

112TH CONGRESS
2D SESSION

H. R. 6157

To create a patient-centered quality of care initiative for seriously ill patients through the establishment of a stakeholder strategic summit, quality of life education and awareness initiative, health care workforce training, an advisory committee, and palliative care focused research, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

JULY 19, 2012

Mr. CLEAVER (for himself and Mr. BACHUS) introduced the following bill;
which was referred to the Committee on Energy and Commerce

A BILL

To create a patient-centered quality of care initiative for seriously ill patients through the establishment of a stakeholder strategic summit, quality of life education and awareness initiative, health care workforce training, an advisory committee, and palliative care focused research, 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 “Patient Centered Qual-
5 ity Care for Life Act”.

1 **SEC. 2. FINDINGS.**

2 Congress finds the following:

3 (1) Studies demonstrate that, despite very high
4 health expenditures, seriously ill patients are not
5 satisfied with the quality of their medical care, char-
6 acterized by untreated symptoms, unmet psycho-
7 social and personal care needs, high caregiver bur-
8 den, and low patient and family satisfaction.

9 (2) Health care delivery systems in the United
10 States are not set up to address the complex chronic
11 care needs that are increasingly becoming the norm
12 for more patients and survivors (and family care-
13 givers of such patients and survivors) facing serious
14 illness like cancer; heart, renal and liver failure; lung
15 disease; Alzheimer’s disease and related dementias,
16 which are care needs that can span over many years
17 or even decades and impose significant burdens on
18 family caregivers.

19 (3) Public outreach and education for seriously
20 ill patients, survivors, and their families to improve
21 awareness of and demand for the benefits of inte-
22 grating symptom management alongside disease-di-
23 rected treatment is essential to improving the quality
24 of life of patients, survivors, and their families,
25 which should be an integral element of quality health
26 care.

1 (4) Palliative care is specialized medical care
2 for seriously ill patients. This type of care is focused
3 on providing patients with relief from the symptoms,
4 pain, and stresses of a serious illness—whatever the
5 diagnosis. The goal is to improve quality of life for
6 both the patient and the family. Palliative care is
7 provided by a team of doctors, nurses, and other
8 specialists who work with a patient’s other doctors
9 to provide an extra layer of support. Palliative care
10 is appropriate at any age and at any stage in a seri-
11 ous illness, and can be provided together with cura-
12 tive treatment.

13 (5) Medical teams that help patients manage
14 pain and stress during, alongside, and after treat-
15 ment provide patients with better quality of life. Evi-
16 dence-based research shows that such care may also
17 lead to increased survival. These teams also reduce
18 preventable suffering and caregiver breakdown.

19 (6) Patients receiving palliative or coordinated
20 care feel better and are more likely to keep their
21 doctor’s appointments, complete their treatment, and
22 take their medications. If patient disease-related and
23 treatment-related symptoms such as pain, nausea,
24 depression, fatigue, and breathlessness are managed,
25 patients are more likely to eat well, exercise, social-

1 ize, and take pleasure in things that can help them
2 feel better emotionally and physically and help them
3 fight chronic illness.

4 (7) A 2010 Harris Interactive poll commis-
5 sioned by the American Cancer Society Cancer Ac-
6 tion Network (ACSCAN) among cancer patients,
7 survivors, and their family caregivers found that
8 fewer than one-third of the patients and survivors
9 were asked by their doctor about what is important
10 to such patients and survivors in terms of quality of
11 life. In that same poll, fewer than one-third of the
12 patients and survivors were asked if they were hav-
13 ing stress, depression, anxiety, or other emotional
14 concerns related to the cancer or discussed ways to
15 help with those emotional effects, though more than
16 one-third of such patients and survivors said they
17 had these emotional concerns.

