clinical, and behavioral research on health conditions disproportionately affecting individuals from health disparity populations, including research to prevent, diagnose, and treat such conditions. Such health conditions shall include all diseases, disorders, and

conditions affecting individuals from health disparity populations that are—

"(A) unique to, more serious, or more prevalent in such individuals;

"(B) for which the factors of medical risk or types of medical intervention may be different for such individuals, or for which it is unknown whether such factors or types are different for such individuals; or

"(C) with respect to which there has been insufficient research involving such individuals as subjects or insufficient data on such individuals.

"(5) HOSPICE CARE.—The term 'hospice care' has the meaning given such term in section 1861(dd)(1) of the Social Security Act (42 U.S.C. 1395x(dd)(1)).

"(6) HOSPICE PROGRAM.—The term 'hospice program' has the meaning given such term in section 1861(dd)(2) of the Social Security Act (42 U.S.C. 1395x(dd)(2)).

"(7) PALLIATIVE CARE.—The term 'palliative care' means comprehensive, interdisciplinary, coordinated, and appropriate care and services provided throughout all stages of disease, from the time of di-

agnosis to the end of life, relating to pain and other symptom management, including psychosocial needs, that seeks to improve quality of life and prevent and alleviate suffering for an individual and, if appropriate, that individual's family or caregivers.

''(8) QUALITY OF CANCER CARE.—The term 'quality of cancer care' means the provision of cancer-related, timely, evidence-based (whenever there is scientific evidence on the effectiveness of interventions), patient-centered care and services of individuals in a technically and culturally competent and appropriate manner, using effective communication and shared decisionmaking to improve clinical outcomes, survival, or quality of life which encompasses—

''(A) the various stages of care, including care and services provided to individuals with a family history of cancer, with an abnormal cancer screening test, or who are clinically diagnosed with cancer, beginning with risk reduction, prevention, and early detection through survivorship, remission, and end-of-life care, and including risk counseling, screening, diagnosis, treatment, followup care, monitoring, rehabilitation, and hospice care; and

''(B) appropriate care and services which should be provided throughout the continuum of care including palliative care and information on treatment options including information regarding clinical trials.

''(b) AUTHORIZATION OF APPROPRIATIONS.—There are authorized to be appropriated to carry out this part, other than section 399FF, such sums as may be necessary for each of fiscal years 2006 through 2010.

''SEC. 399BB. ENHANCING CANCER CARE THROUGH IMPROVED NAVIGATION.

''(a) DEMONSTRATION PROJECTS.—The Secretary shall award competitive grants to eligible entities to develop, implement, and evaluate cancer case management programs to enhance the quality of cancer care through improved access and navigation.

''(b) ELIGIBILITY.—An entity is eligible to receive a grant under this section if such entity is a hospital; health center; an academic institution; a hospice program; a palliative care program, or a program offering a continuum of hospice care, palliative care, and other appropriate care to children and their families; a State health agency; an Indian Health Service hospital or clinic, Indian tribal health facility, or urban Indian facility; a nonprofit organization; a health plan; a primary care practice-based re-

search network as defined by the Agency for Healthcare Research and Quality; a cancer center; or any other entity determined to be appropriate by the Secretary.

''(c) APPLICATION.—An eligible entity seeking a grant under this section shall submit an application to the Secretary at such time, in such manner, and containing such information as the Secretary may require, including assurances that the eligible entity will—

''(1) target patient populations with an unequal burden of cancer through specific outreach activities;

''(2) coordinate culturally competent and appropriate care specified in observance of existing, relevant departmental guidelines, including a special emphasis on underserved populations and how their values and priorities influence screening and treatment decisions;

''(3) coordinate with relevant ombudsman programs and other existing coordination and navigation efforts and services, where possible; and

''(4) evaluate activities and disseminate findings including findings related to repeated difficulties in accessing navigation.

