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December 6, 2022

The Honorable Chiquita Brooks-LaSure  
Administrator  
Centers for Medicare & Medicaid Services  
Department of Health and Human Services  
Attention: CMS-1771-P  
P.O. Box 8013  
Baltimore, MD 21244-1850

**Re: Request for Information: National Directory of Healthcare Providers and Services**

Haystack Project is pleased to respond to the Centers for Medicare & Medicaid Services' (CMS') request for information on establishing a National Directory of Healthcare Providers & Services (NDH) that could serve as a "centralized data hub" for healthcare provider, facility, and entity directory information nationwide.

Haystack Project is a 501(c)(3) non-profit organization enabling rare and ultra-rare disease advocacy organizations to highlight and address systemic access barriers to the therapies they desperately need. We strive to amplify the patient and caregiver voice in disease states where unmet need is high, and treatment delays and inadequacies can be catastrophic. Our core mission is to evolve health care payment and delivery systems, spurring innovation and quality in care toward effective, accessible treatment options for Americans living with rare or ultra-rare conditions. Haystack Project is committed to educating policymakers and other stakeholders about the unique circumstances of extremely rare conditions with respect to product development, commercialization, and fair access to care.

We appreciate that CMS recognizes the need for a reliable, comprehensive directory that patients can rely on to identify and contact clinicians or ascertain whether a particular plan has a sufficient provider network to accommodate their care needs. Our comments provide a brief summary of the challenges our patient communities face, and focus on ensuring that patients, especially those with rare and ultra-rare conditions, can find a provider with the expertise they need.

Approximately 7,000 rare diseases have been identified to date, 90-95% of which have no FDA approved treatment. While each rare disease, by definition, impacts a patient population of under 200,000 (the primarily ultra-rare conditions within the Haystack community impact 20,000 or fewer, and often even 2,000 or fewer) rare diseases cumulatively affect approximately 30,000,000 or 1 in 10 individuals in the U.S.

Oftentimes, the greatest challenges patients with rare and ultra-rare diseases face is simply finding a provider with the expertise to diagnose and treat their condition. A 2021 Report to Congress from the Government Accountability Office (GAO) entitled “RARE DISEASES: Although Limited, Available Evidence Suggests Medical and Other Costs Can Be Substantial” assesses the challenges rare disease patients face accessing diagnostic and treatment services as well as the personal and economic costs associated with treatment delays. Rare disease patients:

- see an average of 4.2 primary care physicians and 4.8 specialists for their rare disease diagnosis
- make an average of 2.4 out-of-state trips related to their diagnosis
- visit an emergency room an average of 3.7 times and
- are hospitalized an average of 1.7 times for reasons related to their rare disease, and prior to diagnosis.<sup>1</sup>

The diagnostic and treatment access challenges common to rare disease patients generally can be an overwhelming burden for people of color and other underserved populations, including rural communities. Patients with rare and ultra-rare conditions and their caregivers would benefit from a reliable, one-stop source of information that could identify in-network specialists with disease-specific expertise.

There is a shared understanding within the stakeholder community that patients, including those with rare and ultra-rare conditions, would benefit from a reliable, one-stop source of information to identify in-network specialists with disease-specific expertise. The American Medical Association (AMA), for example, recently voted to adopt a policy urging Medicare Advantage plans to maintain accurate provider directories. AMA board member Scott Ferguson, MD noted that “[p]atients face a false appearance of choice when Medicare Advantage plans create networks that are too thin and directories that are too flawed. A comprehensive and authoritative source of accurate information is needed from federal authorities to support patients in Medicare Advantage.”

Haystack Project is similarly aware of the challenges CMS will face if it operationalizes this tool before the data infrastructure and interoperability needed to ensure efficiency and reduce burden for both patients and providers are fully designed, built, and implemented. Although the American Hospital Association (AHA) appears to generally support the concept of the NPH, we share its concerns that patients may not know “when to rely on the NDH versus their health plan’s provider directory.”<sup>2</sup> Patients with rare and ultra-rare diseases already face immense

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<sup>1</sup> EveryLife Foundation and the Lewin Group, “National Economic Burden of Rare Disease.” p 19.

<sup>2</sup> [AHA Letter to CMS on Establishment of a National Directory of Health Care Providers and Services \(NDH\) | AHA](#)

burdens in finding a provider capable of treating or even diagnosing their condition. Inaccuracies in provider directories will only exacerbate this burden.

If CMS determines to develop the NDH, we ask that it do so in consultation with patient groups, including rare and ultra-rare disease advocacy organizations, so that the end product is useful, accessible, and efficient for patients and their caregivers. Haystack expects that the types of information that will be most helpful to patients includes, at a minimum:

- Provider name and contact information, including all practice locations
- Complete licensure information
  - This should include all states in which a provider is licensed regardless of physical location, as recent advances in telehealth allow providers to treat across state lines
- All networks and plans to which a provider is enrolled (and their status, i.e., participating in a plan, “accepting” reimbursement as payment in full, out-of-network provider willing to submit claims, etc.)
  - This should include Medicare, Medicare Advantage, Medicaid fee for service (and states for which Medicaid is accepted), Medicaid managed care (including Medicaid plans in other states) and all private insurance
- Provider specialties and sub-specialties
- Years in practice
- Hospital affiliation
- Whether new patients are being accepted
- Average wait time for both new and existing patient appointments
- The availability of telehealth services
- Languages spoken

Haystack also urges CMS to consider including a broader set of providers in the NDH. Individuals with rare and ultra-rare conditions often need ancillary services and supplies, including care from allied health professionals, durable medical equipment, and in-home nursing care.

### ***Conclusion***

Haystack appreciates that CMS has considered undertaking the complex and immense task of creating the NDH. We also believe this is incredibly important work that could provide enormous value to patients. Haystack looks forward to continuing to work with the Agency as it moves forward to develop this important resource.