18 (8) A report commissioned by the Health Re-
19 sources Service Administration (HRSA) in 2002
20 projected significant shortfalls in the number of pal-
21 liative medicine specialists in the United States and
22 called for increased education and training in symp-
23 tom assessment and management and other pallia-
24 tive care core competencies across all clinical special-
25 ties serving seriously ill patients. Several Institute of

1 Medicine cancer reports, including on palliative care
2 in 2001, survivorship in 2006, psychosocial care in
3 2007, and pain in 2011 have also consistently sig-
4 naled the need for skills training to improve health
5 professional communication with patients and fami-
6 lies regarding symptoms, establishing goals of care,
7 tailoring treatments to those goals, and other quality
8 of life concerns.

9 **SEC. 3. NATIONAL PATIENT-CENTERED HEALTH CARE AND**
10 **QUALITY OF LIFE STAKEHOLDER STRATEGIC**
11 **SUMMIT.**

12 (a) SUMMIT.—Not later than one year after the date
13 of the enactment of this section, the Secretary of Health
14 and Human Services shall convene a Patient-Centered
15 Health Care and Quality of Life Stakeholder Strategic
16 Summit (in this Act to be referred to as the “Summit”)
17 to be composed of individuals with appropriate expertise
18 to—

- 19 (1) analyze key health system barriers to pro-
20 viding patient-centered health care that integrates
21 symptom management and other aspects of coordi-
22 nated or palliative care; and
- 23 (2) identify strategic solutions for collectively
24 addressing quality of life concerns for the rapidly ex-
25 panding population of patients and survivors facing

1 serious, complex, and chronic illness in the United
2 States and for the families of such patients and sur-
3 vivors.

4 (b) PARTICIPANTS.—The Summit shall include rep-
5 resentatives from at least the following:

6 (1) Federal agencies, including—

7 (A) the Department of Health and Human
8 Services, including from the Centers for Disease
9 Control and Prevention, the Health Resources
10 and Services Administration, the Agency for
11 Healthcare Research and Quality, the Centers
12 for Medicare & Medicaid Services, and the Na-
13 tional Institutes of Health;

14 (B) the Department of Veterans Affairs;
15 and

16 (C) the Department of Defense.

17 (2) Private organizations, including—

18 (A) health professional organizations that
19 represent physicians, nurses, pharmacists, and
20 social workers;

21 (B) patient non-profit organizations (as
22 defined in section 4(g));

23 (C) private health insurance organizations;

24 (D) faith community representatives; and

1 (E) other professionals as deemed appro-
2 priate by the Secretary.

3 (c) STEERING COMMITTEE.—

4 (1) IN GENERAL.—The Secretary shall establish
5 a Summit Steering Committee to plan the Summit,
6 coordinate participants of the Summit, develop an
7 agenda for the Summit that is in accordance with
8 subsection (d), and draft a summary report detailing
9 recommendations made by the participants of the
10 Summit for a national strategic action agenda to im-
11 prove patient-centered care and quality of life (in
12 this Act to be referred to as the “National Action
13 Agenda”) in accordance with subsection (d)(4). The
14 Secretary shall appoint the representatives described
15 in paragraph (2)(A) and shall seek nominations
16 from relevant stakeholders and, from such nomina-
17 tions, appoint representatives described in paragraph
18 (2)(B).

19 (2) COMPOSITION.—The Summit Steering Com-
20 mittee shall consist of at least the following mem-
21 bers:

22 (A) MEMBERS FROM FEDERAL AGEN-
23 CIES.—

24 (i) The Secretary, who will serve as
25 chair of the Committee.

1 (ii) Four representatives from Federal
 2 agencies described in subsection (b) (or
 3 any other Federal agency deemed appro-
 4 priate by the Secretary), to be appointed
 5 by the Secretary.

6 (B) MEMBERS REPRESENTING STAKE-
 7 HOLDER ENTITIES.—

8 (i) Six representatives of health pro-
 9 fessionals (with each of such 6 representa-
 10 tives having research, clinical, and teaching
 11 or mentoring expertise).

12 (ii) Three representatives of patient
 13 advocacy organizations.

14 (iii) One representative of a private
 15 health insurance organization.

16 (iv) One representative of faith com-
 17 munities.

18 (v) Two physicians.

19 (vi) Two nurses.

20 (vii) One social worker.

