

[DISCUSSION DRAFT]

114TH CONGRESS
1ST SESSION

H. R. _____

To amend title XVIII of the Social Security Act to encourage Medicare beneficiaries to voluntarily adopt advance directives guiding the medical care they receive.

IN THE HOUSE OF REPRESENTATIVES

Mrs. BLACK introduced the following bill; which was referred to the Committee on _____

A BILL

To amend title XVIII of the Social Security Act to encourage Medicare beneficiaries to voluntarily adopt advance directives guiding the medical care they receive.

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 “Medicare Choices Em-
5 powerment and Protection Act”.

1 **SEC. 2. MEDICARE ADVANCE DIRECTIVE CERTIFICATION**
2 **PROGRAM.**

3 Part B of title XVIII of the Social Security Act (42
4 U.S.C. 1395 et seq.) is amended by adding at the end
5 the following new section:

6 “MEDICARE ADVANCE DIRECTIVE CERTIFICATION
7 PROGRAM

8 “SEC. 1849. (a) IN GENERAL.—

9 “(1) ESTABLISHMENT OF PROGRAM.—The Sec-
10 retary shall establish and implement an Advance Di-
11 rective Certification Program (in this section re-
12 ferred to as the ‘Program’) under which the Sec-
13 retary shall encourage eligible beneficiaries to adopt
14 and maintain certified advance directives to guide
15 the delivery of health care to such beneficiaries. The
16 Secretary shall implement the Program not later
17 than 3 years after the date of enactment of this sec-
18 tion.

19 “(2) DEFINITIONS.—In this section:

20 “(A) CERTIFIED ADVANCE DIRECTIVE.—

21 The term ‘certified advance directive’ means
22 any written or electronically stored statement
23 by an eligible beneficiary that—

24 “(i) provides instructions that outline
25 the kind of medical treatments and care
26 that such beneficiary would want or not

1 want under particular conditions, and may
2 also include the identification of a health
3 care proxy or legal representative to make
4 medical treatment decisions for the bene-
5 ficiary if the beneficiary becomes unable to
6 make or communicate those decisions;

7 “(ii) is executed in accordance with
8 the law governing advance directives of the
9 State involved; and

10 “(iii) is offered by an entity that has
11 received accreditation from the Secretary
12 under this section.

13 “(B) ELIGIBLE BENEFICIARY.—The term
14 ‘eligible beneficiary’ means an individual en-
15 rolled under this part.

16 “(3) VOLUNTARY.—Participation in the Pro-
17 gram shall be voluntary with respect to the eligible
18 beneficiary and an eligible beneficiary who has reg-
19 istered a certified advance directive under the Pro-
20 gram may terminate such directive at any time.
21 Nothing in this section shall require an eligible bene-
22 ficiary to adopt or maintain a certified advance di-
23 rective.

24 “(4) BEST PRACTICES.—In establishing and im-
25 plementing the Program, the Secretary shall con-

1 sider best practices within existing advance directive
2 registry technologies, programs, and systems, includ-
3 ing web-based or cloud-based advance directive tech-
4 nologies, which may utilize time and date stamps,
5 video, or other innovative measures to protect the
6 authenticity, improve the quality, and enhance the
7 security of such directives.

8 “(5) ENROLLMENT AND DISENROLLMENT.—
9 The Secretary shall establish procedures for eligible
10 beneficiaries to enroll and disenroll under the Pro-
11 gram. Such procedures shall ensure that enrollment
12 and disenrollment is available both through an on-
13 line and manual process, with Program design pref-
14 erence given to an online process to minimize admin-
15 istrative costs. The Secretary shall also establish
16 procedures to ensure Program participants can up-
17 date or amend an advance directive in a timely and
18 secure manner.

19 “(6) SPECIAL RULE FOR HEALTH CARE PRO-
20 VIDERS.—The Secretary shall require that any ad-
21 vance directive prepared by a health care provider on
22 behalf or in assistance of an eligible beneficiary be
23 created and maintained in an online electronic for-
24 mat. For purposes of the previous sentence, the

1 term ‘health care provider’ means a physician, clin-
2 ical social worker, chaplain, or other similar person.

3 “(7) STATE LAW.—This section shall in no way
4 supercede, abrogate, or otherwise interfere with
5 State law governing advance directives. Under the
6 Program, the Secretary shall establish a process
7 under which the Secretary is required to verify that
8 digital advance directive vendors or other entities
9 providing a digital advance directive participating in
10 the program enable those using their services to
11 complete advance directives that fully comply with
12 the law governing advance directives of the State in-
13 volved.

