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The Honorable Xavier Becerra Secretary U.S. Department of Health & Human Services 200 Independence Avenue, S.W. Washington, D.C. 20201

Re: Request for Information on establishing a National Directory of Healthcare Providers and Services

Dear Secretary Becerra:

We write to offer comments on the Request for Information on establishing a National Directory of Healthcare Providers and Services (NDH) that could serve as a "centralized data hub" for healthcare provider, facility, and entity directory information nationwide.

The undersigned organizations represent millions of patients and consumers facing serious, acute and chronic health conditions across the country. Our organizations have a unique perspective on what patients need to prevent disease, cure illness and manage chronic health conditions. Our breadth enables us to draw upon a wealth of knowledge and expertise that can be an invaluable resource in this discussion.

In March 2017, our organizations agreed upon three overarching principles¹ to guide any work to reform and improve the nation's healthcare system. These principles state that: (1) healthcare should be accessible, meaning that coverage should be easy to understand and not pose a barrier to care; (2) healthcare should be affordable, enabling patients to access the treatments they need to live healthy

¹ Consensus Health Reform Principles. Available at: https://www.lung.org/getmedia/0912cd7f-c2f9-4112-aaa6-f54d690d6e65/ppc-coalition-principles-final.pdf.

and productive lives; and (3) healthcare must be adequate, meaning healthcare coverage should cover treatments patients need, including all the services in the essential health benefit (EHB) package.

We appreciate the Department's efforts to bring greater transparency and certainty to provider networks and agree that a national directory would be a crucial resource for multiple reasons, including for consumers choosing a provider and comparing plan networks, for regulators auditing network adequacy, and for providers coordinating their patients' care. Beyond serving as a central repository for provider information, we believe an NDH presents an opportunity to improve the utility and accuracy of provider network information for patients and consumers. We therefore direct our comments, below, to ways in which we believe the Department can construct an NDH that serves as a one-stop-shop for patients considering their provider and health plan choices based on robust, current and accurate information.

Provider Data Must Be Accurate

Our current fragmented approach to collecting and disseminating provider network information is costly to our health system, cumbersome for consumers to use, and far too often inaccurate. Studies have documented rampant inaccuracies across coverage programs, including Medicare Advantage and marketplace plans.² This longstanding problem can lead to delays in care and serious consequences for patients who rely on provider directories to seek and select clinicians to provide services. Inaccurate provider information can also result in unforeseen and substantial costs for patients who select a provider based on the expectation that they participate in their health plan's network.

A national directory can facilitate providers' compliance with the No Surprises Act requirement that they regularly update their information with the health plans and insurers in which they participate. We believe that providers and their staff would be more likely to keep a single NDH updated and verify it more frequently than is possible under our current fragmented approach, thus improving accuracy with an NDH. A central repository would also reduce administrative burdens and costs associated with requirements for providers to report and keep up-to-date their network status and other data under various health plans and coverage programs, with benefits for consumers and patients seeking up-to-date provider network information.

Provider Data Must Be Responsive to Patient Needs

Though provider directories can advance multiple objectives, we believe the primary purpose of such resources is to help patients identify the providers and services most likely to meet their needs and preferences. The patients and consumers we represent face a range of complex acute and chronic conditions often requiring care from a diverse team of providers, sometimes out of state. Therefore, the directory should identify which states providers have a license in good standing. Furthermore, in order for these patients, and others with varied care needs, to be served well by a national provider directory, it should include a wide range of healthcare-related entities and provider types beyond those traditionally identified in insurers' provider lists. The directory should encompass a wide variety of providers including, but not limited to, allied health professionals, post-acute care providers, emergency

² Michael Adelberg, Austin Frakt, Daniel Polsky, and Michelle Kitchman Strollo, "<u>Improving the Accuracy of Health Plan Provider Directories</u>," The Commonwealth Fund, Jun. 7, 2019. See also Bernard Wolfson, "<u>Health insurance provider directories are required by law but they often have errors</u>," Chicago Sun Times, Jul. 29, 2022; Katherine Ellison, "<u>73 doctors and none available: How ghost networks hamper mental health care</u>," Washington Post, Feb 19, 2022.

medical services, nurse practitioners, physician assistants, behavioral health providers, public health entities, and suppliers of durable medical equipment.

Yet a national directory must do more than identify a range of provider types. It is critical that any national directory include data elements sufficient to allow patients to locate providers who can deliver them culturally competent care, in their own language, and in a setting that is accessible. This means, at minimum, that the directory should: indicate the languages, including American Sign Language, in which the provider and their staff are able to communicate; reflect the accessibility of provider offices and medical diagnostic equipment; identify providers who can provide culturally appropriate care for members of traditionally underserved communities (including, as suggested by CMS, listing providers who have completed cultural competency training); and specify providers' telehealth capabilities, including accessibility features of telehealth software. To list offices and equipment as accessible, they must meet the standards established by the US Access Board.³

Provider Data Must Be Easy to Understand

In addition to the interoperability considerations raised in the RFI -- necessary to ensure information is up-to-date and accurate — we also urge the Department to require data be standardized and clearly defined. Patients must be able to understand whether provider information included in an NDH is reported for a practice of multiple providers, for a single physician, or by location.

We also urge the Department to conduct consumer testing of the consumer-facing information in an NDH to ensure patients and consumers can easily find participating providers, compare providers based on data elements that are important to them, and compare their plan choices based on provider networks, among other uses.

An NDH Must Include Patient Protections

The No Surprises Act protects patients from balance billing in multiple circumstances, including when a patient has relied on an inaccurate provider directory to select an in-network provider. We believe those protections should apply to an NDH as well. A patient that selects a provider they expect to be innetwork based on data gleaned from an NDH must be protected from balance billing. To do otherwise would be inconsistent with the intent of the NSA and the promise of an NDH.

A well-constructed and maintained NDH can empower patients to select providers most responsive to their care needs. To ensure an NDH is most responsive to the needs of stakeholders, particularly patients and consumers, and maximizes the potential uses of a national directory, we urge the Department to regularly seek public feedback that can inform ongoing improvements. We stand ready to assist the Department in that effort.

Thank you for the opportunity to provide these comments. For more information, contact Theresa Alban at the Cystic Fibrosis Foundation at talban@cff.org.

Sincerely,

³ See the guidelines for buildings https://www.access-board.gov/mda/ and medical diagnostic equipment https://www.access-board.gov/mde/

American Heart Association

American Kidney Fund

American Lung Association

Cancer Support Community

Cancer Care

Crohn's & Colitis Foundation

Cystic Fibrosis Foundation

Epilepsy Foundation

Hemophilia Federation of America

Immune Deficiency Foundation

JDRF

Lupus Foundation of America

Muscular Dystrophy Association

National Alliance on Mental Illness (NAMI)

National Eczema Association

National Hemophilia Foundation

National Hemophilia Foundation

National Kidney Foundation

National Multiple Sclerosis Society

National Organization for Rare Disorders

National Psoriasis Foundation

Susan G. Komen

The Leukemia & Lymphoma Society