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(Original Signature of Member)

119TH CONGRESS  
2D SESSION

**H. R.**

To establish a pilot program at the Centers for Disease Control and Prevention to support local jurisdictions in developing neighborhood-level, publicly accessible health data platforms, to establish a National Neighborhood Health Data Repository, and for other purposes.

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IN THE HOUSE OF REPRESENTATIVES

Mr. TORRES of New York introduced the following bill; which was referred to the Committee on \_\_\_\_\_

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**A BILL**

To establish a pilot program at the Centers for Disease Control and Prevention to support local jurisdictions in developing neighborhood-level, publicly accessible health data platforms, to establish a National Neighborhood Health Data Repository, 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 “Community Health  
5 Profiles Act”.

1 **SEC. 2. COMMUNITY HEALTH DATA PILOT PROGRAM.**

2 (a) ESTABLISHMENT.—Not later than 1 year after  
3 the date of enactment of this Act, the Secretary of Health  
4 and Human Services, acting through the Director of the  
5 Centers for Disease Control and Prevention, (in this sec-  
6 tion referred to as the “Secretary”) shall establish a pilot  
7 program (in this section referred to as the “Program”)  
8 to award grants, on a competitive basis, to not more than  
9 25 eligible entities to develop or enhance neighborhood-  
10 level, publicly accessible health data platforms. Such plat-  
11 forms shall submit de-identified, aggregated data to the  
12 National Neighborhood Health Data Repository estab-  
13 lished under subsection (h), consistent with applicable  
14 Federal, State, and local privacy laws.

15 (b) PROGRAM OBJECTIVES.—The objectives of the  
16 Program shall be to—

17 (1) promote equitable access to local health  
18 data;

19 (2) support the integration of Federal, State,  
20 and local surveillance systems into user-friendly,  
21 publicly accessible health data platforms;

22 (3) facilitate data-driven public health planning  
23 and community engagement;

24 (4) provide actionable insights at the State and  
25 local level, with a focus on addressing health dispari-  
26 ties; and

1           (5) support the establishment and maintenance  
2           of the National Neighborhood Health Data Reposi-  
3           tory to enable national comparability while uphold-  
4           ing local data privacy standards.

5           (c) ELIGIBLE ENTITIES.—To be eligible for a grant  
6           under the Program, an entity shall be—

7           (1) a State or local health department; or

8           (2) a municipality or county government.

9           (d) PARTNERSHIP WITH ACADEMIC AND NONPROFIT  
10          INSTITUTIONS.—In administering a grant under the Pro-  
11          gram, an eligible entity may partner with an academic or  
12          nonprofit institution.

13          (e) PRIORITY.—In awarding grants under the Pro-  
14          gram, the Secretary—

15          (1) shall prioritize eligible entities that—

16                  (A) serve populations experiencing health  
17                  disparities, such as medically underserved com-  
18                  munities, low-income communities, or environ-  
19                  mentally burdened communities;

20                  (B) lack a neighborhood-level, publicly ac-  
21                  cessible health data system; and

22                  (C) demonstrate plans to use the data col-  
23                  lected from such a system to reduce health dis-  
24                  parities; and

1           (2) may prioritize eligible entities that propose  
2           innovative indicators beyond traditional public health  
3           surveillance (pursuant to subsection (f)(1)).

4           (f) USE OF FUNDS.—A grant under the Program  
5           may only be used to—

6           (1) develop or expand a publicly accessible  
7           health data platform to provide neighborhood-level  
8           data across key domains, including—

9                   (A) social and economic conditions, such as  
10                  education, economic stress, neighborhood, vio-  
11                  lence, and incarceration;

12                  (B) housing and neighborhood conditions,  
13                  such as the prevalence and quality of air condi-  
14                  tioners, housing quality, and the quality of the  
15                  built environment;

16                  (C) maternal and child health;

17                  (D) healthy living, such as self-reported  
18                  health status;

19                  (E) health care, such as access to care and  
20                  avoidable hospitalization and vaccination; and

21                  (F) health outcomes, such as chronic con-  
22                  ditions, the prevalence or treatment of human  
23                  immunodeficiency virus (commonly known as  
24                  “HIV”) and Hepatitis C, binge drinking and

- 1 psychiatric hospitalizations, infant mortality  
2 and premature death, and life expectancy;
- 3 (2) integrate data from multiple sources, in-  
4 cluding—
- 5 (A) Federal surveillance systems;
- 6 (B) State and local administrative survey  
7 data; and
- 8 (C) local education, housing, and public  
9 safety data;
- 10 (3) ensure data disaggregation by neighbor-  
11 hood, ZIP code, or census tract, and support com-  
12 parability across local jurisdictions where feasible;
- 13 (4) design neighborhood-level, publicly acces-  
14 sible health data platforms with clear citation of  
15 sources and transparent methodology;
- 16 (5) incorporate into such platforms—
- 17 (A) visualization tools, such as charts,  
18 maps, and trend lines; and
- 19 (B) downloadable datasets for public use;
- 20 (6) provide training or technical assistance to  
21 community and local institutions to ensure sustain-  
22 ability and usability of such platforms, including as-  
23 sistance in aligning such platforms with Federal  
24 interoperability standards and model legal frame-

1 works for privacy, confidentiality, and data-sharing  
2 compliance; and

3 (7) submit de-identified, aggregated data col-  
4 lected or generated using grant funds under the Pro-  
5 gram to the National Neighborhood Health Data  
6 Repository, in such standardized format as the Sec-  
7 retary may require.