21 (d) AGENDA.—The agenda for the Summit shall
 22 focus on specific areas that include at least the following:

23 (1) Improving communication and coordination
 24 of health care among primary care providers, med-
 25 ical specialists, and other health professionals and

1 seriously ill patients and families of such patients to
2 ensure that symptoms are managed and other qual-
3 ity of life needs are met to support the continued
4 functioning and well-being of such patients.

5 (2) Examining the appropriate roles of both
6 physician and non-physician professionals (such as
7 nurse practitioners, clinical social workers, physician
8 assistants, and other patient or survivor navigators
9 or case coordinators) in strengthening access to inte-
10 grated, coordinated, or palliative care across care
11 settings for all seriously ill patients and families of
12 such patients.

13 (3) Examining the role of health information
14 technology in promoting delivery of integrated care
15 to such patients.

16 (4) Developing recommendations for a National
17 Action Agenda, which shall specify research, surveil-
18 lance, health information technology, workforce
19 training, delivery of care, and communication activi-
20 ties required to collectively address barriers to
21 achieving integrated palliative care for seriously ill
22 patients in all care settings. Such agenda shall in-
23 clude strategies for reducing disparities among medi-
24 cally underserved populations.

1 (e) REPORT.—Not later than one year after the last
2 day of the Summit, the Secretary of Health and Human
3 Services shall submit to the Committee on Energy and
4 Commerce of the House of Representatives and the Com-
5 mittee on Health, Education, Labor, and Pensions of the
6 Senate a report on the recommendations made by the par-
7 ticipants of the Summit and shall make such recommenda-
8 tions available to the public.

9 (f) SERIOUSLY ILL PATIENT DEFINED.—For pur-
10 poses of this Act, the term “seriously ill patient” means
11 an individual who has a serious health condition (as de-
12 fined in section 101(11) of the Family and Medical Leave
13 Act of 1993 (26 U.S.C. 2911(11)).

14 (g) AUTHORIZATION OF APPROPRIATIONS.—There is
15 authorized to be appropriated to carry out this section
16 such sums as are necessary for each of the fiscal years
17 2013 through 2017.

18 **SEC. 4. QUALITY OF LIFE PATIENT AND PROFESSIONAL**
19 **AWARENESS GRANTS PROGRAM INITIATIVE.**

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 following
22 new part:

1 **“PART W—PROGRAMS RELATING TO PALLIATIVE**
2 **CARE**

3 **“SEC. 39900. QUALITY OF LIFE PATIENT AND PROFES-**
4 **SIONAL AWARENESS GRANTS PROGRAM INI-**
5 **TIATIVE.**

6 “(a) IN GENERAL.—Not later than 6 months after
7 the date of the submission of the report by the Patient-
8 Centered Health Care and Quality of Life Stakeholder
9 Strategic Summit under section 3(e) of the Patient Cen-
10 tered Quality Care for Life Act, the Secretary, through
11 the Director of the Centers for Disease Control and Pre-
12 vention, shall establish a national quality of life education
13 and awareness grants program initiative for seriously ill
14 patients, families of such patients, and health profes-
15 sionals who treat such patients for the purposes of encour-
16 aging an increased demand for and delivery of integrated
17 and patient-centered care for managing pain and symp-
18 toms of such patients and improving the quality of life
19 of such patients. Under the initiative, the Secretary shall,
20 subject to subsection (h), award competitive grants to eli-
21 gible entities described in subsection (b) to develop new
22 and expand existing information, resources, and commu-
23 nication materials about symptom management and other
24 aspects of patient-centered care as an integral part of
25 quality care for serious illnesses such as cancer; heart,
26 renal and liver failure; lung disease; and Alzheimer’s dis-

1 ease and related dementias. Such materials shall be pre-
2 sented in a variety of formats (such as online, print, and
3 public service announcement).

