108TH CONGRESS 1ST SESSION

H. R. 918

To authorize the Health Resources and Services Administration, the National Cancer Institute, and the Indian Health Service to make grants for model programs to provide to individuals of health disparity populations prevention, early detection, treatment, and appropriate follow-up care services for cancer and chronic diseases, and to make grants regarding patient navigators to assist individuals of health disparity populations in receiving such services.

IN THE HOUSE OF REPRESENTATIVES

February 26, 2003

Mr. Menendez (for himself, Ms. Pryce of Ohio, Mr. Green of Texas, Ms. Ros-Lehtinen, Mr. Thompson of Mississippi, Mr. Lincoln Diaz-Balart of Florida, Mr. Rodriguez, Mrs. Wilson of New Mexico, Mrs. Christensen, Mr. Quinn, Mr. Serrano, Mr. McCotter, Mr. Pallone, Mr. Pearce, Mr. Udall of New Mexico, and Mr. Mario Diaz-Balart of Florida) introduced the following bill; which was referred to the Committee on Energy and Commerce and in addition to the Committee on Resources, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

A BILL

To authorize the Health Resources and Services Administration, the National Cancer Institute, and the Indian Health Service to make grants for model programs to provide to individuals of health disparity populations prevention, early detection, treatment, and appropriate follow-up care services for cancer and chronic diseases, and to make grants regarding patient navigators to assist individuals of health disparity populations in receiving such services.

- 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 Navigator,
- 5 Outreach, and Chronic Disease Prevention Act of 2003".

6 SEC. 2. FINDINGS.

- The Congress finds as follows:
- 8 (1) Despite notable progress in the overall
- 9 health of the Nation, there are continuing disparities
- in the burden of illness and death experienced by Af-
- 11 rican Americans, Latinos and Hispanics, Native
- 12 Americans, Alaska Natives, Asian and Pacific Is-
- landers and the poor, compared to the United States
- population as a whole.
- 15 (2) Many racial and ethnic minority groups suf-
- fer disproportionately from cancer. Mortality and
- morbidity rates remain the most important measures
- of the overall progress against cancer. Decreasing
- rates of death from cancer reflect improvements in
- both prevention and treatment. Among all ethnic
- 21 groups in the United States, African American
- males have the highest overall rate of mortality from
- cancer. Some specific forms of cancer affect other
- ethnic minority communities at rates up to several

- times higher than the national averages (such as stomach and liver cancers among Asian American populations, colon and rectal cancer among Alaska natives, and cervical cancer among Hispanic and Vietnamese-American women).
 - (3) Regions characterized by high rates of poverty also have high mortality for some forms of cancer. For example, in Appalachian Kentucky the incidence of lung cancer among white males was 127 per 100,000 in 1992, a rate higher than that for any ethnic minority group in the United States during the same period.
 - (4) Major disparities for other chronic diseases exist among population groups, with a disproportionate burden of death and disability from cardiovascular disease in racial and ethnic minority and low-income populations. Compared with rates for the general population, coronary heart disease mortality was 40 percent lower for Asian Americans but 40 percent higher for African-Americans.
 - (5) Minority populations are disproportionately impacted by diabetes and other chronic diseases. Hispanics are twice as likely to have diabetes as non-Hispanic whites; diabetes is the fourth leading cause of death among Hispanic women and elderly.

1	African Americans are 1.7 times as likely to have di-
2	abetes as the general population. More than 15 per-
3	cent of the combined populations of Native Ameri-
4	cans and Alaska Natives have diabetes.
5	(6) Culturally competent approaches to chronic
6	disease care are needed to encourage increased par-
7	ticipation of racial and ethnic minorities and the
8	medically underserved in chronic disease prevention,
9	early detection and treatment programs.
10	SEC. 3. HRSA GRANTS FOR MODEL COMMUNITY CANCER
11	AND CHRONIC DISEASE CARE AND PREVEN-
12	TION; HRSA GRANTS FOR PATIENT NAVIGA-
13	TORS.
14	Subpart I of part D of title III of the Public Health
15	Service Act (42 U.S.C. 254b et seq.) is amended by adding
16	at the end the following:
17	"SEC. 330I. MODEL COMMUNITY CANCER AND CHRONIC
18	DISEASE CARE AND PREVENTION; PATIENT
19	NAVIGATORS.
20	"(a) Model Community Cancer and Chronic
21	DISEASE CARE AND PREVENTION.—
22	"(1) In General.—The Secretary, acting
23	through the Administrator of the Health Resources
24	and Services Administration, may make grants to
25	public and nonprofit private health centers (includ-

1	ing health centers under section 330, Indian Health
2	Service Centers, tribal governments, urban Indian
3	organizations, tribal organizations, clinics serving
4	Asian Americans and Pacific Islanders and Alaskan
5	Natives, and rural health clinics and qualified non-
6	profit entities that partner with one or more centers
7	providing health care to provide navigation services,
8	which demonstrate the ability to perform all of the
9	functions outlined in this subsection and subsections
10	(b) and (c)) for the development and operation of
11	model programs that—
12	"(A) provide to individuals of health dis-
13	parity populations prevention, early detection,
14	treatment, and appropriate follow-up care serv-
15	ices for cancer and chronic diseases;
16	"(B) ensure that the health services are
17	provided to such individuals in a culturally com-
18	petent manner;
19	"(C) assign patient navigators, in accord-
20	ance with applicable criteria of the Secretary,
21	for managing the care of individuals of health
22	disparity populations to—
23	"(i) accomplish, to the extent possible,
24	the follow-up and diagnosis of an abnormal
25	finding and the treatment and appropriate