''(d) USE OF FUNDS.—An eligible entity shall use amounts received under a grant under this section to carry out programs in which—

''(1) trained individuals (such as representatives from the community, nurses, social workers, cancer survivors, physicians, or patient advocates) are assigned to act as contacts—

''(A) within the community; or

''(B) within the health care system,

to facilitate access to quality cancer care and cancer preventive services;

''(2) partnerships are created with community organizations (which may include cancer centers, hospitals, health centers, hospice programs, palliative care programs, health care providers, home care, nonprofit organizations, health plans, or other entities determined appropriate by the Secretary) to help facilitate access or to improve the quality of cancer care;

''(3) activities are conducted to coordinate cancer care and preventive services and referrals, including referrals to hospice programs, and palliative care programs; or

''(4) the grantee negotiates, mediates, or arbitrates on behalf of the patient with relevant entities to resolve issues that impede access to care.

''(e) MODELS.—Not later than 3 years after the date of enactment of this section, the Secretary shall develop

or modify models to improve the navigation of cancer care for grantees under this section. The Secretary shall update such models as may be necessary to ensure that the best cancer case management practices are being utilized.

"SEC. 399CC. CANCER CARE COORDINATION.

"(a) DEMONSTRATION PROJECTS.—The Secretary shall award competitive grants to eligible entities to facilitate the development of a coordinated system to improve the quality of cancer care.

"(b) ELIGIBILITY.—An entity is eligible to receive a grant under this section if such entity is a hospital; a health center; an academic institution; a hospice program; a palliative care program; a program offering a continuum of hospice care, palliative care, and other appropriate care to children and their families; a State health agency; a nonprofit organization; a health plan; a primary care practice-based research network as defined by the Agency for Healthcare Research and Quality; a cancer center; or any other entity determined to be appropriate by the Secretary.

"(c) APPLICATION.—An eligible entity desiring a grant under this section shall prepare and submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require.

''(d) USE OF FUNDS.—An eligible entity shall use amounts received under a grant under this section to improve coordination of the quality of cancer care, by—

''(1) creating partnerships and enhancing collaboration with health care providers (which may include cancer centers, hospitals, health centers, hospice programs, health care providers, experts in palliative care, preventive service providers) to improve the provision of quality of cancer care;

''(2) developing best practices for the quality of cancer care coordination (with special emphasis provided to those cancers that have low survival rates or individuals with advanced disease), including the development of model systems; and

''(3) evaluating overall activities to identify optimal designs and essential components for cancer practices and models to improve the coordination of cancer care services and activities.

''(e) DISSEMINATION.—The Secretary shall disseminate findings made as a result of activities conducted under this section to the public in coordination with the Agency for Healthcare Research and Quality, the Centers for Medicare & Medicaid Services, or other appropriate Federal agencies.''.

TITLE VI—ESTABLISHING PROGRAMS IN PALLIATIVE CARE

SEC. 601. PROGRAMS TO IMPROVE PALLIATIVE CARE.

Part R of title III of the Public Health Service Act (as added by section 501), is further amended by adding at the end the following:

"SEC. 399DD. PROGRAMS TO IMPROVE PALLIATIVE CARE.

''(a) DEMONSTRATION PROJECTS.—The Secretary shall award competitive grants to eligible entities to develop, implement, and evaluate model programs for the delivery of palliative care throughout all stages of disease for individuals with cancer (with a special emphasis on children) and their families.

''(b) ELIGIBILITY.—An entity is eligible to receive a grant under this section if such entity is a hospital; an academic institution; a hospice program; a palliative care program; a program offering a continuum of hospice care, palliative care, and other appropriate care to children and their families; a nonprofit organization; a State health agency; a health center; a cancer center; or any other entity determined to be appropriate by the Secretary.

''(c) APPLICATION.—An eligible entity desiring a grant under this section shall prepare and submit to the Secretary an application at such time, in such manner,

and containing such information as the Secretary may require.

