

107TH CONGRESS
2D SESSION

S. 2965

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

SEPTEMBER 18, 2002

Mr. KENNEDY (for himself, Mr. FRIST, Mrs. FEINSTEIN, Mrs. HUTCHISON, Mr. HARKIN, Ms. COLLINS, Mr. BIDEN, Mr. BOND, Ms. LANDRIEU, Mr. REID, Mr. BINGAMAN, Mr. DODD, Mrs. CLINTON, Mr. HOLLINGS, and Mr. EDWARDS) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

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

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Quality of Care for
5 Individuals With Cancer Act”.

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Sec. 1. Short title.

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1 **TITLE I—MEASURING THE**
 2 **QUALITY OF CANCER CARE**

3 **SEC. 101. DEVELOPMENT OF CORE SETS OF QUALITY OF**
 4 **CANCER CARE MEASURES.**

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

1 **“SEC. 417E. DEVELOPMENT OF CORE SETS OF QUALITY OF**
2 **CANCER CARE MEASURES.**

3 “(a) IN GENERAL.—The Secretary shall award a con-
4 tract to a national voluntary consensus organization to
5 identify core sets of quality of cancer care measures.

6 “(b) QUALITY OF CANCER CARE MEASURES.—An
7 entity that receives a contract under this section shall
8 identify core sets of quality of cancer care measures in
9 consultation with a panel or advisory group of interested
10 parties, including significant participation from consumer
11 representatives (which shall include survivors of cancer
12 and their families and members of organizations rep-
13 resenting such survivors and their families), health care
14 providers, cancer researchers, payers and purchasers of
15 cancer care services and insurance, and public and private
16 organizations that monitor, accredit, or seek to improve
17 the quality of cancer care.

18 “(c) REPORT BY ENTITY.—Not later than 24 months
19 after the date of enactment of this section, an eligible enti-
20 ty that receives a contract under this section shall submit
21 to the Secretary a report that—

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

24 “(2) identifies those measures that have been
25 scientifically validated, those measures that still re-
26 quire validation, and those aspects of cancer care for

1 which additional measures need to be developed or
2 validated;

3 “(3) recommends a core set of validated quality
4 of cancer care measures, reflecting a voluntary con-
5 sensus of interested parties, for measuring and im-
6 proving the quality of cancer care;

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

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

13 “(d) RECOMMENDATIONS BY SECRETARY.—Not later
14 than 6 months after the date the Secretary receives the
15 report described in subsection (c), the Secretary shall issue
16 recommendations on the areas described in paragraphs (1)
17 through (5) of such subsection and shall transmit such
18 recommendations to the President.

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

24 “(1) provide to the appropriate committees of
25 Congress a report that describes a plan to use the

1 core sets of quality of cancer care measures in pro-
2 grams administered by the Federal Government, in-
3 cluding outlining activities to support the widespread
4 dissemination of the report, and provide any other
5 recommendations the President determines to be ap-
6 propriate; and

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

10 “(f) TECHNICAL SUPPORT.—The Secretary may pro-
11 vide scientific and technical support to ensure that the sci-
12 entific evaluation requirements in this section are met.

13 “(g) AHRQ.—

14 “(1) ANNUAL REPORT.—The Agency for
15 Healthcare Research and Quality shall include in the
16 annual report required under section 913(b)(2) the
17 core set of quality of cancer care measures developed
18 under this section that are suitable for quality moni-
19 toring.

20 “(2) REQUIREMENT.—The Secretary shall en-
21 sure that all agencies within the Department of
22 Health and Human Services shall provide the infor-
23 mation necessary for the report described in para-
24 graph (1) regarding quality of cancer care measures.

1 “(h) SUPPORT.—The Director of the Agency for
2 Healthcare Research and Quality, acting in collaboration
3 with the Director of the National Cancer Institute and the
4 Director of the Centers for Disease Control and Preven-
5 tion, shall support the development and validation of
6 measures identified by the report in subsection (d).

7 “(i) DEFINITIONS OF HOSPICE CARE; PALLIATIVE
8 CARE; QUALITY OF CANCER CARE.—In this section the
9 terms ‘hospice care’, ‘palliative care’ and ‘quality of cancer
10 care’ have the meanings given such terms in section
11 399AA.

12 “(j) AUTHORIZATION OF APPROPRIATIONS.—There
13 is authorized to be appropriated to carry out this section,
14 \$3,000,000 for fiscal year 2003, and such sums as may
15 be necessary for each of fiscal years 2004 through 2007.”.

16 (b) MONITORING.—Not later than 4 years after the
17 date of the transmission of the report required under sec-
18 tion 417E(e) of the Public Health Service Act, the Comp-
19 troller of the General Accounting Office shall submit to
20 the appropriate committees of Congress a report that eval-
21 uates the extent to which Federal and private sector
22 health care delivery programs, States, and State cancer
23 plans are utilizing the core sets of quality of cancer care
24 measures (developed under section 417E of the Public

1 Health Service Act) and the extent to which its adoption
2 is affecting the quality of cancer care.

3 **TITLE II—ENHANCING DATA**
4 **COLLECTION**

5 **SEC. 201. EXPANSION OF NATIONAL PROGRAM OF CANCER**
6 **REGISTRIES.**

7 Part M of title III of the Public Health Service Act
8 (42 U.S.C. 280e et seq.) is amended by inserting after
9 section 399E, the following:

10 **“SEC. 399E-1. MONITORING AND EVALUATING THE QUALITY**
11 **OF CANCER CARE.**

12 “(a) **DEMONSTRATION PROJECTS.**—The Secretary,
13 acting through the Director of the Centers for Disease
14 Control and Prevention, and in coordination with the Di-
15 rector of the National Cancer Institute, shall award com-
16 petitive grants to State cancer registries that receive funds
17 under this part to enable such registries to expand their
18 ability to monitor and evaluate the quality of cancer care,
19 to develop information concerning the quality of cancer
20 care, and to monitor cancer survivorship.

