

**HOUSE . . . . . No. 201**

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**The Commonwealth of Massachusetts**

PRESENTED BY:

*Marjorie C. Decker and Jon Santiago*

*To the Honorable Senate and House of Representatives of the Commonwealth of Massachusetts in General Court assembled:*

The undersigned legislators and/or citizens respectfully petition for the adoption of the accompanying bill:

An Act advancing health care research and decision-making centered on patients and people with disabilities.

PETITION OF:

NAME:	DISTRICT/ADDRESS:	DATE ADDED:
<i>Marjorie C. Decker</i>	<i>25th Middlesex</i>	<i>2/18/2021</i>
<i>Jon Santiago</i>	<i>9th Suffolk</i>	<i>2/18/2021</i>
<i>Lindsay N. Sabadosa</i>	<i>1st Hampshire</i>	<i>2/18/2021</i>

**HOUSE . . . . . No. 201**

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By Representatives Decker of Cambridge and Santiago of Boston, a petition (accompanied by bill, House, No. 201) of Marjorie C. Decker, Jon Santiago and Lindsay N. Sabadosa relative health care research and decision-making centered on patients and persons with disabilities. Children, Families and Persons with Disabilities.

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**The Commonwealth of Massachusetts**

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**In the One Hundred and Ninety-Second General Court  
(2021-2022)**  
\_\_\_\_\_

An Act advancing health care research and decision-making centered on patients and people with disabilities.

*Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:*

1           SECTION 1. Chapter 118E: DIVISION OF MEDICAL ASSISTANCE of the  
2   Massachusetts General Laws, as appearing in the 2018 Official Edition, is hereby amended by  
3   adding the following section:

4           Section 79: Patient-Centeredness

5           Section 79 (a) Standards for Patient-Centeredness in Research & Analysis. The Division  
6   of Medical Assistance shall ensure that any portfolio of research and analysis relied upon for  
7   decision-making, whether provided by a state agency or a third party, impacting enrollee access  
8   to healthcare treatments and services, meets standards of patient-centeredness. The Division of  
9   Medical Assistance shall publicly provide a summary of patient-centeredness standards for any  
10   such analysis that includes, but is not limited to:

11           1) Evaluation of a range of research and analysis that includes outcomes prioritized by  
12 patients and people with disabilities within a specific disease area. If necessary, the Division of  
13 Medical Assistance will commission a survey of patients to identify relevant outcomes within a  
14 disease area.

15           2) Evaluation of a range of research and analysis that looks at relevant patient subgroups  
16 to ensure consideration of important differences in preferences and clinical characteristics within  
17 patient subpopulations.

18           3) Scientific Rigor: The Division of Medical Assistance shall require research and  
19 analysis to comply with good research practices, defined as consideration of the full range of  
20 relevant, peer-reviewed evidence (e.g., real-world evidence, research from range of sponsors  
21 including manufacturers), avoid patient harm through over-interpretation of findings of  
22 “inconclusive” evidence of clinical differences and instead allow time for conduct of additional  
23 research.

24           (b) Prohibition on Reliance on Discriminatory Measures. The Division of Medical  
25 Assistance shall not develop or utilize, directly or indirectly through a contracted entity or other  
26 third-party, a dollars-per-quality adjusted life year or any similar measures or research in  
27 determining whether a particular health care treatment is cost effective, recommended, the value  
28 of a treatment, or in determining coverage, reimbursement, appropriate payment amounts, cost-  
29 sharing, or incentive policies or programs.

30           (c) Appeals and Physician Override Mechanisms. The Division of Medical Assistance  
31 may not implement any policy limiting patient access to healthcare treatment and services which  
32 does not contain an appeals or physician override mechanism. Physicians may not be

33 discriminated against or otherwise negatively impacted for utilizing available physician override  
34 mechanisms.

35 SECTION 2. Title II, Chapter 6D of the General Laws, as appearing in the 2018 Official  
36 Edition, is hereby amended by adding the following section:

37 Section 20. Patient-Centeredness Standards for Health Policy Commission Reviews

38 Section 20 (a) Standards for Patient-Centeredness in Research & Analysis. The Health  
39 Policy Commission shall ensure that any portfolio of research and analysis relied upon for  
40 determining the value of a healthcare treatment or service , whether provided by a state agency  
41 or a third party, impacting enrollee access to healthcare treatments and services, meets standards  
42 of patient-centeredness. The Health Policy Commission shall publicly provide a summary of  
43 patient-centeredness standards for any such analysis that includes, but is not limited to:

44 1) Evaluation of a range of research and analysis that includes outcomes prioritized by  
45 patients and people with disabilities within a specific disease area. If necessary, the Health Policy  
46 Commission will commission a survey of patients to identify relevant outcomes within a disease  
47 area.

48 2) Evaluation of a range of research and analysis that looks at relevant patient subgroups  
49 to ensure consideration of important differences in preferences and clinical characteristics within  
50 patient subpopulations.

51 3) Scientific Rigor: The Health Policy Commission shall require research and analysis to  
52 comply with good research practices, defined as consideration of the full range of relevant, peer-  
53 reviewed evidence (e.g., real-world evidence, research from range of sponsors including

54 manufacturers), avoid patient harm through over-interpretation of findings of “inconclusive”  
55 evidence of clinical differences and instead allow time for conduct of additional research.

56 (b) Prohibition on Reliance on Discriminatory Measures. The Health Policy Commission  
57 shall not develop or utilize, directly or indirectly through a contracted entity or other third-party,  
58 a dollars-per-quality adjusted life year or any similar measures or research in determining  
59 whether a particular health care treatment is cost effective, recommended, the value of a  
60 treatment, or in determining coverage, reimbursement, appropriate payment amounts, cost-  
61 sharing, or incentive policies or programs.