14 “(8) DISPLAY OF STATUTORY AND ALTER-
15 NATIVE ADVANCE DIRECTIVE FORMS.—Under the
16 Program, the Centers for Medicare & Medicaid Serv-
17 ices shall provide, through a clearinghouse website,
18 links to statutory and alternative advance directive
19 forms and a State-by-State index to such forms to
20 allow a beneficiary to create, adopt, modify, and ter-
21 minate an advance directive with any content per-
22 mitted or required, and in any form authorized by
23 a State, in accordance with the requirements of sub-
24 paragraphs (C) and (E) of subsection (e)(1) and
25 subsection (e)(2).

1 “(9) ACCESS IN CASES OF DISPUTE OVER
2 TREATMENT.—Under the Program:

3 “(A) SPECIAL ACCESS.—The Secretary
4 shall establish a process whereby, with respect
5 to a beneficiary with a [certified] advance di-
6 rective, a person described in subparagraph (B)
7 may obtain access to the beneficiary’s advance
8 directive for the purposes of viewing and shar-
9 ing such advance directive when—

10 “(i) the provisions of the advance di-
11 rective have come into force under the ap-
12 plicable State’s law because the beneficiary
13 has become incapable of making health
14 care decisions or under other cir-
15 cumstances provided under State law; and

16 “(ii) at least one person described in
17 subparagraph (B) is questioning or dis-
18 puting the provision, withholding, or with-
19 drawal of medical treatment, food, or
20 fluids with respect to the beneficiary.

21 “(B) INTERESTED INDIVIDUALS.—A per-
22 son described in this subparagraph, with re-
23 spect to a beneficiary, is—

24 “(i) any individual who is a member
25 of any class of persons who, under the ap-

1 plicable State’s law, would potentially be
2 eligible to serve as a health care decision
3 maker for the beneficiary if an advance di-
4 rective had not been executed regardless of
5 whether higher priority for such eligibility
6 would be accorded to another individual or
7 individuals; and

8 “(ii) if the applicable State’s law does
9 not designate persons or classes of persons
10 described in clause (i), any person related
11 within the third degree of consanguinity or
12 affinity to the beneficiary.

13 “(b) REGISTRATION.—

14 “(1) IN GENERAL.—The Secretary shall estab-
15 lish procedures for an eligible beneficiary to register
16 such beneficiary’s adoption of a certified advance di-
17 rective under the Program. Such procedures shall
18 ensure that registration is available both through an
19 online and manual process. The Secretary shall also
20 establish procedures to ensure Program participants
21 can update previously registered information that is
22 no longer accurate and indicate that an advance di-
23 rective has been terminated.

24 “(2) REQUIRED INFORMATION.—In addition to
25 such other information as the Secretary may deem

1 appropriate, an eligible beneficiary seeking to reg-
2 ister a certified advance directive under the Program
3 shall indicate where the advance directive is main-
4 tained.

5 “(3) REGISTRATION PERIODS.—The procedures
6 established under paragraph (1) shall provide that
7 registration under the Program shall occur during—

8 “(A) an eligible beneficiary’s initial [part
9 C enrollment]/[enrollment under an MA plan
10 under part C] as described in paragraph (1) of
11 section 1851(e); and

12 “(B) the annual, coordinated election pe-
13 riod under paragraph (3) of such section.

14 “(4) PRIVACY AND SECURITY.—

15 “(A) IN GENERAL.—The Secretary shall
16 ensure that all aspects of the registration sys-
17 tem comply with the Federal regulations (con-
18 cerning the privacy of individually identifiable
19 health information) promulgated under section
20 264(c) of the Health Insurance Portability and
21 Accountability Act of 1996 subject to the access
22 authorized under subsection (a)(7) and sub-
23 section (e)(2)(D).

24 “(B) ACCESS.—The Secretary shall utilize
25 standardized data protections and privacy

1 standards, including the Federal regulations de-
2 scribed in paragraph (1), to ensure that the
3 registration record of an eligible beneficiary can
4 only be accessed by—

5 “(i) the beneficiary, through the proc-
6 ess established under paragraph (1);

7 “(ii) those authorized to access the
8 advance directive under subsection (a)(7)
9 and subsection (c)(2)(D); and

10 “(iii) providers of services and sup-
11 pliers participating under this title,
12 through a process established by the Sec-
13 retary.