21 “(b) **ELIGIBILITY.**—To be eligible to receive a grant
22 under subsection (a), a State cancer registry shall be cer-
23 tified by the North American Association of Central Can-
24 cer Registries or other similar certification organization.

1 “(c) APPLICATION.—A State cancer registry desiring
2 a grant under this section shall submit an application to
3 the Secretary at such time, in such manner, and con-
4 taining such information as the Secretary may require.

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

11 “(e) USE OF FUNDS.—A State cancer registry receiv-
12 ing a grant under this section shall use amounts received
13 under such grant to—

14 “(1) collect information for public health sur-
15 veillance and quality improvement activities using
16 the quality of cancer care measures developed under
17 section 417E (where appropriate), including data
18 concerning traditionally underserved populations and
19 populations within the State that may have a dis-
20 parity in incidence or survival from cancer;

21 “(2) develop linkages between State cancer reg-
22 istry data and other databases, including those that
23 collect outpatient data, to gather information con-
24 cerning the quality of cancer care;

1 “(3) identify, develop, and disseminate evi-
2 dence-based best practices relating to cancer care re-
3 garding how States use registry data and how to
4 better link and coordinate the sharing of such data;

5 “(4) identify geographic areas and populations
6 within the State that have an increased need for
7 awareness regarding cancer risk reduction, screen-
8 ing, prevention, and treatment activities;

9 “(5) increase coordination between State cancer
10 registries and other entities, including academic in-
11 stitutions, hospitals, health centers, researchers,
12 health care providers, cancer centers, or nonprofit
13 organizations;

14 “(6) incorporate the collection of data on cancer
15 survivors for the purpose of improving the quality of
16 cancer care;

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

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

22 “(f) PRIVACY.—A State cancer registry receiving a
23 grant or an entity receiving a contract under this section
24 shall comply with appropriate security and privacy proto-
25 cols (including protocols required under the regulations

1 promulgated under section 264(c) of the Health Insurance
2 Portability and Accountability Act of 1996 (42 U.S.C.
3 1320d–2 note)), if applicable, with respect to information
4 collected under this title. Nothing in this section shall be
5 construed to supersede applicable Federal or State privacy
6 laws.

7 “(g) DATABASES.—

8 “(1) IN GENERAL.—In carrying out this sec-
9 tion, a State cancer registry may utilize appropriate
10 databases, including—

11 “(A) the National Death Index;

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

15 “(C) other databases maintained by the
16 Department of Health and Human Services (in-
17 cluding those maintained at the Agency for
18 Healthcare Research and Quality, the Centers
19 for Disease Control and Prevention, the Centers
20 for Medicare & Medicaid Services, and the Na-
21 tional Institutes of Health).

22 “(2) ADDITIONAL DATA.—A State cancer reg-
23 istry may utilize data in addition to the databases
24 described in paragraph (1), including data main-

1 tained by private insurance plans and health care
2 delivery organizations.

3 “(h) RULE OF CONSTRUCTION.—Nothing in this sec-
4 tion shall be construed to require an individual or entity
5 to submit information to a State cancer registry under this
6 section.

7 “(i) DEFINITIONS.—In this section:

8 “(1) HEALTH CENTER.—The term ‘health cen-
9 ter’ has the meaning given the term ‘federally quali-
10 fied health center’ in section 1861(aa)(4) of the So-
11 cial Security Act (12 U.S.C. 1395x(aa)(4)).

12 “(2) QUALITY OF CANCER CARE.—The term
13 ‘quality of cancer care’ has the meaning given such
14 term in section 399AA.

15 “(j) AUTHORIZATION OF APPROPRIATIONS.—There
16 is authorized to be appropriated to carry out this section,
17 \$3,000,000 for fiscal year 2003 and such sums as may
18 be necessary for each of fiscal years 2004 through 2007.

19 **“SEC. 399E-2. CANCER SURVEILLANCE SYSTEM.**

20 “(a) IN GENERAL.—The Secretary, acting through
21 the Director of the Centers for Disease Control and Pre-
22 vention, and in coordination with the Director of the Na-
23 tional Cancer Institute, shall—

24 “(1) establish the Cancer Surveillance System
25 (referred to in this section as the ‘System’) to mon-

1 itor State cancer registries funded under section
2 399B; and

3 “(2) provide for the development, expansion,
4 and evaluation of such registries.

5 “(b) DUTIES.—The System shall—

6 “(1) facilitate timely access to and exchange of
7 accurate quality of cancer care information among
8 State cancer registries including the use of the qual-
9 ity of cancer care measures developed under section
10 417E, where appropriate;

11 “(2) develop guidelines permitting State cancer
12 registries to access the national registry clearing-
13 house established under paragraph (3);

14 “(3) establish and maintain a registry informa-
15 tion clearinghouse to collect, synthesize, and dissemi-
16 nate information concerning evidence-based best
17 practices for the creative use of State cancer reg-
18 istries, including maintaining an Internet website
19 where such information may be accessed;

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

22 “(5) identify and develop evidence-based best
23 practices for coordination between cancer registries
24 and other entities; and

1 (2) by striking “2003” and inserting “2008”.