4 “(b) ELIGIBLE ENTITIES.—For purposes of this sec-
5 tion, an eligible entity includes only a State health depart-
6 ment, community health center, State or territory pro-
7 gram supported by the National Comprehensive Cancer
8 Control Program of the Centers for Disease Control and
9 Prevention, health profession school, chronic disease or
10 cancer center, academic medical center, physician practice,
11 home health care agency, palliative care or psychosocial
12 care team (as defined in subsection (g)), hospice program,
13 patient non-profit organization (as defined in subsection
14 (g)), clinical pastoral education program, long-term care
15 facility, faith community organization, or other public or
16 private entity or organization addressing patient-centered
17 care and quality of life concerns of seriously ill patients.

18 “(c) APPLICATION.—To be eligible to receive a grant
19 under this section, an entity shall submit to the Secretary
20 an application at such time, in such manner, and con-
21 taining such information as the Director may require, in-
22 cluding assurances that the entity will—

23 “(1) evaluate programs carried out by the enti-
24 ty through a grant provided under this section;

1 “(2) submit to the Secretary a report on the
2 findings of such evaluations; and

3 “(3) coordinate the dissemination of such find-
4 ings with the Secretary.

5 “(d) USE OF FUNDS.—An entity awarded a grant
6 under this section shall use such grant to carry out pro-
7 grams described in subsection (e), for patients and fami-
8 lies of such patients that further the purposes described
9 in subsection (a).

10 “(e) PROGRAMS.—Programs described in this sub-
11 section, for which a grant awarded under this section may
12 be used, include programs to—

13 “(1) navigate the health system, including as-
14 sistance to patients with finding health professionals
15 to support quality of life needs, care decisionmaking
16 and coordination, and transitions across care set-
17 tings;

18 “(2) provide general advocacy on behalf of pa-
19 tients and survivors to provide patients information
20 to help them effectively communicate with health
21 care providers about pain, physical and psychosocial
22 symptoms, and barriers they are facing in adhering
23 to curative or disease-directed treatments;

24 “(3) encourage health professionals to request
25 coordinated patient-centered care consults for pa-

1 tients that are integrated alongside disease directed
2 treatment in various care settings; and

3 “(4) collect and analyze data related to the ef-
4 fectiveness of the initiative under subsection (a).

5 “(f) PRIORITY.—In carrying out the grant program
6 under this section, the Secretary shall give priority to ap-
7 plications that include an emphasis on addressing out-
8 reach efforts for seriously ill patients who are among
9 medically underserved populations (as defined in section
10 1302(7)) and families of such patients or health profes-
11 sionals serving medically underserved populations. Such
12 populations would include pediatric patients, young adult
13 and adolescent patients, racial and ethnic minority popu-
14 lations, and other priority populations specified by the
15 Secretary.

16 “(g) DEFINITIONS.—For purposes of this section:

17 “(1) PSYCHOSOCIAL CARE TEAM.—The term
18 ‘psychosocial care team’ means health professionals
19 focused on addressing social and emotional concerns
20 of serious illness, and may include professionals such
21 as social workers, psychiatrists, psychologists,
22 nurses, child life specialists, teachers, chaplains,
23 spiritual counselors, physical and occupational thera-
24 pists, nutritionists, integrative medicine specialists,

1 patient service coordinators, patient navigators, and
 2 patient representatives.

3 “(2) PATIENT NON-PROFIT ORGANIZATION.—

4 The term ‘patient non-profit organization’ means a
 5 nonprofit entity primarily engaged in raising funds
 6 for health-related research, such as disease preven-
 7 tion, health education, and patient services.

8 “(h) AUTHORIZATION OF APPROPRIATIONS.—There
 9 is authorized to be appropriated to carry out this section
 10 such sums as are necessary.”.