14 “(c) ACCREDITATION.—

15 “(1) IN GENERAL.—Under the Program, the
16 Secretary shall—

17 “(A) grant accreditation to advance direc-
18 tive vendors and other entities providing ad-
19 vance directives that meet the accreditation cri-
20 teria established under paragraph (2); and

21 “(B) establish a process whereby advance
22 directive vendors and other entities providing
23 advance directives may obtain accreditation
24 under this subsection.

1 “(2) ACCREDITATION CRITERIA.—The Sec-
2 retary, in consultation with the General Accounting
3 Office, shall establish accreditation criteria for ad-
4 vance directive vendors and other entities providing
5 advance directives that seek to offer advance direc-
6 tives to be certified under the Program. Such cri-
7 teria shall consist of the following:

8 “(A) PROCESS FOR ADOPTING ADVANCE
9 DIRECTIVE.—The advance directive vendor or
10 other entity providing an advance directive shall
11 allow a beneficiary to create, adopt, modify, and
12 terminate an advance directive—

13 “(i) through an online process; and

14 “(ii) as an alternative to the online
15 process, through a manual process that
16 employs paper documents.

17 “(B) VENDORS.—The advance directive
18 vendor or other entity providing an advance di-
19 rective shall comply with an annual quality re-
20 view to be conducted by the [Secretary].

21 “(C) USE OF STATUTORY AND ALTER-
22 NATIVE ADVANCE DIRECTIVE FORMS.—The ad-
23 vance directive vendor or other entity providing
24 an advance directive shall enable a beneficiary
25 to access, complete, modify, and adopt any ad-

1 vance directive applicable to the State indicated
2 by the beneficiary that is posted as provided
3 under subparagraphs (C) and (E) of subsection
4 (e)(1) and of subsection (e)(2).

5 “(D) ACCESS.—The advance directive ven-
6 dor or other entity providing an advance direc-
7 tive shall maintain advance directives in such a
8 way that—

9 “(i) an eligible beneficiary who has
10 adopted an advance directive with such
11 vendor or entity and any family member,
12 legal representative, or health care proxy
13 legally designated by such beneficiary has
14 direct, near real-time online access to the
15 beneficiary’s advance directive for purposes
16 of viewing and sharing such advance direc-
17 tive;

18 “(ii) in the case of an eligible bene-
19 ficiary who has adopted an advance direc-
20 tive with such vendor or entity or any fam-
21 ily member, legal representative, or health
22 care proxy legally designated by such bene-
23 ficiary who is unable or unwilling to use
24 the online access under subparagraph (A),
25 such individual is able to obtain a hard

1 copy of the beneficiary's advance directive
2 for the purposes of viewing and sharing
3 such advance directive; and

4 “(iii) providers of services and sup-
5 pliers participating under this title have
6 near real-time access to the advance direc-
7 tive of an eligible beneficiary who has
8 adopted an advance directive with such
9 vendor or entity.

10 “(E) PRIVACY PROTECTIONS.—

11 “(i) IN GENERAL.—The advance di-
12 rective vendor or other entity providing an
13 advance directive shall comply with the
14 Federal regulations (concerning the privacy
15 of individually identifiable health informa-
16 tion) promulgated under section 264(c) of
17 the Health Insurance Portability and Ac-
18 countability Act of 1996 (42 U.S.C.
19 1320d–2 note), subject to the access au-
20 thorized under subparagraph (D) and sub-
21 section (a)(7).

22 “(ii) ACCESS.—Such vendor or entity
23 shall utilize standardized data protections
24 and privacy standards, including the Fed-
25 eral regulations described in clause (i), to

1 ensure that the content of an eligible bene-
2 ficiary's advance directive is owned and
3 maintained by the beneficiary and can only
4 be accessed by—

5 “(I) the beneficiary or the bene-
6 ficiary's designee pursuant to clauses
7 (i) and (ii) of subparagraph (D);

8 “(II) **[Review overlap: If the ref-**
9 *erence to subparagraph (D) is kept*
10 *here, why are subclauses (I) and (III)*
11 *needed?]* those authorized to access
12 the advance directive under subpara-
13 graph (D) and subsection (a)(7); and

14 “(III) a provider of services or a
15 supplier pursuant to subparagraph
16 (D)(iii).

17 “(F) SECURITY AND TESTING.—The ad-
18 vance directive vendor or other entity providing
19 an advance directive shall certify that—

20 “(i) all data management and data
21 transfer elements involved in adopting,
22 maintaining, and accessing the advance di-
23 rective have successfully passed rigorous
24 independent testing regarding standards of
25 timeliness, accuracy, and efficiency;

1 “(ii) the data management and data
2 transfer elements involved in adopting,
3 maintaining, and accessing the advance di-
4 rective meet widely accepted industry secu-
5 rity standards; and

6 “(iii) the system that provides access
7 to the advance directive has passed real-
8 time tests simulating a realistic volume of
9 beneficiaries and providers accessing ad-
10 vance directives simultaneously.