2 **SEC. 203. MATCHING FUNDS; RELATIONSHIP TO CERTIFI-**
3 **CATION.**

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

7 (b) **RELATIONSHIP TO CERTIFICATION.**—Section
8 399E of the Public Health Service Act (42 U.S.C. 280e–
9 3) is amended—

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

12 (2) by inserting after subsection (c) the fol-
13 lowing:

14 “(d) **RELATIONSHIP TO CERTIFICATION.**—The Cen-
15 ters for Disease Control and Prevention is encouraged to
16 work with eligible entities through the provision of tech-
17 nical assistance and funding authority under the National
18 Program of Cancer Registries to assist such entities in
19 complying with the certification process of the North
20 American Association of Central Cancer Registries or
21 similar certification organization.”.

1 **TITLE III—MONITORING AND**
2 **EVALUATING QUALITY OF**
3 **CANCER CARE AND OUT-**
4 **COMES**

5 **SEC. 301. PARTNERSHIPS TO DEVELOP MODEL SYSTEMS**
6 **FOR MONITORING AND EVALUATING QUAL-**
7 **ITY OF CANCER CARE AND OUTCOMES.**

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

11 **“SEC. 904. AREAS OF SPECIAL EMPHASIS.**

12 “(a) QUALITY OF CANCER CARE.—The Secretary,
13 acting through the Director and in collaboration with the
14 Director of the Centers for Disease Control and Preven-
15 tion and the Director of the National Cancer Institute,
16 shall conduct and support research pertaining to the meas-
17 urement, evaluation, and improvement of the quality of
18 cancer care, take steps to enhance the usefulness of such
19 research to improve patient care, and appropriately dis-
20 seminate such information by—

21 “(1) expanding the evidence base concerning ef-
22 fective interventions for improving the quality of
23 cancer care;

24 “(2) ensuring effective analysis of data collected
25 by State cancer registries funded under section

1 399B by developing evidence-based best practices
2 for—

3 “(A) the real-time recording of and auto-
4 mated transfer of cancer care data to State
5 cancer care registries; and

6 “(B) the linkage of registry data with pri-
7 vate sector claims data and other existing data
8 systems for purposes of analytic academic re-
9 search;

10 “(3) developing and validating quality of cancer
11 care indicators and evaluate their use and useful-
12 ness; and

13 “(4) developing volume-based quality indicators,
14 as appropriate, and evaluate ongoing efforts to inte-
15 grate volume-based measures into cancer quality im-
16 provement programs and their impact on patient de-
17 cisionmaking.

18 “(b) PARTNERSHIPS TO SPEED THE PACE OF IM-
19 PROVEMENTS IN THE QUALITY OF CANCER CARE.—

20 “(1) IN GENERAL.—The Secretary, acting
21 through the Director and in collaboration with the
22 Director of the Centers for Disease Control and Pre-
23 vention and the Director of the National Cancer In-
24 stitute, shall award competitive grants, contracts, or

1 enter into cooperative agreements with eligible enti-
2 ties to—

3 “(A) foster the development or adoption of
4 model systems of cancer care;

5 “(B) speed the pace of improvement in the
6 quality of cancer care; or

7 “(C) when appropriate, carry out the other
8 requirements of this section.

9 “(2) ELIGIBILITY.—In accordance with the lim-
10 itations of section 926(c), an applicant eligible to re-
11 ceive a grant, contract, or cooperative agreement
12 under this subsection shall be a consortium con-
13 sisting of public- and private-sector entities. Each
14 consortium shall include an institution of higher
15 learning or other research entity and 1 or more of
16 the following:

17 “(A) An entity that delivers or purchases
18 cancer care.

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

22 “(C) A consumer or patient organization.

23 “(D) An entity involved in the monitoring
24 of quality of cancer care or efforts to improve

1 cancer care (including a State or local health
2 department).

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

9 “(e) DEFINITIONS.—In this section, the term ‘quality
10 of cancer care’ has the meaning given such term in section
11 399AA.”.

12 (b) AUTHORIZATION OF APPROPRIATIONS.—Section
13 927 of the Public Health Service Act (42 U.S.C. 299c–
14 6) is amended by adding at the end the following:

15 “(e) QUALITY OF CANCER CARE.—For the purpose
16 of carrying out the activities under section 904, there is
17 authorized to be appropriated \$5,000,000 for fiscal year
18 2003, and such sums as may be necessary for each of fis-
19 cal years 2004 through 2007.”.

1 **TITLE IV—STRENGTHENING**
2 **COMPREHENSIVE CANCER**
3 **CONTROL**

4 **SEC. 401. COMPREHENSIVE CANCER CONTROL PROGRAM.**

5 Part B of title III of the Public Health Service Act
6 (42 U.S.C. 243 et seq.) is amended by adding at the end
7 the following:

8 **“SEC. 320B. COMPREHENSIVE CANCER CONTROL PRO-**
9 **GRAM.**

10 “(a) ESTABLISHMENT.—The Secretary, acting
11 through the Director of the Centers for Disease Control
12 and Prevention and in consultation with the Director of
13 the Agency for Healthcare Research and Quality and the
14 Director of the National Cancer Institute, shall establish
15 a National Comprehensive Cancer Control Program (re-
16 ferred to in this section as the ‘Program’) to improve the
17 quality of cancer care.