1	follow-up care of cancer or other chronic
2	disease; and
3	"(ii) facilitate access to appropriate
4	health care services within the health care
5	system to ensure optimal patient utiliza-
6	tion of such services, including aid in co-
7	ordinating and scheduling appointments
8	and referrals, community outreach, assist
9	ance with transportation arrangements
10	and assistance with insurance issues and
11	other barriers to care and providing infor-
12	mation about clinical trials;
13	"(D) require training for patient naviga-
14	tors employed through such model programs to
15	ensure the ability of navigators to perform al
16	of the duties required in this subsection and in
17	subsection (b), including training to ensure that
18	navigators are informed about health insurance
19	systems and are able to aid patients in resolve
20	ing access issues; and
21	"(E) ensure that consumers have direct ac
22	cess to patient navigators during regularly
23	scheduled hours of business operation.
24	"(2) Outreach services.—A condition for
25	the receipt of a grant under paragraph (1) is that

the applicant involved agree to provide ongoing outreach activities while receiving the grant, in a manner that is culturally competent for the health disparity population served by the program, to inform the public and the specific community that the program is serving of the services of the model program under the grant. Such activities shall include facilitating access to appropriate health care services and patient navigators within the health care system to ensure optimal patient utilization of these services.

"(3) Data collection and report.—In order to allow for effective program evaluation, the grantee shall collect specific patient data recording services provided to each patient served by the program and shall establish and implement procedures and protocols, consistent with applicable Federal and State laws (including 45 C.F.R. 160 and 164) to ensure the confidentiality of all information shared by a participant in the program, or their personal representative and their health care providers, group health plans, or health insurance insurers with the program. The program may, consistent with applicable Federal and State confidentiality laws, collect, use or disclose aggregate information that is not individually identifiable (as defined in 45 C.F.R. 160

and 164). With this data, the grantee shall submit an annual report to the Secretary that summarizes and analyzes these data, provides information on needs for navigation services, types of access difficulties resolved, sources of repeated resolution and flaws in the system of access, including insurance barriers.

"(4) APPLICATION FOR GRANT.—A grant may be made under paragraph (1) only if an application for the grant is submitted to the Secretary and the application is in such form, is made in such manner, and contains such agreements, assurances, and information as the Secretary determines to be necessary to carry out this section.

"(5) Evaluations.—

"(A) IN GENERAL.—The Secretary, acting through the Administrator of the Health Resources and Services Administration, shall, directly or through grants or contracts, provide for evaluations to determine which outreach activities under paragraph (2) were most effective in informing the public and the specific community that the program is serving of the model program services and to determine the extent to which such programs were effective in providing

culturally competent services to the health disparity population served by the programs.

"(B) DISSEMINATION OF FINDINGS.—The Secretary shall as appropriate disseminate to public and private entities the findings made in evaluations under subparagraph (A).

"(6) COORDINATION WITH OTHER PROGRAMS.—The Secretary shall coordinate the program under this subsection with the program under subsection (b), with the program under section 417D, and to the extent practicable, with programs for prevention centers that are carried out by the Director of the Centers for Disease Control and Prevention.

"(b) Program for Patient Navigators.—

"(1) IN GENERAL.—The Secretary, acting through the Administrator of the Health Resources and Services Administration, may make grants to public and nonprofit private health centers (including health centers under section 330, Indian Health Service Centers, tribal governments, urban Indian organizations, tribal organizations, clinics serving Asian Americans and Pacific Islanders and Alaskan Natives, and rural health clinics and qualified non-profit entities that partner with one or more centers

providing health care to provide navigation services,
which demonstrate the ability to perform all of the
functions outlined in this subsection and subsections
(a) and (c)) for the development and operation of
programs to pay the costs of such health centers
in—

"(A) assigning patient navigators, in accordance with applicable criteria of the Secretary, for managing the care of individuals of health disparity populations for the duration of receiving health services from the health centers, including aid in coordinating and scheduling appointments and referrals, community outreach, assistance with transportation arrangements, and assistance with insurance issues and other barriers to care and providing information about clinical trials;

"(B) ensuring that the services provided by the patient navigators to such individuals include case management and psychosocial assessment and care or information and referral to such services;

"(C) ensuring that patient navigators with direct knowledge of the communities they serve

1	provide services to such individuals in a cul-
2	turally competent manner;
3	"(D) developing model practices for patient
4	navigators, including with respect to—
5	"(i) coordination of health services,
6	including psychosocial assessment and
7	care;
8	"(ii) appropriate follow-up care, in-
9	cluding psychosocial assessment and care;
10	"(iii) determining coverage under
11	health insurance and health plans for all
12	services;
13	"(iv) ensuring the initiation, continu-
14	ation and/or sustained access to care pre-
15	scribed by the patients' health care pro-
16	viders; and
17	"(v) aiding patients with health insur-
18	ance coverage issues;
19	"(E) requiring training for patient naviga-
20	tors to ensure the ability of navigators to per-
21	form all of the duties required in this sub-
22	section and in subsection (a), including training
23	to ensure that navigators are informed about
24	health insurance systems and are able to aid
25	patients in resolving access issues; and

1 "(F) ensuring that consumers have direct 2 access to patient navigators during regularly 3 scheduled hours of business operation.