''(d) USE OF FUNDS.—An entity shall use amounts received under a grant under this section to—

''(1) integrate palliative care with such entities as academic institutions, community organizations, hospice programs, hospitals, cancer patient and survivorship organizations, health care providers, cancer centers, or other entities determined appropriate by the Secretary;

''(2) conduct outreach and education activities to encourage the dissemination of evidence-based clinical best practices relating to palliative care;

''(3) increase public awareness, including outreach campaigns, particularly to underserved populations;

''(4) disseminate evidence-based information to health care providers and individuals with cancer and their families regarding available palliative care programs and services;

''(5) provide and evaluate education and training programs in palliative care for health care providers, including—

''(A) establishing pilot training programs (including faculty training programs) in medi-

cine, including oncology (including pediatric oncology), family medicine, psychiatry, psychology, pain, nursing, pharmacology, physical therapy, occupational therapy, social work, and other relevant disciplines; or

''(B) developing, implementing, and evaluating pilot training programs for the staff of hospices, nursing homes, hospitals, home health agencies, outpatient care clinics, and other entities determined appropriate by the Secretary;

''(6) design or implement model palliative care programs for individuals with cancer and their families including improving access to clinical trials, where appropriate;

''(7) develop and evaluate pilot programs to address the special needs of children or other underserved populations and their families in palliative care programs;

''(8) conduct demonstration projects to enhance or develop online support networks for individuals with cancer and their families, including those networks for individuals who are homebound, and develop other methods to reach underserved cancer patients; or

''(9) determine whether strategies developed for palliative care for individuals with cancer and their families would be applicable to individuals with other diseases.

''(e) DISSEMINATION.—The Secretary shall disseminate findings made as a result of activities conducted under this section to the public in coordination with the Director of the Agency for Healthcare Research and Quality, the Administrator of the Centers for Medicare & Medicaid Services, and the heads other appropriate Federal agencies.''.

TITLE VII—ESTABLISHING SURVIVORSHIP PROGRAMS

SEC. 701. PROGRAMS FOR SURVIVORSHIP.

Subpart 1 of Part C of title IV of the Public Health Service Act (42 U.S.C. 285 et seq.) (as amended by section 101), is further amended by adding at the end the following:

''SEC. 417F. PROGRAMS FOR SURVIVORSHIP.

''(a) DEMONSTRATION PROJECTS.—The Secretary shall conduct and support research regarding the unique health challenges associated with cancer survivorship and carry out demonstration projects to develop and implement post-treatment public health programs and services including followup care and monitoring to support and im-

prove the long-term quality of life for cancer survivors, including children.

''(b) ELIGIBILITY.—An entity is eligible to receive a competitive grant under this section if such entity is an academic institution, nonprofit organization, State health agency, cancer center, health center, or other entity determined to be appropriate by the Secretary.

''(c) APPLICATION.—An entity desiring a grant under this section shall prepare and submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require.

''(d) USE OF FUNDS.—An entity shall use amounts received under a grant under this section to plan, implement, and evaluate demonstration projects that—

''(1) design protocols for followup care, monitoring, and other survivorship programs (including peer support and mentor programs);

''(2) increase public awareness about appropriate followup care, monitoring and other survivorship programs (including peer support and mentor programs) by disseminating information to health care providers and survivors and their families; and

''(3) support programs to improve the quality of life among cancer survivors, referenced by the quality of cancer care measures developed under section

417E (where appropriate), with particular emphasis on underserved populations, including children.

''(e) AUTHORIZATION OF APPROPRIATIONS.—There are authorized to be appropriated to carry out this section, such sums as may be necessary for each of fiscal years 2006 through 2010.''.

SEC. 702. CANCER CONTROL PROGRAMS.

Section 412 of the Public Health Service Act (42 U.S.C. 285a–1) is amended—

(1) in the matter preceding paragraph (1), by striking ''cancer and for rehabilitation and counseling respecting cancer.'' and inserting ''cancer and for survivorship, rehabilitation, and counseling respecting cancer.'';

(2) in paragraph (1)(B), by striking ''and the families of cancer patients'' and inserting ''the families of cancer patients, and cancer survivors''; and

(3) in paragraph (3), by striking ''diagnosis, and treatment and control of cancer'' and inserting ''diagnosis, treatment, survivorship programs, and control of cancer.''.

TITLE VIII—PROGRAMS FOR END-OF-LIFE CARE

SEC. 801. PROGRAMS FOR END-OF-LIFE CARE.

Part R of title III of the Public Health Service Act (as amended by section 601), is further amended by adding the following:

"SEC. 399EE. PROGRAMS FOR END-OF-LIFE CARE.