18 “(b) PROGRAM.—In carrying out the Program the
19 Secretary shall—

20 “(1) establish guidelines regarding the design
21 and implementation of comprehensive cancer control
22 plans; and

23 “(2) award competitive grants to eligible enti-
24 ties to develop, update, implement, and evaluate
25 comprehensive cancer control plans.

1 “(c) ELIGIBILITY.—An entity is eligible to receive as-
2 sistance under the Program if such entity is a State health
3 department, territory, Indian tribe, or tribal organization
4 or its designee.

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

10 “(1) a description of how assistance under such
11 grant will be used to develop and implement com-
12 prehensive cancer control programs, including pro-
13 grams to monitor the quality of cancer care (which
14 may include the use of quality of cancer care meas-
15 ures developed under section 417E);

16 “(2) a description of how the applicant will in-
17 tegrate its activities with academic institutions, non-
18 profit organizations, or other appropriate entities in
19 planning and implementing comprehensive cancer
20 control plans; and

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

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

1 “(1) convene stakeholders, including stake-
2 holders from the public, private, and nonprofit sec-
3 tors, to determine priorities for the State, territory,
4 or tribe involved;

5 “(2) develop, update, implement, or evaluate
6 comprehensive cancer control plans;

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

9 “(4) develop and disseminate best practices,
10 where appropriate, and evaluate the application of
11 such practices as necessary.

12 “(f) DEFINITIONS.—In this section:

13 “(1) COMPREHENSIVE CANCER CONTROL
14 PLAN.—The term ‘comprehensive cancer control
15 plan’ means a plan developed with assistance pro-
16 vided under this section that provides for an inte-
17 grated and coordinated approach to reducing the in-
18 cidence, morbidity, and mortality of cancer, with a
19 particular emphasis on preventing and controlling
20 cancer among populations most at risk and reducing
21 cancer disparities among underserved populations.

22 “(2) COMPREHENSIVE CANCER CONTROL PRO-
23 GRAM.—The term ‘comprehensive cancer control
24 program’ means a program to fulfill the comprehen-
25 sive control plan.

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

4 “(4) INDIAN TRIBE; TRIBAL ORGANIZATION.—
5 The terms ‘Indian tribe’ and ‘tribal organization’
6 have the meanings given such terms in subsections
7 (b) and (c) of section 4 of the Indian Self-Deter-
8 mination and Education Assistance Act (25 U.S.C.
9 450b).

10 “(g) AUTHORIZATION OF APPROPRIATIONS.—There
11 is authorized to be appropriated to carry out this section,
12 \$15,000,000 for fiscal year 2003 and such sums as may
13 be necessary for each of fiscal years 2004 through 2007.”.

14 **TITLE V—IMPROVING NAVIGA-**
15 **TION AND SYSTEM COORDI-**
16 **NATION**

17 **SEC. 501. ENHANCING CANCER CARE THROUGH IMPROVED**
18 **NAVIGATION AND CANCER CARE COORDINA-**
19 **TION.**

20 Title III of the Public Health Service Act (42 U.S.C.
21 241 et seq.) is amended by adding at the end the fol-
22 lowing:

1 “PART R—CANCER PREVENTION AND TREATMENT
2 **“SEC. 399AA. DEFINITIONS; AUTHORIZATION OF APPRO-**
3 **PRIATIONS.**

4 (a) DEFINITIONS.—In this part:

5 “(1) HEALTH CENTER.—The term ‘health cen-
6 ter’ has the meaning given such term in section
7 399E–1.

8 “(2) HOSPICE CARE.—The term ‘hospice care’
9 has the meaning given such term in section
10 1861(dd)(1) of the Social Security Act (42 U.S.C.
11 1395x(dd)(1)).

12 “(3) HOSPICE PROGRAM.—The term ‘hospice
13 program’ has the meaning given such term in sec-
14 tion 1861(dd)(2) of the Social Security Act (42
15 U.S.C. 1395x(dd)(2)).

16 “(4) PALLIATIVE CARE.—The term ‘palliative
17 care’ means comprehensive, interdisciplinary, coordi-
18 nated, and appropriate care and services provided
19 throughout all stages of disease, from the time of di-
20 agnosis to the end of life, relating to pain and other
21 symptom management, including psychosocial needs,
22 that seeks to improve quality of life and prevent and
23 alleviate suffering for an individual and, if appro-
24 priate, that individual’s family or caregivers.

1 “(5) QUALITY OF CANCER CARE.—The term
2 ‘quality of cancer care’ means the provision of can-
3 cer-related, timely, evidence-based (whenever there is
4 scientific evidence on the effectiveness of interven-
5 tions), patient-centered care and services of individ-
6 uals in a technically and culturally competent and
7 appropriate manner, using effective communication
8 and shared decisionmaking to improve clinical out-
9 comes, survival, or quality of life which
10 encompasses—

11 “(A) the various stages of care, including
12 care and services provided to individuals with a
13 family history of cancer, with an abnormal can-
14 cer screening test, or who are clinically diag-
15 nosed with cancer, beginning with risk reduc-
16 tion, prevention, and early detection through
17 survivorship, remission, and end-of-life care,
18 and including risk counseling, screening, diag-
19 nosis, treatment, followup care, monitoring, re-
20 habilitation, and hospice care; and

21 “(B) appropriate care and services which
22 should be provided throughout the continuum of
23 care including palliative care and information
24 on treatment options including information re-
25 garding clinical trials.