> "(2) Outreach services.—A condition for the receipt of a grant under paragraph (1) is that the applicant involved agree to provide ongoing outreach activities while receiving the grant, in a manner that is culturally competent for the health disparity population served by the program, to inform the public and the specific community that the patient navigator is serving of the services of the model program under the grant.

> "(3) Data collection and report.—In order to allow for effective patient navigator program evaluation, the grantee shall collect specific patient data recording navigation services provided to each patient served by the program and shall establish and implement procedures and protocols, consistent with applicable Federal and State laws (including 45 C.F.R. 160 and 164) to ensure the confidentiality of all information shared by a participant in the program, or their personal representative and their health care providers, group health plans, or health insurance insurers with the program. The patient navigator program may, consistent with appli-

cable Federal and State confidentiality laws, collect, use or disclose aggregate information that is not individually identifiable (as defined in 45 C.F.R. 160 and 164). With this data, the grantee shall submit an annual report to the Secretary that summarizes and analyzes these data, provides information on needs for navigation services, types of access difficulties resolved, sources of repeated resolution and flaws in the system of access, including insurance barriers.

"(4) APPLICATION FOR GRANT.—A grant may be made under paragraph (1) only if an application for the grant is submitted to the Secretary and the application is in such form, is made in such manner, and contains such agreements, assurances, and information as the Secretary determines to be necessary to carry out this section.

"(5) Evaluations.—

"(A) IN GENERAL.—The Secretary, acting through the Administrator of the Health Resources and Services Administration, shall, directly or through grants or contracts, provide for evaluations to determine the effects of the services of patient navigators on the individuals of health disparity populations for whom the

1	services were provided, taking into account the
2	matters referred to in paragraph (1)(C).
3	"(B) Dissemination of Findings.—The
4	Secretary shall as appropriate disseminate to
5	public and private entities the findings made in
6	evaluations under subparagraph (A).
7	"(6) Coordination with other pro-
8	GRAMS.—The Secretary shall coordinate the pro-
9	gram under this subsection with the program under
10	subsection (a) and with the program under section
11	417D.
12	"(c) Requirements Regarding Fees.—
13	"(1) In general.—A condition for the receipt
14	of a grant under subsection $(a)(1)$ or $(b)(1)$ is that
15	the program for which the grant is made have in ef-
16	fect—
17	"(A) a schedule of fees or payments for
18	the provision of its health care services related
19	to the prevention and treatment of disease that
20	is consistent with locally prevailing rates or
21	charges and is designed to cover its reasonable
22	costs of operation; and
23	"(B) a corresponding schedule of discounts
24	to be applied to the payment of such fees or

- 1 payments, which discounts are adjusted on the
- 2 basis of the ability of the patient to pay.
- 3 "(2) Rule of Construction.—Nothing in
- 4 this section shall be construed to require payment
- 5 for navigation services or to require payment for
- 6 health care services in cases where care is provided
- 7 free of charge, including the case of services pro-
- 8 vided through programs of the Indian Health Serv-
- 9 ice.
- 10 "(d) Model.—Not later than five years after the
- 11 date of the enactment of this section, the Secretary shall
- 12 develop a peer-reviewed model of systems for the services
- 13 provided by this section. The Secretary shall update such
- 14 model as may be necessary to ensure that the best prac-
- 15 tices are being utilized.
- 16 "(e) DURATION OF GRANT.—The period during
- 17 which payments are made to an entity from a grant under
- 18 subsection (a)(1) or (b)(1) may not exceed five years. The
- 19 provision of such payments are subject to annual approval
- 20 by the Secretary of the payments and subject to the avail-
- 21 ability of appropriations for the fiscal year involved to
- 22 make the payments. This subsection may not be construed
- 23 as establishing a limitation on the number of grants under
- 24 such subsection that may be made to an entity.
- 25 "(f) Definitions.—For purposes of this section:

1	"(1) The term 'culturally competent', with re-
2	spect to providing health-related services, means
3	services that, in accordance with standards and
4	measures of the Secretary, are designed to effec-
5	tively and efficiently respond to the cultural and lin-
6	guistic needs of patients.
7	"(2) The term 'appropriate follow-up care' in-
8	cludes palliative and end-of-life care.
9	"(3) The term 'health disparity population'
10	means a population where there exists a significant
11	disparity in the overall rate of disease incidence,
12	morbidity, mortality, or survival rates in the popu-
13	lation as compared to the health status of the gen-
14	eral population. Such term includes—
15	"(A) racial and ethnic minority groups as
16	defined in section 1707; and
17	"(B) medically underserved groups, such
18	as rural and low-income individuals and individ-
19	uals with low levels of literacy.
20	"(4)(A) The term 'patient navigator' means an
21	individual whose functions include—
22	"(i) assisting and guiding patients with a
23	symptom or an abnormal finding or diagnosis of
24	cancer or other chronic disease within the
25	health care system to accomplish the follow-up

1	and diagnosis of an abnormal finding as well as
2	the treatment and appropriate follow-up care of
3	cancer or other chronic disease including pro-
4	viding information about clinical trials; and
5	"(ii) identifying, anticipating, and helping
6	patients overcome barriers within the health
7	care system to ensure prompt diagnostic and
8	treatment resolution of an abnormal finding of
9	cancer or other chronic disease.
10	"(B) Such term includes representatives of the
11	target health disparity population, such as nurses,
12	social workers, cancer survivors, and patient advo-
13	cates.
14	"(g) Authorization of Appropriations.—
15	"(1) In general.—
16	"(A) Model programs.—For the purpose
17	of carrying out subsection (a) (other than the
18	purpose described in paragraph (2)(A)), there
19	are authorized to be appropriated such sums as
20	may be necessary for each of the fiscal years
21	2004 through 2008.
22	"(B) PATIENT NAVIGATORS.—For the pur-
23	pose of carrying out subsection (b) (other than
24	the purpose described in paragraph (2)(B)),
25	there are authorized to be appropriated such