8 (g) ADMINISTRATION AND EVALUATION.—

9 (1) ADMINISTRATION.—In administering the  
10 Program, the Secretary shall—

11 (A) issue program guidance and technical  
12 assistance for platform development, data inte-  
13 gration, and public accessibility, including—

14 (i) standards for secure data reporting  
15 to the National Neighborhood Health Data  
16 Repository and alignment with Federal,  
17 State, and local laws; and

18 (ii) model provisions on confidentiality  
19 and comparability;

20 (B) provide technical assistance to grant  
21 recipients on data methodology, privacy protec-  
22 tion, and system interoperability; and

23 (C) facilitate collaboration and peer learn-  
24 ing among grant recipients to share best prac-  
25 tices and promote replicability.

1 (2) EVALUATION.—

2 (A) INITIAL REPORT.—Not later than 1  
3 year after the establishment of the Program,  
4 the Secretary shall submit to Congress a report  
5 that—

6 (i) summarizes the outcomes of the  
7 Program and the progress made on the de-  
8 velopment of neighborhood-level, publicly  
9 accessible health data platforms;

10 (ii) assesses improvements the Pro-  
11 gram has made in public access to health  
12 data, data usability, and community en-  
13 gagement; and

14 (iii) identifies lessons learned and  
15 makes recommendations for whether and  
16 how the Program could be expanded na-  
17 tionally or extended beyond the 4-year ter-  
18 mination period described in subsection  
19 (k).

20 (B) UPDATES.—The Secretary may update  
21 or supplement the report described in subpara-  
22 graph (A) as the Secretary determines appro-  
23 priate.

24 (h) NATIONAL NEIGHBORHOOD HEALTH DATA RE-  
25 POSITORY.—

1           (1) ESTABLISHMENT.—The Secretary shall es-  
2           tablish and maintain a publicly accessible, searchable  
3           National Neighborhood Health Data Repository to  
4           aggregate de-identified, neighborhood-level health  
5           data from recipients of grants under the Program.

6           (2) ELEMENTS.—The Repository shall—

7                   (A) display data submitted by recipients of  
8                   grants under the Program;

9                   (B) enable comparisons across local juris-  
10                  dictions; and

11                  (C) include tools for visualization, filtering,  
12                  and downloading of data.

13           (3) OVERSIGHT.—The Secretary shall provide  
14           oversight of the Repository by—

15                   (A) reviewing data submissions;

16                   (B) developing and implementing a meth-  
17                   odology for the aggregation of health data as  
18                   described in paragraph (4); and

19                   (C) in consultation with States and local  
20                   jurisdictions, enforcing national data standards  
21                   for quality and consistency.

22           (4) REVIEW OF METHODOLOGY BY INDE-  
23           PENDENT PANEL.—

24                   (A) ESTABLISHMENT.—The Secretary  
25                   shall establish an independent advisory panel

1 (in this paragraph referred to as the “panel”)  
2 for the purposes of reviewing the methodology  
3 developed by the Secretary under subparagraph  
4 (C).

5 (B) APPOINTMENT OF MEMBERS.—The  
6 Comptroller General of the United States shall  
7 develop, maintain, and make publicly available  
8 a list of nominees to serve as members of the  
9 panel. The Secretary shall appoint a member of  
10 the panel only after reviewing such list. Such  
11 members shall be experts in epidemiology, sta-  
12 tistics, public health surveillance, and data pri-  
13 vacy.

14 (C) REVIEW AUTHORITY.—The Secretary  
15 shall develop and implement a methodology for  
16 the aggregation of health data for the purposes  
17 of the Repository, which shall go into effect  
18 only upon certification by the panel that such  
19 methodology—

20 (i) reflects scientific best practices;

21 and

22 (ii) maintains public accessibility, pri-  
23 vacy protections, and data comparability  
24 across jurisdictions.

25 (i) DEFINITIONS.—In this section:

1           (1) HEALTH DISPARITY.—The term “health  
2           disparity” means a difference in health outcomes or  
3           access to health services that is closely linked to so-  
4           cial, economic, environmental, racial, ethnic, or other  
5           demographic factors.

6           (2) LOCAL JURISDICTION.—The term “local ju-  
7           risdiction” means a municipality, county, local  
8           health department, or regional public health author-  
9           ity with the capacity to implement a neighborhood-  
10          level, publicly accessible health data platform.

11          (3) MEDICALLY UNDERSERVED COMMUNITY.—  
12          The term “medically underserved community” has  
13          the meaning given such term in section 799B of the  
14          Public Health Service Act (42 U.S.C. 295p).

15          (4) NATIONAL NEIGHBORHOOD HEALTH DATA  
16          REPOSITORY.—The term “National Neighborhood  
17          Health Data Repository” means the National Neigh-  
18          borhood Health Data Repository established under  
19          subsection (h).

20          (5) NEIGHBORHOOD-LEVEL.—The term “neigh-  
21          borhood-level” means, with respect to a publicly ac-  
22          cessible health data platform, that such health data  
23          platform focuses on a geographic area within a local  
24          jurisdiction that is smaller than the municipal or

1 county level, such as a ZIP code, census tract, or  
2 community district.

3 (6) PUBLICLY ACCESSIBLE HEALTH DATA  
4 PLATFORM.—The term “publicly accessible health  
5 data platform” means an online tool, website, or  
6 dashboard that makes health data accessible to the  
7 general public through visualizations, downloadable  
8 datasets, or written summaries.

9 (j) RULE OF CONSTRUCTION.—Nothing in this sec-  
10 tion shall be construed to preempt or supersede any appli-  
11 cable Federal, State, or local privacy laws.

12 (k) TERMINATION.—The Program shall terminate on  
13 the date that is 4 years after the date on which the Sec-  
14 retary establishes the Program.