''(a) DEMONSTRATION PROJECTS.—The Secretary shall award competitive grants to eligible entities to develop, implement, and evaluate evidence-based programs for the delivery of quality of cancer care during the end-of-life to individuals with cancer (with a special emphasis on children) and their families.

''(b) ELIGIBILITY.—An entity is eligible to receive a grant under this section if such entity is a hospital; an academic institution; a hospice program; a palliative care program; a program offering a continuum of hospice care, palliative care, and other appropriate care to children and their families; a nonprofit organization; a State health agency; a health center; a cancer center; or any other entity determined to be appropriate by the Secretary.

''(c) APPLICATION.—An entity desiring a grant under this section shall prepare and submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require.

''(d) USE OF FUNDS.—An entity shall use amounts received under a grant under this section to—

''(1) integrate palliative care or end-of-life care programs with entities including academic institutions, community organizations, hospice programs, hospitals, cancer patient and survivorship organizations, health care providers, cancer centers, or other entities determined appropriate by the Secretary;

''(2) conduct outreach and education activities to encourage the dissemination of evidence-based clinical best practices relating to end-of-life care;

''(3) increase public awareness, including outreach campaigns, particularly to underserved populations;

''(4) disseminate information to health care providers and individuals with cancer and their families regarding available end-of-life programs, including hospice programs;

''(5) provide and evaluate education and training in end-of-life care for health care providers, including—

''(A) establishing pilot training programs (including faculty training programs) in medicine including oncology (including pediatric oncology), family medicine, psychiatry, psychology,

pain, nursing, pharmacology and social work, and other disciplines; or

''(B) developing, implementing, and evaluating pilot training programs for the staff of hospices, nursing homes, hospitals, home health agencies, outpatient care clinics, and other entities determined appropriate by the Secretary;

''(6) design or implement model end-of-life care programs for individuals with cancer and their families including improving access to clinical trials where appropriate;

''(7) develop and evaluate pilot programs to address the special needs of children or other underserved populations and their families in end-of-life programs;

''(8) integrate palliative care and hospice care activities in the delivery of end-of-life care; or

''(9) determine whether strategies developed for end-of-life care for individuals with cancer and their families would be applicable to individuals with other diseases.

''(e) DISSEMINATION.—The Secretary shall disseminate findings made as a result of activities conducted under this section to the public in coordination with the Director of the Agency for Healthcare Research and Qual-

ity, the Administrator of the Centers for Medicare & Medicaid Services, and the heads of other appropriate Federal agencies.''.

TITLE IX—DEVELOPING TRAINING CURRICULA

SEC. 901. CURRICULUM DEVELOPMENT.

Part R of title III of the Public Health Service Act (as amended by section 801), is further amended by adding at the end the following:

''SEC. 399FF. CURRICULUM DEVELOPMENT.

''(a) IN GENERAL.—The Secretary shall award competitive grants for the development of curricula for health care provider training regarding the assessment, monitoring, improvement, and delivery of quality of cancer care.

''(b) ELIGIBILITY.—To be eligible to receive a grant under this section, an entity shall be an academic institution, nonprofit organization, cancer center, health center, medical school, or other entity determined appropriate by the Secretary.

''(c) APPLICATION.—An entity desiring a grant under this section shall prepare and submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require.

''(d) USE OF FUNDS.—An entity shall use amounts received under a grant under this subsection to—

''(1) evaluate methods of delivery of the quality of cancer care, including palliative care, hospice care, end-of-life care, or cancer survivorship by health care providers;

''(2) develop curricula concerning the delivery of quality of cancer care including palliative care, hospice care, end-of-life care, or cancer survivorship; and

''(3) provide recommendations for training protocols for medical and nursing education, fellowships, and continuing education in quality of cancer care including palliative care, hospice care, survivorship, or end-of-life care for health care providers.

''(e) AUTHORIZATION OF APPROPRIATIONS.—There is authorized to be appropriated to carry out this section, such sums as may be necessary for each of fiscal years 2006 through 2010.''.

SEC. 902. CANCER CARE WORKFORCE AND TRANSLATIONAL RESEARCH.