1	sums as may be necessary for each of the fiscal
2	years 2004 through 2008.
3	"(C) Bureau of Primary Health
4	CARE.—Amounts appropriated under subpara-
5	graph (A) or (B) shall be administered through
6	the Bureau of Primary Health Care.
7	"(2) Programs in Rural Areas.—
8	"(A) Model programs.—For the purpose
9	of carrying out subsection (a) by making grants
10	under such subsection for model programs in
11	rural areas, there are authorized to be appro-
12	priated such sums as may be necessary for each
13	of the fiscal years 2004 through 2008.
14	"(B) PATIENT NAVIGATORS.—For the pur-
15	pose of carrying out subsection (b) by making
16	grants under such subsection for programs in
17	rural areas, there are authorized to be appro-
18	priated such sums as may be necessary for each
19	of the fiscal years 2004 through 2008.
20	"(C) Office of Rural Health Pol-
21	ICY.—Amounts appropriated under subpara-
22	graph (A) or (B) shall be administered through
23	the Office of Rural Health Policy.
24	"(3) Relation to other authorizations.—
25	Authorizations of appropriations under paragraphs

1	(1) and (2) are in addition to other authorizations
2	of appropriations that are available for the purposes
3	described in such paragraphs.".
4	SEC. 4. NCI GRANTS FOR MODEL COMMUNITY CANCER AND
5	CHRONIC DISEASE CARE AND PREVENTION;
6	NCI GRANTS FOR PATIENT NAVIGATORS.
7	Subpart 1 of part C of title IV of the Public Health
8	Service Act (42 U.S.C. 285 et seq.) is amended by adding
9	at the end following section:
10	"SEC. 417D. MODEL COMMUNITY CANCER AND CHRONIC
11	DISEASE CARE AND PREVENTION; PATIENT
12	NAVIGATORS.
13	"(a) Model Community Cancer and Chronic
14	DISEASE CARE AND PREVENTION.—
15	"(1) In general.—The Director of the Insti-
16	tute may make grants to eligible entities for the de-
17	velopment and operation of model programs that—
18	"(A) provide to individuals of health dis-
19	parity populations prevention, early detection,
20	treatment, and appropriate follow-up care serv-
21	ices for cancer and chronic diseases;
22	"(B) ensure that the health services are
23	provided to such individuals in a culturally com-
24	petent manner;

1	"(C) assign patient navigators, in accord-
2	ance with applicable criteria of the Secretary,
3	for managing the care of individuals of health
4	disparity populations to—
5	"(i) accomplish, to the extent possible,
6	the follow-up and diagnosis of an abnormal
7	finding and the treatment and appropriate
8	follow-up care of cancer or other chronic
9	disease; and
10	"(ii) facilitate access to appropriate
11	health care services within the health care
12	system to ensure optimal patient utiliza-
13	tion of such services, including aid in co-
14	ordinating and scheduling appointments
15	and referrals, community outreach, assist-
16	ance with transportation arrangements,
17	and assistance with insurance issues and
18	other barriers to care and providing infor-
19	mation about clinical trials;
20	"(D) require training for patient naviga-
21	tors employed through such model programs to
22	ensure the ability of navigators to perform all
23	of the duties required in this subsection and in
24	subsection (b), including training to ensure that

navigators are informed about health insurance

systems and are able to aid patients in resolving access issues; and

"(E) ensure that consumers have direct access to patient navigators during regularly scheduled hours of business operation.

"(2) ELIGIBLE ENTITIES.—For purposes of this section, an eligible entity is a designated cancer center of the Institute, an academic institution, Indian Health Service Clinics, tribal governments, urban Indian organizations, tribal organizations, a hospital, a qualified nonprofit entity that partners with one or more centers providing health care to provide navigation services, which demonstrates the ability to perform all of the functions outlined in this subsection and subsections (b) and (c), or any other public or private entity determined to be appropriate by the Director of the Institute, that provides services described in paragraph (1)(A) for cancer and chronic diseases.

"(3) Data collection and report.—In order to allow for effective program evaluation, the grantee shall collect specific patient data recording services provided to each patient served by the program and shall establish and implement procedures and protocols, consistent with applicable Federal and

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State laws (including 45 C.F.R. 160 and 164) to ensure the confidentiality of all information shared by a participant in the program, or their personal representative and their health care providers, group health plans, or health insurance insurers with the program. The program may, consistent with applicable Federal and State confidentiality laws, collect, use or disclose aggregate information that is not individually identifiable (as defined in 45 CFR 160 and 164). With this data, the grantee shall submit an annual report to the Secretary that summarizes and analyzes these data, provides information on needs for navigation services, types of access difficulties resolved, sources of repeated resolution and flaws in the system of access, including insurance barriers.

"(4) Outreach services.—A condition for the receipt of a grant under paragraph (1) is that the applicant involved agree to provide ongoing outreach activities while receiving the grant, in a manner that is culturally competent for the health disparity population served by the program, to inform the public and the specific community that the program is serving of the services of the model program under the grant. Such activities shall include facili-

tating access to appropriate health care services and patient navigators within the health care system to ensure optimal patient utilization of these services.