11 **SEC. 5. PROFESSIONAL WORKFORCE TRAINING GRANTS**

12 **PROGRAM INITIATIVE.**

13 Part W of title III of the Public Health Service Act,
 14 as added by section 4, is amended by adding at the end
 15 the following new section:

16 **“SEC. 39900-1. PROFESSIONAL WORKFORCE TRAINING**

17 **GRANTS PROGRAM INITIATIVE.**

18 “(a) INITIATIVE.—

19 “(1) IN GENERAL.—Not later than 6 months
 20 after the date of the submission of the report by the
 21 Patient-Centered Health Care and Quality of Life
 22 Stakeholder Strategic Summit under section 3(e) of
 23 the Patient Centered Quality Care for Life Act, the
 24 Secretary, through the Administrator of the Health
 25 Resources and Services Administration, shall estab-

1 lish a health care professional workforce training
2 grants program initiative for the purposes of pro-
3 moting and enhancing symptom assessment and
4 management, communications skills, coordinated pa-
5 tient-centered care, and other quality of life focused
6 clinical core competencies (as described in paragraph
7 (2)) across all clinical specialties that serve seriously
8 ill patients and patients with multiple or complex
9 chronic diseases, such as patients with cancer; heart,
10 renal, and liver failure; lung disease; and Alz-
11 heimer’s disease and related dementias. Under such
12 initiative, the Secretary shall, subject to subsection
13 (i), award competitive grants to eligible entities to
14 provide evidence-based training and develop new
15 training for health professionals, including physi-
16 cians, nurses, social workers, and professional chap-
17 lains for the purposes described in the previous sen-
18 tence.

19 “(2) QUALITY OF LIFE FOCUSED CLINICAL
20 CORE COMPETENCIES DESCRIBED.—For purposes of
21 paragraph (1), quality of life focused clinical core
22 competencies include, at a minimum, the assessment
23 and management of physical, psychological, and
24 spiritual symptoms; establishment of patient-cen-
25 tered goals of care; support to patient and family

1 caregivers; and management of transitions across
2 care sites.

3 “(b) ELIGIBLE ENTITIES.—For purposes of sub-
4 section (a), an eligible entity is an entity described in sec-
5 tion 39900(b).

6 “(c) APPLICATION.—To be eligible to receive a grant
7 under this section, an entity shall submit to the Secretary
8 an application at such time, in such manner, and con-
9 taining such information as the Secretary may require, in-
10 cluding assurances that the entity will—

11 “(1) evaluate programs carried out by the enti-
12 ty through the grant provided under this section;

13 “(2) submit to the Secretary a report on the
14 findings of such evaluations; and

15 “(3) coordinate the dissemination of such find-
16 ings with the Secretary.

17 “(d) USE OF FUNDS.—An entity awarded a grant
18 under this section shall use such grant to carry out pro-
19 grams described in subsection (e) to train health care pro-
20 fessionals described in subsection (a)(1) for the purposes
21 described in such subsection.

22 “(e) PROGRAMS.—Programs described in this sub-
23 section, for which a grant awarded under this section may
24 be used, include programs to—

1 “(1) enhance health professional communication
2 skills in caring for seriously ill patients and sur-
3 vivors, establishing goals of care, and tailoring treat-
4 ments;

5 “(2) improve health profession identification of
6 patient populations that benefit from coordinated
7 palliative care and appropriate referral of patients
8 for consultations with specialized interdisciplinary
9 palliative care teams;

10 “(3) improve health professional skills in symp-
11 toms assessment and management, developing com-
12 prehensive care coordination and discharge plans to
13 support transitions across care settings, managing
14 patients with complex or multiple chronic conditions,
15 and preparing survivorship care plans;

16 “(4) promote quality of life focused clinical core
17 competencies (as described in subsection (a)(2))
18 across all clinical specialties serving seriously ill pa-
19 tients;

20 “(5) provide technical assistance to hospitals
21 and other care settings to establish coordinated pal-
22 liative care teams;

23 “(6) create and expand coordinated palliative
24 care leadership centers (as defined in subsection
25 (h));

1 “(7) provide mentoring and training to health
2 professionals;

3 “(8) improve cultural sensitivity communication
4 and patient care for minority and medically under-
5 served populations, including by addressing the par-
6 ticular needs of children, adolescents, and families of
7 such children and adolescents; racial and ethnic
8 groups; and other medically underserved patient and
9 survivor populations; and

10 “(9) collect and analyze data related to the ef-
11 fectiveness of health professional education and
12 training efforts carried out pursuant to this section.