1 “(b) AUTHORIZATION OF APPROPRIATIONS.—There
2 are authorized to be appropriated to carry out this part,
3 other than section 399FF, such sums as may be necessary
4 for each of fiscal years 2003 through 2007.

5 **“SEC. 399BB. ENHANCING CANCER CARE THROUGH IM-**
6 **PROVED NAVIGATION.**

7 “(a) DEMONSTRATION PROJECTS.—The Secretary
8 shall award competitive grants to eligible entities to de-
9 velop, implement, and evaluate cancer case management
10 programs to enhance the quality of cancer care through
11 improved access and navigation.

12 “(b) ELIGIBILITY.—An entity is eligible to receive a
13 grant under this section if such entity is a hospital; health
14 center; an academic institution; a hospice program; a pal-
15 liative care program, or a program offering a continuum
16 of hospice care, palliative care, and other appropriate care
17 to children and their families; a State health agency; an
18 Indian Health Service hospital or clinic, Indian tribal
19 health facility, or urban Indian facility; a nonprofit organi-
20 zation; a health plan; a primary care practice-based re-
21 search network as defined by the Agency for Healthcare
22 Research and Quality; a cancer center; or any other entity
23 determined to be appropriate by the Secretary.

24 “(c) APPLICATION.—An eligible entity seeking a
25 grant under this section shall submit an application to the

1 Secretary at such time, in such manner, and containing
2 such information as the Secretary may require, including
3 assurances that the eligible entity will—

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

6 “(2) coordinate culturally competent and appro-
7 priate care specified in observance of existing, rel-
8 evant departmental guidelines, including a special
9 emphasis on underserved populations and how their
10 values and priorities influence screening and treat-
11 ment decisions;

12 “(3) coordinate with relevant ombudsman pro-
13 grams and other existing coordination and naviga-
14 tion efforts and services, where possible; and

15 “(4) evaluate activities and disseminate findings
16 including findings related to repeated difficulties in
17 accessing navigation.

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

21 “(1) trained individuals (such as representatives
22 from the community, nurses, social workers, cancer
23 survivors, physicians, or patient advocates) are as-
24 signed to act as contacts—

25 “(A) within the community; or

1 “(B) within the health care system,
2 to facilitate access to quality cancer care and cancer
3 preventive services;

4 “(2) partnerships are created with community
5 organizations (which may include cancer centers,
6 hospitals, health centers, hospice programs, pallia-
7 tive care programs, health care providers, home care,
8 nonprofit organizations, health plans, or other enti-
9 ties determined appropriate by the Secretary) to
10 help facilitate access or to improve the quality of
11 cancer care;

12 “(3) activities are conducted to coordinate can-
13 cer care and preventive services and referrals, in-
14 cluding referrals to hospice programs, and palliative
15 care programs; or

16 “(4) the grantee negotiates, mediates, or arbi-
17 trates on behalf of the patient with relevant entities
18 to resolve issues that impede access to care.

19 “(e) MODELS.—Not later than 3 years after the date
20 of enactment of this section, the Secretary shall develop
21 or modify models to improve the navigation of cancer care
22 for grantees under this section. The Secretary shall update
23 such models as may be necessary to ensure that the best
24 cancer case management practices are being utilized.

1 **“SEC. 399CC. CANCER CARE COORDINATION.**

2 “(a) **DEMONSTRATION PROJECTS.**—The Secretary
3 shall award competitive grants to eligible entities to facili-
4 tate the development of a coordinated system to improve
5 the quality of cancer care.

6 “(b) **ELIGIBILITY.**—An entity is eligible to receive a
7 grant under this section if such entity is a hospital; a
8 health center; an academic institution; a hospice program;
9 a palliative care program; a program offering a continuum
10 of hospice care, palliative care, and other appropriate care
11 to children and their families; a State health agency; a
12 nonprofit organization; a health plan; a primary care prac-
13 tice-based research network as defined by the Agency for
14 Healthcare Research and Quality; a cancer center; or any
15 other entity determined to be appropriate by the Sec-
16 retary.

17 “(c) **APPLICATION.**—An eligible entity desiring a
18 grant under this section shall prepare and submit to the
19 Secretary an application at such time, in such manner,
20 and containing such information as the Secretary may re-
21 quire.

22 “(d) **USE OF FUNDS.**—An eligible entity shall use
23 amounts received under a grant under this section to im-
24 prove coordination of the quality of cancer care, by—

25 “(1) creating partnerships and enhancing col-
26 laboration with health care providers (which may in-

1 include cancer centers, hospitals, health centers, hos-
 2 pice programs, health care providers, experts in pal-
 3 liative care, preventive service providers) to improve
 4 the provision of quality of cancer care;

5 “(2) developing best practices for the quality of
 6 cancer care coordination (with special emphasis pro-
 7 vided to those cancers that have low survival rates
 8 or individuals with advanced disease), including the
 9 development of model systems; and

10 “(3) evaluating overall activities to identify op-
 11 timal designs and essential components for cancer
 12 practices and models to improve the coordination of
 13 cancer care services and activities.