11 “(G) CERTIFIED ADVANCE DIRECTIVES.—
12 The advance directive vendor or other entity
13 providing an advance directive shall agree to
14 offer certified advance directives (as defined in
15 subsection (a)(2)(A)).

16 “(H) BENEFICIARY SURVEYS.—The ad-
17 vance directive vendor or other entity providing
18 an advance directive shall **【agree to】** admin-
19 ister annual beneficiary surveys **【on ____】** and
20 submit the results of such surveys to the Cen-
21 ters for Medicare & Medicaid Services.

22 “(d) INCENTIVE.—

23 “(1) IN GENERAL.—The Secretary shall make a
24 one-time payment of the amount specified in para-
25 graph (2) to each eligible beneficiary that adopts a

1 certified advance directive and registers such direc-
2 tive with the Program.

3 “(2) AMOUNT.—

4 “(A) IN GENERAL.—For purposes of para-
5 graph (1), the amount specified in this para-
6 graph is—

7 “(i) for a beneficiary who registers a
8 certified advance directive with the Pro-
9 gram in 2015—

10 “(I) in the case of a beneficiary
11 that creates, adopts, and registers a
12 certified advance directive using on-
13 line processes only, \$75; or

14 “(II) in the case of a beneficiary
15 that creates, adopts, or registers a
16 certified advance directive using a
17 manual process, \$50; and

18 “(ii) for a beneficiary who registers a
19 certified advance directive with the Pro-
20 gram in a subsequent year, the amount
21 specified in this paragraph for the pre-
22 ceding year increased by the percentage in-
23 crease in the Chained Consumer Price
24 Index for All Urban Consumers (as pub-
25 lished by the Bureau of Labor Statistics of

1 the Department of Labor) over the pre-
2 ceding year.

3 “(B) ROUNDING.—If any amount deter-
4 mined under subparagraph (A) is not a multiple
5 of 10 cents, such amount shall be rounded to
6 the nearest multiple of 10 cents.

7 “(3) ADMINISTRATION.—The Secretary shall,
8 through a full notice and comment rulemaking pro-
9 cess, establish procedures for—

10 “(A) making the incentive payment di-
11 rectly to the eligible beneficiary or a personal
12 account maintained by the beneficiary at a fi-
13 nancial institution that has been designated by
14 the beneficiary, and ensuring that no other enti-
15 ty receives the payment on the beneficiary’s be-
16 half; and

17 “(B) ensuring that a beneficiary does not
18 receive an incentive payment under this section
19 more than once.

20 “(e) EDUCATION AND OUTREACH.—

21 “(1) IN GENERAL.—The Secretary shall provide
22 for—

23 “(A) the inclusion of the statement set
24 forth in paragraph (3) in the Medicare and You
25 handbook under section 1804 and on a clear-

1 inghouse website linked to the Internet website
2 of the Centers for Medicare & Medicaid Serv-
3 ices;

4 “(B) the promotion of the benefits of elec-
5 tronic advance directives services, as they be-
6 come available, through the use of mass com-
7 munications and other means;

8 “(C) the inclusion, under the heading
9 ‘Statutory Advance Directive Forms’, of any
10 relevant forms, whether mandatory or optional,
11 specified in the statutes of regulations of the
12 States to be displayed on a clearinghouse
13 website;

14 “(D) the inclusion, under the heading ‘Al-
15 ternative Advance Directive Forms,’ on a sepa-
16 rate clearinghouse website, and in accordance
17 with paragraph (2)—

18 “(i) of other advance directive forms
19 submitted to the Secretary by individuals
20 and groups in an electronic format speci-
21 fied by the Secretary for which the submit-
22 ting entity includes, for each form sub-
23 mitted, an opinion by an attorney licensed
24 to practice in the relevant State dem-

1 onstrating that the submitted form com-
2 plies with the law of that State; and

3 “(ii) of the following disclaimer, which
4 shall be prominently posted on the website:
5 ‘This website includes for your consider-
6 ation alternative advance directive forms
7 submitted by individuals or groups reflect-
8 ing different perspectives on advance
9 health care decisions which you may wish
10 to review before completing your own ad-
11 vance directive.’; and

12 “(E) the inclusion of a user friendly index
13 on the clearinghouse website by State and, in
14 the case of the ‘Alternative Advance Directive
15 Forms’, by the name of the provider, so that a
16 user may readily access those statutory and al-
17 ternative forms.

