



The CARIN Alliance

Creating Access to Real-time Information Now through Consumer-Directed Exchange

Chiquita Brooks-LaSure, Administrator
Centers for Medicare & Medicaid Services,
Department of Health and Human Services,
Attention: CMS-0058-NC
P.O. Box 8013,
Baltimore, MD 21244-8013

Re: Request for information solicits public comments 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.

Dear Administrator Brooks-LaSure,

On behalf of the CARIN Alliance, we thank you for the opportunity to comment on the request for information on the potential establishment of a National Directory of Healthcare Providers and Services. We appreciate your consideration of our comments.

The CARIN Alliance is a multi-sector group of stakeholders representing numerous hospitals, thousands of physicians, and millions of consumers, individuals, and caregivers. We are committed to enabling consumers and their authorized caregivers easy access to their personal health information. Specifically, we are promoting the ability for consumers and their authorized caregivers to gain digital access to their health information via open APIs.

We appreciate CMS’s ongoing focus on patient-centered care and patient access to their health information. As you know, over the past several years, CMS has taken significant steps to facilitate consumer-directed health information exchange. From the establishment of the Blue Button Program to the Interoperability and Patient Access rules and support for ONC’s information blocking activity, CMS has been a government and market leader in advancing consumer access to their health information. The CARIN Alliance is proud to have worked with CMS on the creation of the CARIN Implementation Guide (IG) for Blue Button which has allowed millions of consumers digital access to their claims information across more than 900 CMS payers include CMS Blue Button, state Medicaid agencies, QHPs, and Medicare/Medicaid plans.

However, numerous challenges remain to make consumer access to health information, and consumer directed health information exchange, a greater reality and a better tool for the entire health care ecosystem. Challenges include the need for access to more data from more

sources, the standardization of data exchange and data formats, consumer education, data-holder education, and many additional activities. Important to this RFI, the ability for consumer-facing applications to discover FHIR endpoints remains a significant barrier to consumer collection of their health information and, ultimately, the sharing of that information for health care decision-making. We applaud CMS for seeking to better understand the barriers to directory accuracy and endpoint discovery.

This comment will focus on issues directly related to consumer access to their health information. While a number of additional issues contemplated in this RFI impact consumers, patients, caregivers, and care partners, and while CARIN members have divergent views on those issues, we offer comment on how CMS could advance consumer-directed health information exchange, patient access to information, and the realization of some of the promise of other CMS initiatives.

Endpoint Discovery

As noted in the RFI, “there is neither an authoritative source for digital contact information nor a consistent method for locating such information.” This lack of an authoritative source, or even a consistent method to locate information, has created a challenge for many of the consumer-facing applications in the CARIN community. While a number of fee-based and free endpoint directories are beginning to emerge in the market, the current process by which consumer-facing applications connect to FHIR endpoints is incredibly manual and tedious. While some providers, payers, and technology vendors are working to streamline endpoint discovery and registration, CARIN members describe the ongoing need to telephone many individual providers or payers to discover how to connect their application to the payer’s/provider’s data source using an application registration process that includes FHIR endpoint discovery, developer portal requirements, and registration questionnaires.

The CARIN Alliance has worked to address some of the challenges of application registration, including dynamic endpoint discovery, in our [Application Registration Guide](#), which seeks to establish best practices for application onboarding in accordance with the requirements of the CMS Interoperability and Patient Access Final Rule.¹ Other efforts, have sought to establish proprietary or open-source FHIR Endpoint Directories. One of these efforts is supported by another FHIR Accelerator, the Argonaut Project, the “Argonaut Patient-Access Brands and Endpoints”.² The goal of their project was not just to make the endpoints available, but also provide a way - if desired - to provide a complete directory of locations for the health system via a standard API. While it would be too early to suggest that HHS adopt something like this,

¹ [CARIN Alliance App Registration Implementation Guide - Patient Access APIs - WIP](#)

² <https://hackmd.io/@argonaut/patient-access-brands>

we think it is important to point out that such a guide exists and has been developed with input from a broad set of stakeholders.

As noted, the CARIN Registration Guide has limitations on adoption and is not a registry for FHIR Endpoints. Current proprietary and open-source FHIR Endpoint Directories also create challenges for consumers and the applications that they use because of their pricing, the lack of complete data, their immaturity, or the inaccuracies noted in the RFI. The CARIN Alliance believes that CMS could provide a significant public and market service by advancing endpoint directories. In this work, we encourage CMS to include a data dictionary to make sure directory participants know what they are supposed to publish and those seeking endpoints can do so in a uniform way. It will be critical for actors to understand if they are seeking access to sandbox or developer endpoints, production endpoints, patient access endpoints, or other FHIR endpoints. Including this level of granularity will be critical to ensuring that directory users derive as much benefit as CMS intends. In advancing this work, we believe CMS will need support from providers, EHR and HIT vendors, and other data holders and support systems.