"(5) APPLICATION FOR GRANT.—A grant may be made under paragraph (1) only if an application for the grant is submitted to the Director of the Institute and the application is in such form, is made in such manner, and contains such agreements, assurances, and information as the Director determines to be necessary to carry out this section.

"(6) Evaluations.—

"(A) In general.—The Director of the Institute, directly or through grants or contracts, shall provide for evaluations to determine which outreach activities under paragraph (3) were most effective in informing the public and the specific community that the program is serving of the model program services and to determine the extent to which such programs were effective in providing culturally competent services to the health disparity population served by the programs.

"(B) DISSEMINATION OF FINDINGS.—The Director of the Institute shall as appropriate disseminate to public and private entities the

findings made in evaluations under subparagraph (A).

"(7) COORDINATION WITH OTHER PROGRAMS.—The Secretary shall coordinate the program under this subsection with the program under subsection (b), with the program under section 330I, and to the extent practicable, with programs for prevention centers that are carried out by the Director of the Centers for Disease Control and Prevention.

"(b) Program for Patient Navigators.—

"(1) In general.—The Director of the Institute may make grants to eligible entities for the development and operation of programs to pay the costs of such entities in—

"(A) assigning patient navigators, in accordance with applicable criteria of the Secretary, for managing the care of individuals of health disparity populations for the duration of receiving health services from the health centers, including aid in coordinating and scheduling appointments and referrals, community outreach, assistance with transportation arrangements, and assistance with insurance issues and other barriers to care and providing information about clinical trials;

1	"(B) ensuring that the services provided by
2	the patient navigators to such individuals in-
3	clude case management and psychosocial as-
4	sessment and care or information and referral
5	to such services;
6	"(C) ensuring that the patient navigators
7	with direct knowledge of the communities they
8	serve provide services to such individuals in a
9	culturally competent manner;
10	"(D) developing model practices for patient
11	navigators, including with respect to—
12	"(i) coordination of health services,
13	including psychosocial assessment and
14	care;
15	"(ii) follow-up services, including psy-
16	chosocial assessment and care;
17	"(iii) determining coverage under
18	health insurance and health plans for all
19	services;
20	"(iv) ensuring the initiation, continu-
21	ation and/or sustained access to care pre-
22	scribed by the patients' health care pro-
23	viders; and
24	"(v) aiding patients with health insur-
25	ance coverage issues;

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- "(E) requiring training for patient navigators to ensure the ability of navigators to perform all of the duties required in this subsection and in subsection (a), including training to ensure that navigators are informed about health insurance systems and are able to aid patients in resolving access issues; and
 - "(F) ensuring that consumers have direct access to patient navigators during regularly scheduled hours of business operation.
 - "(2) Outreach services.—A condition for the receipt of a grant under paragraph (1) is that the applicant involved agree to provide ongoing outreach activities while receiving the grant, in a manner that is culturally competent for the health disparity population served by the program, to inform the public and the specific community that the patient navigator is serving of the services of the model program under the grant.
 - "(3) Data collection and report.—In order to allow for effective patient navigator program evaluation, the grantee shall collect specific patient data recording navigation services provided to each patient served by the program and shall establish and implement procedures and protocols, con-

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sistent with applicable Federal and State laws (including 45 C.F.R. 160 and 164) to ensure the confidentiality of all information shared by a participant in the program, or their personal representative and their health care providers, group health plans, or health insurance insurers with the program. The patient navigator program may, consistent with applicable Federal and State confidentiality laws, collect, use or disclose aggregate information that is not individually identifiable (as defined in 45 C.F.R. 160 and 164). With this data, the grantee shall submit an annual report to the Secretary that summarizes and analyzes these data, provides information on needs for navigation services, types of access difficulties resolved, sources of repeated resolution and flaws in the system of access, including insurance barriers.

"(4) APPLICATION FOR GRANT.—A grant may be made under paragraph (1) only if an application for the grant is submitted to the Director of the Institute and the application is in such form, is made in such manner, and contains such agreements, assurances, and information as the Director determines to be necessary to carry out this section.

"(5) Evaluations.—

1	"(A) IN GENERAL.—The Director of the
2	Institute, directly or through grants or con-
3	tracts, shall provide for evaluations to deter-
4	mine the effects of the services of patient navi-
5	gators on the health disparity population for
6	whom the services were provided, taking into
7	account the matters referred to in paragraph
8	(1)(C).
9	"(B) DISSEMINATION OF FINDINGS.—The
10	Director of the Institute shall as appropriate
11	disseminate to public and private entities the
12	findings made in evaluations under subpara-
13	graph (A).
14	"(6) Coordination with other pro-
15	GRAMS.—The Secretary shall coordinate the pro-
16	gram under this subsection with the program under
17	subsection (a) and with the program under section
18	330I.
19	"(c) Requirements Regarding Fees.—
20	"(1) IN GENERAL.—A condition for the receipt
21	of a grant under subsection $(a)(1)$ or $(b)(1)$ is that
22	the program for which the grant is made have in ef-
23	feet—
24	"(A) a schedule of fees or payments for
25	the provision of its health care services related

to the prevention and treatment of disease that

is consistent with locally prevailing rates or

charges and is designed to cover its reasonable

costs of operation; and

- "(B) a corresponding schedule of discounts to be applied to the payment of such fees or payments, which discounts are adjusted on the basis of the ability of the patient to pay.
- 9 "(2) RULE OF CONSTRUCTION.—Nothing in 10 this section shall be construed to require payment 11 for navigation services or to require payment for 12 health care services in cases where care is provided 13 free of charge, including the case of services pro-14 vided through programs of the Indian Health Serv-15 ice.
- "(d) Model.—Not later than five years after the date of the enactment of this section, the Director of the Institute shall develop a peer-reviewed model of systems for the services provided by this section. The Director shall update such model as may be necessary to ensure that the best practices are being utilized.
- "(e) DURATION OF GRANT.—The period during which payments are made to an entity from a grant under subsection (a)(1) or (b)(1) may not exceed five years. The provision of such payments are subject to annual approval