13 “(f) PRIORITY.—In carrying out the grant program
14 under this section, the Secretary shall give priority to ap-
15 plications that include an emphasis on addressing out-
16 reach efforts for seriously ill patients who are among
17 medically underserved populations (as defined in section
18 1302(7)) and families of such patients or health profes-
19 sionals serving medically underserved populations. Such
20 populations would include pediatric patients, young adult
21 and adolescent patients, racial and ethnic minority popu-
22 lations, and other priority populations specified by the
23 Secretary.

24 “(g) STUDY.—Not later than one year after the date
25 of the enactment of the Patient Centered Quality Care for

1 Life Act, the Secretary shall update and expand the Sep-
2 tember 2002 report of the Health Resources and Services
3 Administration, titled ‘The Supply, Demand and Use of
4 Palliative Care Physicians in the United States’. Such up-
5 date and expansion shall be based on an examination of
6 workforce trends, workforce capacity, and training needs
7 for palliative medicine physicians, physician assistants,
8 nurse practitioners, and other palliative care team mem-
9 bers in all care settings in the United States, as well as
10 training needs for other medical specialists and non-physi-
11 cian clinicians.

12 “(h) PALLIATIVE CARE LEADERSHIP CENTER DE-
13 FINED.—For purposes of this section, the term ‘palliative
14 care leadership center’ means a center—

15 “(1) that trains hospital palliative care pro-
16 grams;

17 “(2) that provides intensive operational training
18 and mentoring for palliative care programs at every
19 stage of development and growth; and

20 “(3) that provides training oriented to teams
21 rather than individuals, and involves participation by
22 teams of hospital and hospice health care profes-
23 sionals involved in starting or running a palliative
24 care program, including physicians, nurses, social
25 workers, administrators and financial managers.

1 “(i) AUTHORIZATION OF APPROPRIATIONS.—There is
2 authorized to be appropriated to carry out this section
3 such sums as are necessary for each of the fiscal years
4 2013 through 2018.”.

5 **SEC. 6. QUALITY OF LIFE CROSS-AGENCY ADVISORY COM-**
6 **MITTEE.**

7 Part W of title III of the Public Health Service Act,
8 as added by section 4 and amended by section 5, is further
9 amended by adding at the end the following new section:
10 **“SEC. 39900–2. QUALITY OF LIFE CROSS-AGENCY ADVISORY**
11 **COMMITTEE.**

12 “(a) ESTABLISHMENT.—Not later than 90 days after
13 the date of the enactment of this section and subject to
14 subsection (e), the Secretary shall establish a Quality of
15 Life Cross-Agency Advisory Committee (in this section to
16 be referred to as the ‘Advisory Committee’) to advise, co-
17 ordinate, and assist the Centers for Disease Control and
18 Prevention and the Health Resources and Services Admin-
19 istration in creating and conducting the national quality
20 of life education and awareness initiative under section
21 39900 and the health care professional workforce train-
22 ing initiative under section 39900–1 and disseminate
23 findings that have been identified from such initiatives for
24 cross agency implementation of best practices.

1 “(b) MEMBERSHIP.—The Advisory Committee shall
2 be composed of members who shall be appointed by the
3 Secretary and shall include representatives of—

4 “(1) the Department of Health and Human
5 Services, including from the Centers for Disease
6 Control and Prevention, the Health Resources and
7 Services Administration, the Agency for Healthcare
8 Research and Quality, the Centers for Medicare &
9 Medicaid Services, and the National Institutes of
10 Health;

11 “(2) the Department of Veterans Affairs;

12 “(3) the Department of Defense;

13 “(4) public and private organizations with ex-
14 pertise in patient-centered care, palliative care, psy-
15 chosocial care, and symptom management and survi-
16 vorship; and

17 “(5) such other representatives as the Secretary
18 deems necessary.