14 “(e) DISSEMINATION.—The Secretary shall dissemi-
 15 nate findings made as a result of activities conducted
 16 under this section to the public in coordination with the
 17 Agency for Healthcare Research and Quality, the Centers
 18 for Medicare & Medicaid Services, or other appropriate
 19 Federal agencies.”.

20 **TITLE VI—ESTABLISHING PRO-** 21 **GRAMS IN PALLIATIVE CARE**

22 **SEC. 601. PROGRAMS TO IMPROVE PALLIATIVE CARE.**

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

1 **“SEC. 399DD. PROGRAMS TO IMPROVE PALLIATIVE CARE.**

2 “(a) DEMONSTRATION PROJECTS.—The Secretary
3 shall award competitive grants to eligible entities to de-
4 velop, implement, and evaluate model programs for the de-
5 livery of palliative care throughout all stages of disease
6 for individuals with cancer (with a special emphasis on
7 children) and their families.

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

16 “(c) APPLICATION.—An eligible entity desiring a
17 grant under this section shall prepare and submit to the
18 Secretary an application at such time, in such manner,
19 and containing such information as the Secretary may re-
20 quire.

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

23 “(1) integrate palliative care with such entities
24 as academic institutions, community organizations,
25 hospice programs, hospitals, cancer patient and sur-
26 vivorship organizations, health care providers, cancer

1 centers, or other entities determined appropriate by
2 the Secretary;

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

6 “(3) increase public awareness, including out-
7 reach campaigns, particularly to underserved popu-
8 lations;

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

13 “(5) provide and evaluate education and train-
14 ing programs in palliative care for health care pro-
15 viders, including—

16 “(A) establishing pilot training programs
17 (including faculty training programs) in medi-
18 cine, including oncology (including pediatric on-
19 cology), family medicine, psychiatry, psychology,
20 pain, nursing, pharmacology, physical therapy,
21 occupational therapy, social work, and other rel-
22 evant disciplines; or

23 “(B) developing, implementing, and evalu-
24 ating pilot training programs for the staff of
25 hospices, nursing homes, hospitals, home health

1 agencies, outpatient care clinics, and other enti-
2 ties determined appropriate by the Secretary;

3 “(6) design or implement model palliative care
4 programs for individuals with cancer and their fami-
5 lies including improving access to clinical trials,
6 where appropriate;

7 “(7) develop and evaluate pilot programs to ad-
8 dress the special needs of children or other under-
9 served populations and their families in palliative
10 care programs;

11 “(8) conduct demonstration projects to enhance
12 or develop online support networks for individuals
13 with cancer and their families, including those net-
14 works for individuals who are homebound, and de-
15 velop other methods to reach underserved cancer pa-
16 tients; or

17 “(9) determine whether strategies developed for
18 palliative care for individuals with cancer and their
19 families would be applicable to individuals with other
20 diseases.

21 “(e) DISSEMINATION.—The Secretary shall dissemi-
22 nate findings made as a result of activities conducted
23 under this section to the public in coordination with the
24 Director of the Agency for Healthcare Research and Qual-
25 ity, the Administrator of the Centers for Medicare & Med-

1 icaid Services, and the heads other appropriate Federal
2 agencies.”.

3 **TITLE VII—ESTABLISHING**
4 **SURVIVORSHIP PROGRAMS**

5 **SEC. 701. PROGRAMS FOR SURVIVORSHIP.**

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

10 **“SEC. 417F. PROGRAMS FOR SURVIVORSHIP.**

11 “(a) DEMONSTRATION PROJECTS.—The Secretary
12 shall conduct and support research regarding the unique
13 health challenges associated with cancer survivorship and
14 carry out demonstration projects to develop and imple-
15 ment post-treatment public health programs and services
16 including followup care and monitoring to support and im-
17 prove the long-term quality of life for cancer survivors,
18 including children.

19 “(b) ELIGIBILITY.—An entity is eligible to receive a
20 competitive grant under this section if such entity is an
21 academic institution, nonprofit organization, State health
22 agency, cancer center, health center, or other entity deter-
23 mined to be appropriate by the Secretary.

24 “(c) APPLICATION.—An entity desiring a grant under
25 this section shall prepare and submit to the Secretary an

1 application at such time, in such manner, and containing
2 such information as the Secretary may require.

3 “(d) USE OF FUNDS.—An entity shall use amounts
4 received under a grant under this section to plan, imple-
5 ment, and evaluate demonstration projects that—

6 “(1) design protocols for followup care, moni-
7 toring, and other survivorship programs (including
8 peer support and mentor programs);

9 “(2) increase public awareness about appro-
10 priate followup care, monitoring and other survivor-
11 ship programs (including peer support and mentor
12 programs) by disseminating information to health
13 care providers and survivors and their families; and

14 “(3) support programs to improve the quality of
15 life among cancer survivors, referenced by the qual-
16 ity of cancer care measures developed under section
17 417E (where appropriate), with particular emphasis
18 on underserved populations, including children.

19 “(e) AUTHORIZATION OF APPROPRIATIONS.—There
20 are authorized to be appropriated to carry out this section,
21 such sums as may be necessary for each of fiscal years
22 2003 through 2007.”.