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1 by the Director of the Institute of the payments and subject to the availability of appropriations for the fiscal year involved to make the payments. This subsection may not be construed as establishing a limitation on the number of grants under such subsection that may be made to an 6 entity. 7 "(f) Definitions.—For purposes of this section: 8 "(1) The term 'culturally competent', with re-9 spect to providing health-related services, means 10 services that, in accordance with standards and 11 measures of the Secretary, are designed to effec-12 tively and efficiently respond to the cultural and lin-13 guistic needs of patients. 14 "(2) the term 'appropriate follow-up care' in-15 cludes palliative and end-of-life care. "(3) the term 'health disparity population' 16 17 means a population where there exists a significant 18 disparity in the overall rate of disease incidence, 19 morbidity, mortality, or survival rates in the popu-20 lation as compared to the health status of the gen-21 eral population. Such term includes— "(A) racial and ethnic minority groups as 22

defined in section 1707; and

1	"(B) medically underserved groups, such
2	as rural and low-income individuals and individ-
3	uals with low levels of literacy.
4	"(4)(A) the term 'patient navigator' means an
5	individual whose functions include—
6	"(i) assisting and guiding patients with a
7	symptom or an abnormal finding or diagnosis of
8	cancer or other chronic disease within the
9	health care system to accomplish the follow-up
10	and diagnosis of an abnormal finding as well as
11	the treatment and appropriate follow-up care of
12	cancer or other chronic disease, including pro-
13	viding information about clinical trials; and
14	"(ii) identifying, anticipating, and helping
15	patients overcome barriers within the health
16	care system to ensure prompt diagnostic and
17	treatment resolution of an abnormal finding of
18	cancer or other chronic disease.
19	"(B) Such term includes representatives of the
20	target health disparity population, such as nurses,
21	social workers, cancer survivors, and patient advo-
22	cates.
23	"(g) Authorization of Appropriations.—
24	"(1) Model programs.—For the purpose of
25	carrying out subsection (a), there are authorized to

- be appropriated such sums as may be necessary for
 each of the fiscal years 2004 through 2008.
- "(2) Patient Navigators.—For the purpose of carrying out subsection (b), there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2004 through 2008.
- 7 "(3) RELATION TO OTHER AUTHORIZATIONS.—
 8 Authorizations of appropriations under paragraphs
 9 (1) and (2) are in addition to other authorizations
 10 of appropriations that are available for the purposes
 11 described in such paragraphs.".
- 12 SEC. 5. IHS GRANTS FOR MODEL COMMUNITY CANCER AND
- 13 CHRONIC DISEASE CARE AND PREVENTION;
- 14 IHS GRANTS FOR PATIENT NAVIGATORS.
- 15 (a) Model Community Cancer and Chronic Dis-16 Ease Care and Prevention.—
- 17 (1) IN GENERAL.—The Director of the Indian 18 Health Service may make grants to Indian Health 19 Service Centers, tribal governments, urban Indian 20 organizations, tribal organizations, and qualified 21 nonprofit entities demonstrating the ability to per-22 form all of the functions outlined in this subsection 23 and subsections (b) and (c) that partner with pro-24 viders or centers providing health care serving Na-25 tive American populations to provide navigation

1	services, for the development and operation of model
2	programs that—
3	(A) provide to individuals of health dis-
4	parity populations prevention, early detection,
5	treatment, and appropriate follow-up care serv-
6	ices for cancer and chronic diseases;
7	(B) ensure that the health services are pro-
8	vided to such individuals in a culturally com-
9	petent manner;
10	(C) assign patient navigators, in accord-
11	ance with applicable criteria of the Secretary,
12	for managing the care of individuals of health
13	disparity populations to—
14	(i) accomplish, to the extent possible,
15	the follow-up and diagnosis of an abnormal
16	finding and the treatment and appropriate
17	follow-up care of cancer or other chronic
18	disease; and
19	(ii) facilitate access to appropriate
20	health care services within the health care
21	system to ensure optimal patient utiliza-
22	tion of such services, including aid in co-
23	ordinating and scheduling appointments
24	and referrals, community outreach, assist-
25	ance with transportation arrangements,

and assistance with insurance issues and other barriers to care and providing information about clinical trials;

- (D) require training for patient navigators employed through such model programs to ensure the ability of navigators to perform all of the duties required in this subsection and in subsection (b), including training to ensure that navigators are informed about health insurance systems and are able to aid patients in resolving access issues; and
- (E) ensure that consumers have direct access to patient navigators during regularly scheduled hours of business operation.
- (2) Outreach services.—A condition for the receipt of a grant under paragraph (1) is that the applicant involved agree to provide ongoing outreach activities while receiving the grant, in a manner that is culturally competent for the health disparity population served by the program, to inform the public and the specific community that the program is serving of the services of the model program under the grant. Such activities shall include facilitating access to appropriate health care services and pa-

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tient navigators within the health care system to ensure optimal patient utilization of these services.