19 “(c) DUTIES.—The Advisory Committee shall—

20 “(1) evaluate the results of the programs fund-
21 ed by the grants awarded under section 39900(b)
22 and under section 39900–1(b);

23 “(2) coordinate and implement a cross-agency
24 strategic plan, with respect to the agencies specified

1 in subsection (b), to disseminate findings from such
2 programs;

3 “(3) advise the Secretary of Health and Human
4 Services on strategies for disseminating across agen-
5 cies specified in subsection (b) recommendations
6 from the National Action Agenda described in sec-
7 tion 3(c)(1) of the Patient Centered Quality Care for
8 Life Act;

9 “(4) consider and summarize recent advances
10 achieved in symptom management and survivorship
11 research relevant to the goals of this part and make
12 recommendations to the Director of the National In-
13 stitutes of Health on gaps in basic, clinical, behav-
14 ioral, or other research required to achieve further
15 improvements in care to support quality of life and
16 survivorship;

17 “(5) develop a strategy for developing new and
18 enhancing health surveillance tools used to track
19 symptoms, late effects, and quality care trends over
20 time, including national surveys of the overall popu-
21 lation of the United States, such as the National
22 Health Interview Survey and the Behavioral Risk
23 Factor Surveillance System conducted by the Cen-
24 ters for Disease Control and Prevention and the
25 Health Information National Trends Survey con-

1 ducted by the National Institutes of Health, as well
2 as administrative databases and disease registries
3 such as databases of the Centers for Medicare &
4 Medicaid Services, the Surveillance Epidemiology
5 and End Results (SEER) cancer registries program
6 of the National Cancer Institute, the SEER–Medi-
7 care Linked Database of the National Cancer Insti-
8 tute, and the National Program of Cancer Registries
9 of the Centers for Disease Control and Prevention;
10 and

11 “(6) make appropriate updates and addendums
12 annually to the National Action Agenda.

13 “(d) MEETINGS.—The Advisory Committee shall
14 meet at least once a year.

15 “(e) AUTHORIZATION OF APPROPRIATIONS.—There
16 are authorized to be appropriated to carry out this section
17 such sums as are necessary for each of the fiscal years
18 2013 through 2018.”.

19 **SEC. 7. ENHANCING RESEARCH IN SUPPORT OF PATIENT**
20 **QUALITY OF LIFE.**

21 “(a) IN GENERAL.—Part W of title III of the Public
22 Health Service Act, as added by section 4 and amended
23 by sections 5 and 6, is further amended by adding at the
24 end the following new section:

1 **“SEC. 39900–3. ENHANCING RESEARCH IN SUPPORT OF PA-**
2 **TIENT QUALITY OF LIFE.**

3 “(a) IN GENERAL.—The Secretary, acting through
4 the Director of the National Institutes of Health, shall de-
5 velop and implement a strategy to be applied across the
6 institutes and centers of the National Institutes of Health
7 that is in accordance with recommendations of the Advi-
8 sory Committee established under section 39900–2 to ex-
9 pand national research programs in symptom manage-
10 ment, palliative, psychosocial, and survivorship care.

11 “(b) RESEARCH PROGRAMS.—The Director of the
12 National Institutes of Health shall expand and intensify
13 research programs in symptom management and pallia-
14 tive, psychosocial, and survivorship care and research pro-
15 grams that address the quality of life needs for the rapidly
16 growing population in the United States of seriously ill
17 patients (with illnesses such as cancer; heart, renal and
18 live failure; lung disease; and Alzheimer’s disease and re-
19 lated dementias).”.

20 (b) EXPANDING TRANS-NIH RESEARCH REPORTING
21 TO INCLUDE QUALITY OF LIFE AND SURVIVORSHIP RE-
22 SEARCH.—

23 (1) IN GENERAL.—Section 402A(c)(2)(B)(i) of
24 the Public Health Service Act (42 U.S.C.
25 282a(c)(2)(B)(i)) is amended by inserting “and for
26 conducting or supporting research with respect to

1 quality of life and survivorship” after “or national
2 centers”.

3 (2) EFFECTIVE DATE.—The amendment made
4 by paragraph (1) shall apply with respect to reports
5 required on or after January 1, 2013.

○