18 “(2) ALTERNATIVE ADVANCE DIRECTIVE
19 FORMS.—

20 “(A) IN GENERAL.—For purposes of para-
21 graph (1)(D), the following shall apply:

22 “(i) Not later than 60 days after re-
23 ceiving an advance directive form sub-
24 mitted under such paragraph, the Sec-
25 retary shall either post the submitted form

1 on a clearinghouse website or provide to
2 the submitting entity a detailed expla-
3 nation of the basis for the Secretary's de-
4 termination that the submitted form does
5 not comply with relevant State or Federal
6 law, which determination shall be subject
7 to judicial review under section 702 of title
8 5 of the United States Code; and

9 “(ii) the Secretary shall either remove
10 or refuse to post any submitted form if
11 provided with an official determination by
12 the Attorney General of the applicable
13 State that the form is not in compliance
14 with State law, subject to applicable State
15 law described in subparagraph (B).

16 “(B) STATE LAW DESCRIBED.—For pur-
17 poses of subparagraph (A), State law described
18 in this subparagraph is—

19 “(i) a ruling by a court of the applica-
20 ble State, or by a Federal court applying
21 that State's law, subject to subsequent rul-
22 ings by a court or courts with authority to
23 supercede that ruling; or

24 “(ii) a statute or regulation of the ap-
25 plicable State that provides for a specific

1 procedure for officially determining wheth-
2 er particular advance directive forms com-
3 ply with State law.

4 “(3) STATEMENT.—For purposes of paragraph
5 (1)(A), the statement included in this paragraph is
6 the following statement, with appropriate insertions
7 in the bracketed segments updated at least annually:

8 “WHY YOU MAY WANT TO CONSIDER AN ‘AD-
9 VANCE DIRECTIVE’ Do you ever worry what would
10 happen if you became unable to make health care decisions
11 for yourself because of an illness or injury? That’s what
12 an ‘advance directive’ is for. You can use it to give direc-
13 tions for your health care providers and family about your
14 health care to be followed if you are no longer able to
15 speak for yourself. You can also name someone you trust,
16 like a family member or friend, to give health care direc-
17 tions for you when you can’t do so yourself.

18 “You should consider carefully who to choose to
19 speak for you and what directions you want to give to en-
20 sure your representative clearly reflects your own values
21 and treatment preferences. You should not feel pressured
22 to violate your own values and preferences, and you are
23 entitled to implement them without discrimination based
24 on age or degree of disability.

25 “There are many resources to help you.

1 “By choosing the name of a state at [INSERT name
2 of webpage for the index provided in paragraph 4 of this
3 subsection and its URL (and, on the clearinghouse
4 website, include a hyperlink to it)], you can find sample
5 advance directives for that state. You can see any sample
6 or required forms given in state law, as well as others from
7 individuals or groups with different viewpoints on advance
8 health care decisions which you may wish to review before
9 completing your own advance directive.

10 “ Below is contact information for accredited vendors
11 who will arrange for your advance directive to be confiden-
12 tially kept online, where it can be seen by doctors who
13 are treating you so they are made aware of your wishes.
14 You can also give permission to certain other people, like
15 family members or friends, you want to be able to get a
16 copy of your advance directive. If a disagreement about
17 your treatment develops, depending on your state’s law
18 certain other people may also be allowed to see it.

19 “ These vendors can also help you create an advance
20 directive online or with paper documents, if you wish. On-
21 line directives allow you to change or cancel one that no
22 longer fits with your wishes in a more timely manner.

23 “[INSERT, in alphabetical order, the names and
24 contact information for currently accredited advance di-

1 rective vendors (and, on the clearinghouse website,
2 hyperlinks to their websites).]

3 “Although any adult who is capable of doing so can
4 use these resources to complete an advance directive at
5 any time, Medicare beneficiaries are particularly encour-
6 aged to do so when enrolling in Medicare or during the
7 annual enrollment period when you can choose among dif-
8 ferent Medicare health insurance alternatives.

9 “By completing an advance directive you can not only
10 make it more likely that your wishes about health care
11 will be known if you are unable to tell them at the time,
12 but also spare family, friends, and doctors the difficulty
13 of trying to figure out what you would have wanted. These
14 are matters of the highest importance that can affect life-
15 or-death decisions, as well as your future comfort and
16 well-being. You are encouraged to think about them care-
17 fully, and give serious consideration to recording your
18 wishes in an advance directive.”.