23 **SEC. 702. CANCER CONTROL PROGRAMS.**

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

1 (1) in the matter preceding paragraph (1), by
2 striking “cancer and for rehabilitation and coun-
3 seling respecting cancer.” and inserting “cancer and
4 for survivorship, rehabilitation, and counseling re-
5 specting cancer.”;

6 (2) in paragraph (1)(B), by striking “and the
7 families of cancer patients” and inserting “the fami-
8 lies of cancer patients, and cancer survivors”; and

9 (3) in paragraph (3), by striking “diagnosis,
10 and treatment and control of cancer” and inserting
11 “diagnosis, treatment, survivorship programs, and
12 control of cancer.”.

13 **TITLE VIII—PROGRAMS FOR** 14 **END-OF-LIFE CARE**

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

16 Part R of title III of the Public Health Service Act
17 (as amended by section 601), is further amended by add-
18 ing the following:

19 **“SEC. 399EE. PROGRAMS FOR END-OF-LIFE CARE.**

20 “(a) **DEMONSTRATION PROJECTS.**—The Secretary
21 shall award competitive grants to eligible entities to de-
22 velop, implement, and evaluate evidence-based programs
23 for the delivery of quality of cancer care during the end-
24 of-life to individuals with cancer (with a special emphasis
25 on children) and their families.

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

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

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

15 “(1) integrate palliative care or end-of-life care
16 programs with entities including academic institu-
17 tions, community organizations, hospice programs,
18 hospitals, cancer patient and survivorship organiza-
19 tions, health care providers, cancer centers, or other
20 entities determined appropriate by the Secretary;

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

1 “(3) increase public awareness, including out-
2 reach campaigns, particularly to underserved popu-
3 lations;

4 “(4) disseminate information to health care
5 providers and individuals with cancer and their fami-
6 lies regarding available end-of-life programs, includ-
7 ing hospice programs;

8 “(5) provide and evaluate education and train-
9 ing in end-of-life care for health care providers,
10 including—

11 “(A) establishing pilot training programs
12 (including faculty training programs) in medi-
13 cine including oncology (including pediatric on-
14 cology), family medicine, psychiatry, psychology,
15 pain, nursing, pharmacology and social work,
16 and other disciplines; or

17 “(B) developing, implementing, and evalu-
18 ating pilot training programs for the staff of
19 hospices, nursing homes, hospitals, home health
20 agencies, outpatient care clinics, and other enti-
21 ties determined appropriate by the Secretary;

22 “(6) design or implement model end-of-life care
23 programs for individuals with cancer and their fami-
24 lies including improving access to clinical trials
25 where appropriate;

1 “(7) develop and evaluate pilot programs to ad-
2 dress the special needs of children or other under-
3 served populations and their families in end-of-life
4 programs;

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

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

11 “(e) DISSEMINATION.—The Secretary shall dissemi-
12 nate findings made as a result of activities conducted
13 under this section to the public in coordination with the
14 Director of the Agency for Healthcare Research and Qual-
15 ity, the Administrator of the Centers for Medicare & Med-
16 icaid Services, and the heads of other appropriate Federal
17 agencies.”.

18 **TITLE IX—DEVELOPING**
19 **TRAINING CURRICULA**

20 **SEC. 901. CURRICULUM DEVELOPMENT.**

21 Part R of title III of the Public Health Service Act
22 (as amended by section 801), is further amended by add-
23 ing at the end the following:

1 **“SEC. 399FF. CURRICULUM DEVELOPMENT.**

2 “(a) IN GENERAL.—The Secretary shall award com-
3 petitive grants for the development of curricula for health
4 care provider training regarding the assessment, moni-
5 toring, improvement, and delivery of quality of cancer
6 care.

7 “(b) ELIGIBILITY.—To be eligible to receive a grant
8 under this section, an entity shall be an academic institu-
9 tion, nonprofit organization, cancer center, health center,
10 medical school, or other entity determined appropriate by
11 the Secretary.

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

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

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

22 “(2) develop curricula concerning the delivery of
23 quality of cancer care including palliative care, hos-
24 pice care, end-of-life care, or cancer survivorship;
25 and

1 “(3) provide recommendations for training pro-
 2 tocols for medical and nursing education, fellow-
 3 ships, and continuing education in quality of cancer
 4 care including palliative care, hospice care, survivor-
 5 ship, or end-of-life care for health care providers.

6 “(e) AUTHORIZATION OF APPROPRIATIONS.—There
 7 is authorized to be appropriated to carry out this section,
 8 \$3,000,000 for fiscal year 2003 and such sums as may
 9 be necessary for each of fiscal years 2004 through 2007.”.

10 **SEC. 902. CANCER CARE WORKFORCE AND**
 11 **TRANSLATIONAL RESEARCH.**

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

15 (1) by striking “The Director of the Institute”
 16 and inserting the following:

17 “(a) IN GENERAL.—The Director of the Institute”;

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

20 “(2) annual and long-term training goals to as-
 21 sure an adequate and diverse cancer care workforce
 22 including—

23 “(A) preparing and implementing a plan to
 24 provide assistance to health professionals in
 25 health professions experiencing the most severe

1 shortages including the provision of grants,
2 scholarships, fellowships, post-doctoral stipends,
3 or loans to eligible individuals to increase the
4 cancer care workforce; and

5 “(B) educating students of health profes-
6 sions and health professionals in—

7 “(i) effective methods for the preven-
8 tion and early detection of cancer;

9 “(ii) the identification of individuals
10 with a high risk of developing cancer;

11 “(iii) improved methods of patient re-
12 ferral to appropriate centers for early diag-
13 nosis and treatment of cancer;

14 “(iv) methods to deliver culturally
15 competent care; and

16 “(v) other appropriate methods for
17 providing quality of cancer care; and”; and

18 (3) by adding at the end the following:

19 “(b) COORDINATION WITH EXISTING PROGRAMS.—
20 In carrying out the activities under subsection (a)(2), the
21 Director of the Institute shall coordinate with existing pro-
22 grams, including programs at the Health Resources and
23 Services Administration, to prevent duplication.”.