In addition to these comments, CARIN is interested in the ongoing operationalization of the CMS Interoperability and Patient Access Rule (CMS 9115-F). While we recognize that this forum may not be the best for additional input on the ongoing activity in that space, we will be writing to the Office of Burden Reduction and Health Informatics on issues of standardized application registration and onboarding, consumer education and disclosures, endpoint registration, and others.

Related Questions from the RFI:

What specific health information exchange or use cases would be important for an NDH to support? Are there other types of data transactions or use cases beyond those already discussed that would be helpful for an NDH to support?

CARIN Response:

As noted, CARIN believes that one of the most important uses cases for an NDH to support relates to consumer access to their digital health information. In order to support this health information exchange, access to digital endpoints, specifically those related to the Individual Access API, is critical. Additional information related to non-digital consumer access, such as information about where consumers, patients, or caregivers should go to request additional paper, images, or other information not yet available electronically (such as contact information for the Health Information Management Department) could also be considered.

CMS Provider Directory Action to Help with Consumer Directed Exchange

In addition to the action recommended above, the CARIN Alliance believes that consumer empowerment and consumer access to information could be advanced through broader centralization of activity for identifying providers, facilities, and services through modern, open-source technology infrastructure. We believe the basis for better identifying individual providers, facilities and services is already underway in some situations. Below, we outline the foundation upon which CMS could build a net-new solution that would better identify individuals, facilities, and services to advance consumerism in the health sector.

Currently, the Drug Enforcement Administration under the Department of Justice requires providers that are authorized to prescribe controlled substances to go through an identity proofing process to that meets the LOA3 standards. Currently, about 800,000 providers have been through this process. We believe that CMS could leverage those identities, and the identity proofing process contained therein, to start building a new provider directory. This credential is more accurate than NPI and the process can be replicated in a way that confirms identity to a much higher degree.

We recognize that additional identity work for additional providers, facilities, and services could create an initial challenge in some areas. However, we believe that long-term burden reduction would result. Current federal partners and credential service providers could be leveraged for this work. In addition to what is done for individuals through IAL2, organizations within and without CARIN have started work on entity identification, including identifying individual health care facilities like hospitals and clinics. While it would take time to build the capability of identifying as many providers, facilities, and services as you reference in the RFI, and though additional information would be needed outside of current identity proofing activities, we believe that over time these procedures could help centralize information about providers, facilities, and services, increasing the utility of information to all directory users, including, and especially, consumers, patients, and caregivers.

Again, core to the CARIN Alliance's mission of facilitating consumer-directed health information exchange, we believe that the establishment of a more universal and accurate provider and service directory is a pre-requisite for endpoint discovery and usage described in other sections of this comment letter. We recognize that this work won't be done overnight but we believe CMS can dramatically advance consumerism in health care by advancing an initiative to improve data quality, data accuracy, and data access in the directory space.

Questions:

As noted above, CARIN appreciates the actions undertaken to advance consumer transparency around provider access and access to information. However, we have a number of operational questions that we encourage CMS to address in any future rulemaking, including:

- Who is going to own the technical and data updates? As you know, there are significant challenges to updating current directories and significant burden that providers, plans, and directory providers face in updating information. How will updates be effectuated?
- Is CMS going to maintain? As noted in the RFI and across the industry, NPPES and other government sources have data accuracy and completeness limitations. Does CMS intend to maintain this new directory itself?
- What does surveillance look like? In addition to initial validation and verification, surveillance activities are critical across the provider directory universe and the endpoint directory use cases. How will CMS surveillance work to ensure data is timely and current and that access to endpoint information is not being used maliciously?

Additional Points

One area that is not contemplated in the RFI is the creation of a consumer-facing application section of the directory. CARIN members believe that an application gallery, similar to what has been already developed on the CARIN MyHealthApplication.com website, could help individual consumers identify applications that they would like to use and help providers and payers recommend specific applications to their patients and enrollees. While this may not be immediately appropriate for a national directory, and an app gallery serves a distinct function than a directory, we believe that activity in this space by CMS could help instill confidence in consumer-facing applications by end-users. We believe additional work would be needed to validate the applications and specific data (such as privacy policy information), but the NDH could eventually serve as a unique clearinghouse for consumer-facing applications.

Again, we appreciate your work here and your consideration of our comments. If you have any questions or additional follow-up, please contact me at david.lee@leavittpartners.com.

Thank you for considering our comments and recommendations.

David Lee
Leavitt Partners
On behalf of the CARIN Alliance