(a) CANCER CONTROL PROGRAMS.—Section 412 of the Public Health Service Act (42 U.S.C. 285a–1) is amended—

(1) by striking ''The Director of the Institute'' and inserting the following:

''(a) IN GENERAL.—The Director of the Institute'';

(2) by striking paragraph (2) and inserting the following:

''(2) annual and long-term training goals to assure an adequate and diverse cancer care workforce including—

''(A) preparing and implementing a plan to provide assistance to health professionals in health professions experiencing the most severe shortages including the provision of grants, scholarships, fellowships, post-doctoral stipends, or loans to eligible individuals to increase the cancer care workforce; and

''(B) educating students of health professions and health professionals in—

''(i) effective methods for the prevention and early detection of cancer;

''(ii) the identification of individuals with a high risk of developing cancer;

''(iii) improved methods of patient referral to appropriate centers for early diagnosis and treatment of cancer;

''(iv) methods to deliver culturally competent care; and

''(v) other appropriate methods for providing quality of cancer care; and''; and

(3) by adding at the end the following:

''(b) COORDINATION WITH EXISTING PROGRAMS.—In carrying out the activities under subsection (a)(2), the Director of the Institute shall coordinate with existing programs, including programs at the Health Resources and Services Administration, to prevent duplication.''.

(b) NATIONAL CANCER RESEARCH AND DEMONSTRATION CENTERS.—Section 414(b) of the Public Health Service Act (42 U.S.C. 285a–3(b)) is amended by striking paragraph (3) and inserting the following:

''(3) clinical training (including training for allied health professionals), loan forgiveness or postdoctoral stipends for bench researchers, continuing education for health professionals and allied health professionals, and information programs for the public regarding cancer; and''.

(c) TRANSLATIONAL CANCER RESEARCH.—Subpart 1 of part C of title IV of the Public Health Service Act (42 U.S.C. 285 et seq.) is amended by inserting after section 414 the following:

"SEC. 414A. TRANSLATIONAL CANCER RESEARCH.

''(a) IN GENERAL.—The Director of the Institute, in collaboration with the Director of the Agency for Healthcare Research and Quality shall enter into cooperative agreements with, and make grants to, public or nonprofit entities to conduct multidisciplinary, translational cancer research.

''(b) USE OF FUNDS.—

''(1) IN GENERAL.—The Director of the Institute may use funds provided under this section to establish networks and partnerships to link community cancer providers to programs funded under this section.

''(2) CONSTRUCTION OF NEW FACILITIES.—Funds provided under this section shall not be used for the construction of new facilities.

''(c) STRATEGIC PLAN.—Not later than October 1, 2006, the Director of the Institute shall develop and implement a strategic plan, in collaboration with entities performing translational research, for identifying, expanding, and disseminating the results of translational cancer research to health care providers.

''(d) DUTIES.—An entity receiving a grant under this section shall—

''(1) conduct research with the potential to improve the prevention, diagnosis, and treatment of

cancer and to improve the quality of cancer care, including palliation;

''(2) conduct clinical research studies on promising cancer treatments including clinical trials; and

''(3) evaluate tests, techniques, or technologies in individuals being evaluated for the presence of cancer.

''(e) DEFINITION OF TRANSLATIONAL CANCER RESEARCH.—As used in this section, the term 'translational cancer research' means scientific laboratory and clinical research and testing necessary to transform scientific or medical discoveries into new approaches, products, or processes that can assist in preventing, diagnosing, or controlling cancer.''

(d) AUTHORIZATION OF APPROPRIATIONS.—Section 417B(a) of the Public Health Service Act (42 U.S.C. 285a–8(a)) is amended by striking ''1996'' and inserting ''2010''.

TITLE X—BREAST AND CERVICAL CANCER

SEC. 1001. WAIVERS RELATING TO GRANTS FOR PREVENTIVE HEALTH MEASURES WITH RESPECT TO BREAST AND CERVICAL CANCERS.