24 (b) NATIONAL CANCER RESEARCH AND DEMONSTRA-
25 TION CENTERS.—Section 414(b) of the Public Health

1 Service Act (42 U.S.C. 285a–3(b)) is amended by striking
2 paragraph (3) and inserting the following:

3 “(3) clinical training (including training for al-
4 lied health professionals), loan forgiveness or post-
5 doctoral stipends for bench researchers, continuing
6 education for health professionals and allied health
7 professionals, and information programs for the pub-
8 lic regarding cancer; and”.

9 (c) **TRANSLATIONAL CANCER RESEARCH.**—Subpart
10 1 of part C of title IV of the Public Health Service Act
11 (42 U.S.C. 285 et seq.) is amended by inserting after sec-
12 tion 414 the following:

13 **“SEC. 414A. TRANSLATIONAL CANCER RESEARCH.**

14 “(a) **IN GENERAL.**—The Director of the Institute
15 shall enter into cooperative agreements with, and make
16 grants to, public or nonprofit entities to conduct multi-
17 disciplinary, translational cancer research.

18 “(b) **USE OF FUNDS.**—

19 “(1) **IN GENERAL.**—The Director of the Insti-
20 tute may use funds provided under this section to
21 establish networks and partnerships to link commu-
22 nity cancer providers to programs funded under this
23 section.

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

4 “(c) STRATEGIC PLAN.—Not later than October 1,
5 2004, the Director of the Institute shall develop and im-
6 plement a strategic plan, in collaboration with entities per-
7 forming translational research, for identifying, expanding,
8 and disseminating the results of translational cancer re-
9 search to health care providers.

10 “(d) DUTIES.—An entity receiving a grant under this
11 section shall—

12 “(1) conduct research with the potential to im-
13 prove the prevention, diagnosis, and treatment of
14 cancer and to improve the quality of cancer care, in-
15 cluding palliation;

16 “(2) conduct clinical research studies on prom-
17 ising cancer treatments including clinical trials; and

18 “(3) evaluate tests, techniques, or technologies
19 in individuals being evaluated for the presence of
20 cancer.

21 “(e) DEFINITION OF TRANSLATIONAL CANCER RE-
22 SEARCH.—As used in this section, the term ‘translational
23 cancer research’ means scientific laboratory and clinical
24 research and testing necessary to transform scientific or
25 medical discoveries into new approaches, products, or

1 processes that can assist in preventing, diagnosing, or con-
2 trolling cancer.”

3 (d) AUTHORIZATION OF APPROPRIATIONS.—Section
4 417B(a) of the Public Health Service Act (42 U.S.C.
5 285a–8(a)) is amended by striking “1996” and inserting
6 “2007”.

7 **TITLE X—CONDUCTING** 8 **REPORTS**

9 **SEC. 1001. STUDIES AND REPORTS BY THE INSTITUTE OF** 10 **MEDICINE.**

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

13 (1) evaluate Federal and State activities relat-
14 ing to comprehensive cancer control programs and
15 activities;

16 (2) evaluate the quality of cancer care (includ-
17 ing palliative care, end-of-life care, and survivorship)
18 that medicare and medicaid beneficiaries receive and
19 the extent to which medicare and medicaid coverage
20 and reimbursement policies affect access to quality
21 cancer care;

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

1 (4) evaluate access to clinical trials and the re-
2 lationship of such access to the quality of cancer
3 care, especially with respect to medically underserved
4 populations; and

5 (5) assess existing gaps in and impediments to
6 the quality of cancer care, including gaps in data,
7 research and translation, seamless patient care and
8 navigation, palliative care, and care provided to un-
9 derserved populations.

10 (b) REPORTS.—

11 (1) IN GENERAL.—Not later than 4 years after
12 the date of enactment of this Act, the Institute of
13 Medicine shall submit to the Secretary of Health
14 and Human Services a report containing information
15 on the evaluation conducted under paragraphs (1)
16 through (5) of subsection (a), including data col-
17 lected at the State level through contracts with ap-
18 propriate organizations as designated by the Insti-
19 tute of Medicine.

20 (2) 8 YEARS.—Not later than 8 years after the
21 date of enactment of this Act, the Institute of Medi-
22 cine shall submit to the Secretary of Health and
23 Human Services a report containing information and
24 recommendations on the areas described in sub-

1 section (a), including data collected from relevant
2 demonstration projects.

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

7 (c) DEFINITIONS.—

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

12 (2) COMPREHENSIVE CANCER CONTROL PRO-
13 GRAM.—The term ‘comprehensive cancer control
14 program’ has the meaning given such term in sec-
15 tion 320B of the Public Health Service Act.

16 (d) AUTHORIZATION OF APPROPRIATIONS.—There is
17 authorized to be appropriated to carry out this section,
18 \$2,500,000 for fiscal year 2003, and such sums as may
19 be necessary for each of fiscal years 2004 through 2007.

○