> (3) Data collection and report.—In order to allow for effective program evaluation, the grantee shall collect specific patient data recording services provided to each patient served by the program and shall establish and implement procedures and protocols, consistent with applicable Federal and State laws (including 45 C.F.R. 160 and 164) to ensure the confidentiality of all information shared by a participant in the program, or their personal representative and their health care providers, group health plans, or health insurance insurers with the program. The program may, consistent with applicable Federal and State confidentiality laws, collect, use or disclose aggregate information that is not individually identifiable (as defined in 45 C.F.R. 160 and 164). With this data, the grantee shall submit an annual report to the Secretary that summarizes and analyzes these data, provides information on needs for navigation services, types of access difficulties resolved, sources of repeated resolution and flaws in the system of access, including insurance barriers.

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(4) APPLICATION FOR GRANT.—A grant may be made under paragraph (1) only if an application for the grant is submitted to the Secretary and the application is in such form, is made in such manner, and contains such agreements, assurances, and information as the Secretary determines to be necessary to carry out this section.

(5) Evaluations.—

- (A) In General.—The Secretary, acting through the Director of the Indian Health Service, shall, directly or through grants or contracts, provide for evaluations to determine which outreach activities under paragraph (2) were most effective in informing the public and the specific community that the program is serving of the model program services and to determine the extent to which such programs were effective in providing culturally competent services to the health disparity population served by the programs.
- (B) DISSEMINATION OF FINDINGS.—The Secretary shall as appropriate disseminate to public and private entities the findings made in evaluations under subparagraph (A).

1 (6) COORDINATION WITH OTHER PROGRAMS.—
2 The Secretary shall coordinate the program under
3 this subsection with the program under subsection
4 (b), with the program under section 417D, and to
5 the extent practicable, with programs for prevention
6 centers that are carried out by the Director of the
7 Centers for Disease Control and Prevention.

(b) Program for Patient Navigators.—

(1)IN GENERAL.—The Secretary, acting through the Director of the Indian Health Service, may make grants to Indian Health Service Centers, tribal governments, urban Indian organizations, tribal organizations, and qualified nonprofit entities demonstrating the ability to perform all of the functions outlined in this subsection and subsections (a) and (c) that partner with providers or centers providing health care serving Native American populations to provide navigation services, for the development and operation of model programs to pay the costs of such organizations in—

(A) assigning patient navigators, in accordance with applicable criteria of the Secretary, for individuals of health disparity populations for the duration of receiving health services from the health centers, including aid in coordi-

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1	nating and scheduling appointments and refer-
2	rals, community outreach, assistance with
3	transportation arrangements, and assistance
4	with insurance issues and other barriers to care
5	and providing information about clinical trials
6	(B) ensuring that the services provided by
7	the patient navigators to such individuals in-
8	clude case management and psychosocial as-
9	sessment and care or information and referral
10	to such services;
11	(C) ensuring that patient navigators with
12	direct knowledge of the communities they serve
13	provide services to such individuals in a cul-
14	turally competent manner;
15	(D) developing model practices for patient
16	navigators, including with respect to—
17	(i) coordination of health services, in-
18	cluding psychosocial assessment and care;
19	(ii) appropriate follow-up care, includ-
20	ing psychosocial assessment and care;
21	(iii) determining coverage under
22	health insurance and health plans for all
23	services;
24	(iv) ensuring the initiation, continu-
25	ation and/or sustained access to care pre-

1	scribed by the patients' health care pro-
2	viders; and
3	(v) aiding patients with health insur-
4	ance coverage issues;
5	(E) requiring training for patient naviga-
6	tors to ensure the ability of navigators to per-
7	form all of the duties required in this sub-
8	section and in subsection (a), including training
9	to ensure that navigators are informed about
10	health insurance systems and are able to aid
11	patients in resolving access issues; and
12	(F) ensuring that consumers have direct
13	access to patient navigators during regularly
14	scheduled hours of business operation.
15	(2) Outreach services.—A condition for the
16	receipt of a grant under paragraph (1) is that the
17	applicant involved agree to provide ongoing outreach
18	activities while receiving the grant, in a manner that
19	is culturally competent for the health disparity popu-
20	lation served by the program, to inform the public
21	and the specific community that the patient navi-
22	gator is serving of the services of the model program
23	under the grant.
24	(3) Data collection and report.—In order
25	to allow for effective patient navigator program eval-

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uation, the grantee shall collect specific patient data recording navigation services provided to each patient served by the program and shall establish and implement procedures and protocols, consistent with applicable Federal and State laws (including 45 C.F.R. 160 and 164) to ensure the confidentiality of all information shared by a participant in the program, or their personal representative and their health care providers, group health plans, or health insurance insurers with the program. The patient navigator program may, consistent with applicable Federal and State confidentiality laws, collect, use or disclose aggregate information that is not individually identifiable (as defined in 45 C.F.R. 160 and 164). With this data, the grantee shall submit an annual report to the Secretary that summarizes and analyzes these data, provides information on needs for navigation services, types of access difficulties resolved, sources of repeated resolution and flaws in the system of access, including insurance barriers.

(4) APPLICATION FOR GRANT.—A grant may be made under paragraph (1) only if an application for the grant is submitted to the Secretary and the application is in such form, is made in such manner, and contains such agreements, assurances, and in-

formation as the Secretary determines to be necessary to carry out this section.