(a) IN GENERAL.—Section 1503 of the Public Health Service Act (42 U.S.C. 300m) is amended by adding at the end the following:

''(d) WAIVER OF SERVICES REQUIREMENT ON DIVISION OF FUNDS.—

''(1) IN GENERAL.—The Secretary may waive the requirements under paragraphs (1) and (4) of subsection (a) if—

''(A)(i) the State involved will use the waiver to leverage private funds to supplement each of the services or activities described in paragraphs (1) and (2) of section 1501(a); or

''(ii) the application of such requirement would result in a barrier to the enrollment of qualifying women;

''(B) the Secretary finds that granting such a waiver to a State will not reduce the number of women in the State that receive each of the services or activities described in paragraphs (1) and (2) of section 1501(a), including

making available screening procedures for both breast and cervical cancers; and

''(C) the Secretary finds that granting such a waiver to a State will not adversely affect the quality of each of the services or activities described in paragraphs (1) and (2) of section 1501(a).

''(2) DURATION OF WAIVER.—

''(A) IN GENERAL.—In granting waivers under paragraph (1), the Secretary—

''(i) shall grant such waivers for a period of 2 years; and

''(ii) upon request of a State, may extend a waiver for additional 2-year periods in accordance with subparagraph (B).

''(B) ADDITIONAL PERIODS.—The Secretary, upon the request of a State that has received a waiver under paragraph (1), shall, at the end of each 2-year waiver period described in subparagraph (A), review performance under the waiver and may extend the waiver for an additional 2-year period if the Secretary determines that—

''(i)(I) without an extension of the waiver, there will be a barrier to the enrollment of qualifying women; or

''(II) the State requesting such extended waiver will use the waiver to leverage private funds to supplement each of the services or activities described in paragraphs (1) and (2) of section 1501(a);

''(ii) the waiver has not, and will not, reduce the number of women in the State that receive each of the services or activities described in paragraphs (1) and (2) of section 1501(a); and

''(iii) the waiver has not, and will not, result in lower quality in the State of each of the services or activities described in paragraphs (1) and (2) of section 1501(a).

''(3) REPORTING REQUIREMENT.—The Secretary shall include as part of the evaluations and reports required under section 1508, the following:

''(A) A description of the total amount of dollars leveraged annually from private entities in States receiving a waiver under paragraph (1) and how these amounts were used.

''(B) With respect to States receiving a waiver under paragraph (1), a description of the percentage of the grant that is expended on providing each of the services or activities described in paragraphs (1) and (2) and paragraphs (3) through (6) of section 1501(a).

''(C) A description of the number of States receiving waivers under paragraph (1) annually.

''(D) With respect to States receiving a waiver under paragraph (1), a description of the number of women receiving services under paragraphs (1), (2), and (3) of section 1501(a) in programs before and after the granting of such waiver.''.

(b) AUTHORIZATION OF APPROPRIATIONS.—Section 1510(a) of the Public Health Service Act (42 U.S.C. 300n-5(a)) is amended by striking ''$50,000,000'' and all that follows through the period, and inserting ''such sums as may be necessary for each of fiscal years 2004 through 2009.''.

TITLE XI—COLORECTAL CANCER

SEC. 1101. PROGRAMS TO IMPROVE COLORECTAL CANCER SCREENING.

Title XV of the Public Health Service Act (42 U.S.C. 300k et seq.) is amended by adding at the end the following:

"SEC. 1511. COLORECTAL CANCER SCREENING DEMONSTRATION PROJECT.

''(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall award competitive grants to public and nonprofit private entities to enable such entities to establish demonstration programs pursuant to the general authority of title III to carry out colorectal screening activities including—

''(1) screening asymptomatic individuals as determined by the Secretary in accordance with category A or B recommendation rating of the U.S. Preventive Service Task Force or as otherwise determined by the Secretary;

''(2) providing appropriate case management and referrals for medical treatment of individuals screened pursuant to this section;

''(3) establishing activities to improve the education, training, and skills of health professionals

(including allied health professionals) in the detection and control of colorectal cancer, as a part of their participation in the screening program established under the grant;

''(4) evaluating the programs under this section through appropriate surveillance or program monitoring activities;

''(5) developing and disseminating findings derived through such evaluations and outcomes data collection; and

''(6) promoting the benefits of and participation in the colorectal cancer screening program established under the grant.