(5) EVALUATIONS.—

- (A) IN GENERAL.—The Secretary, acting through the Director of the Indian Health Service, shall, directly or through grants or contracts, provide for evaluations to determine the effects of the services of patient navigators on the individuals of health disparity populations for whom the services were provided, taking into account the matters referred to in paragraph (1)(C).
- (B) DISSEMINATION OF FINDINGS.—The Secretary shall as appropriate disseminate to public and private entities the findings made in evaluations under subparagraph (A).
- (6) COORDINATION WITH OTHER PROGRAMS.—
 The Secretary shall coordinate the program under this subsection with the program under subsection (a) and with the program under section 417D.

(c) REQUIREMENTS REGARDING FEES.—

(1) IN GENERAL.—A condition for the receipt of a grant under subsection (a)(1) or (b)(1) is that the program for which the grant is made have in effect—

- 1 (A) a schedule of fees or payments for the 2 provision of its health care services related to 3 the prevention and treatment of disease that is 4 consistent with locally prevailing rates or 5 charges and is designed to cover its reasonable 6 costs of operation; and
 - (B) a corresponding schedule of discounts to be applied to the payment of such fees or payments, which discounts are adjusted on the basis of the ability of the patient to pay.
 - (2) Rule of construction.—Nothing in this section shall be construed to require payment for navigation services or to require payment for health care services in cases, such as with the Indian Health Service, where care is provided free of charge.
- 17 (d) Model.—Not later than five years after the date
 18 of the enactment of this section, the Secretary shall de19 velop a peer-reviewed model of systems for the services
 20 provided by this section. The Secretary shall update such
 21 model as may be necessary to ensure that the best prac22 tices are being utilized.
- 23 (e) DURATION OF GRANT.—The period during which 24 payments are made to an entity from a grant under sub-25 section (a)(1) or (b)(1) may not exceed five years. The

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- provision of such payments are subject to annual approval by the Secretary of the payments and subject to the avail-3 ability of appropriations for the fiscal year involved to 4 make the payments. This subsection may not be construed 5 as establishing a limitation on the number of grants under 6 such subsection that may be made to an entity. 7 (f) Definitions.—For purposes of this section: 8 (1) The term "culturally competent", with re-9 spect to providing health-related services, means 10 services that, in accordance with standards and 11 measures of the Secretary, are designed to effec-12 tively and efficiently respond to the cultural and lin-13 guistic needs of patients. (2) The term "appropriate follow-up care" in-14 15 cludes palliative and end-of-life care. (3) The term "health disparity population" 16 17 means a population where there exists a significant 18 disparity in the overall rate of disease incidence, 19 morbidity, mortality, or survival rates in the popu-20 lation as compared to the health status of the gen-
- 22 (A) racial and ethnic minority groups as 23 defined in section 1707; and

eral population. Such term includes—

1	(B) medically underserved groups, such as
2	rural and low-income individuals and individ-
3	uals with low levels of literacy.
4	(4)(A) The term "patient navigator" means an
5	individual whose functions include—
6	(i) assisting and guiding patients with a
7	symptom or an abnormal finding or diagnosis of
8	cancer or other chronic disease within the
9	health care system to accomplish the follow-up
10	and diagnosis of an abnormal finding as well as
11	the treatment and appropriate follow-up care of
12	cancer or other chronic disease, including pro-
13	viding information about clinical trials; and
14	(ii) identifying, anticipating, and helping
15	patients overcome barriers within the health
16	care system to ensure prompt diagnostic and
17	treatment resolution of an abnormal finding of
18	cancer or other chronic disease.
19	(B) Such term includes representatives of the
20	target health disparity population, such as nurses,
21	social workers, cancer survivors, and patient advo-
22	cates.
23	(g) Authorization of Appropriations.—
24	(1) In general.—

1	(A) Model programs.—For the purpose
2	of carrying out subsection (a) (other than the
3	purpose described in paragraph (2)(A)), there
4	are authorized to be appropriated such sums as
5	may be necessary for each of the fiscal years
6	2004 through 2008.
7	(B) PATIENT NAVIGATORS.—For the pur-
8	pose of carrying out subsection (b) (other than
9	the purpose described in paragraph (2)(B)),
10	there are authorized to be appropriated such
11	sums as may be necessary for each of the fiscal
12	years 2004 through 2008.
13	(C) Bureau of Primary Health 13
14	CARE.—Amounts appropriated under subpara-
15	graph (A) or (B) shall be administered through
16	the Bureau of Primary Health Care.
17	(2) Programs in Rural Areas.—
18	(A) Model programs.—For the purpose
19	of carrying out subsection (a) by making grants
20	under such subsection for model programs in
21	rural areas, there are authorized to be appro-
22	priated such sums as may be necessary for each
23	of the fiscal years 2004 through 2008.
24	(B) Patient Navigators.—For the pur-

pose of carrying out subsection (b) by making

grants under such subsection for programs in
rural areas, there are authorized to be appro-
priated such sums as may be necessary for each
of the fiscal years 2004 through 2008.

- (C) OFFICE OF RURAL HEALTH POLICY.—
 Amounts appropriated under subparagraph (A) or (B) shall be administered through the Office of Rural Health Policy.
- (3) RELATION TO OTHER AUTHORIZATIONS.—Authorizations of appropriations under paragraphs (1) and (2) are in addition to other authorizations of appropriations that are available for the purposes described in such paragraphs.

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