''(b) REQUIREMENTS.—

''(1) PRIORITY.—To be eligible for a grant under subsection (a), an entity shall agree with respect to activities and services under the grant to target low-income—

''(A) individuals who are at least 50 years of age; or

''(B) individuals at high risk for colorectal cancer (as defined in section 1861(pp)(2) of the Social Security Act (42 U.S.C. 1395x(pp)(2))).

''(2) RELATIONSHIP TO ITEMS AND SERVICES UNDER OTHER PROGRAMS.—To be eligible for a

grant under subsection (a), an entity shall agree that grant funds will not be expended to make payments for any item or service to the extent that payment has been made, or can reasonably be expected to be made, with respect to such item or service—

''(A) under any State compensation program, under an insurance policy, or under any Federal or State health benefits program; or

''(B) by an entity that provides health service on a prepaid basis.

''(3) RECORDS AND AUDITS.—To be eligible for a grant under subsection (a), an entity shall agree that the entity will—

''(A) establish such fiscal control and fund accounting procedures as may be necessary to ensure proper disbursal of, and accounting for, amounts received under this section; and

''(B) provide agreed upon annual reports to the Secretary or the Comptroller of the United States for the purposes of auditing the expenditures by the entity.

''(4) REPORTS.—To be eligible for a grant under subsection (a), an entity shall agree to submit to the Secretary such reports as the Secretary determines appropriate.

''(c) AUTHORIZATION OF APPROPRIATIONS.—There is authorized to be appropriated to carry out this section, such sums as may be necessary for each of fiscal years 2005 through 2009.''.

TITLE XII—CONDUCTING REPORTS

SEC. 1201. STUDIES AND REPORTS BY THE INSTITUTE OF MEDICINE.

(a) CONTRACT.—The Secretary shall enter into a contract with the Institute of Medicine to—

(1) evaluate Federal and State activities relating to comprehensive cancer control programs and activities;

(2) evaluate the quality of cancer care (including palliative care, end-of-life care, and survivorship) that medicare and medicaid beneficiaries receive and the extent to which medicare and medicaid coverage and reimbursement policies affect access to quality cancer care;

(3) evaluate data from the Centers for Medicare & Medicaid Services and other agencies on volume-outcome relationships;

(4) evaluate access to clinical trials and the relationship of such access to the quality of cancer

care, especially with respect to health disparity populations; and

(5) assess existing gaps in and impediments to the quality of cancer care, including gaps in data, research and translation, seamless patient care and navigation, palliative care, and care provided to underserved populations.

(b) REPORTS.—

(1) IN GENERAL.—Not later than 4 years after the date of enactment of this Act, the Institute of Medicine shall submit to the Secretary of Health and Human Services a report containing information on the evaluation conducted under paragraphs (1) through (5) of subsection (a), including data collected at the State level through contracts with appropriate organizations as designated by the Institute of Medicine.

(2) 8 YEARS.—Not later than 8 years after the date of enactment of this Act, the Institute of Medicine shall submit to the Secretary of Health and Human Services a report containing information and recommendations on the areas described in subsection (a), including data collected from relevant demonstration projects.

(3) REPORTS.—The Secretary of Health and Human Services shall submit the reports described in paragraphs (1) and (2) to the relevant committees of Congress.

(c) DEFINITIONS.—

(1) PALLIATIVE CARE; QUALITY OF CANCER CARE.—The terms 'palliative care' and 'quality of cancer care' have the meanings given such terms in section 399AA of the Public Health Service Act.

(2) COMPREHENSIVE CANCER CONTROL PROGRAM.—The term 'comprehensive cancer control program' has the meaning given such term in section 320B of the Public Health Service Act.

(3) HEALTH DISPARITY POPULATION AND HEALTH DISPARITIES RESEARCH.—The terms ''health disparity population'' and ''health disparities research'' have the meanings given such terms in section 399AA of the Public Health Service Act.

(d) AUTHORIZATION OF APPROPRIATIONS.—There is authorized to be appropriated to carry out this section, such sums as may be necessary for each of fiscal years 2006 through 2010.

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