2021 Cambia Grove Innovator Fellowship Program

CARIN Alliance Executive Summary
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Introduction

The CARIN alliance is a bipartisan, multi-sector collaborative working to advance consumer-directed exchange of health information. This accelerator project is designed to address the needs of patients and their caregivers in the health care system, dealing with payers, providers, and third-party applications solutions rooted in FHIR based interoperability.

Interviews

The process of collecting information on the value proposition of CARIN Alliance Implementation Guides (IGs) was initiated by a point of contact at the project, who identified subject matter experts (SME) for each use case. Through a series of interviews with different use case implementers, fellows capture various value statements which were used and summarized in the 2021 Value Metrics Framework. The framework can act as a guide for existing or future use case implementers to identify points of value in implementing specific use cases.

Common Themes

The CARIN Alliance IGs range from highly specific applied solutions to low level foundational components, but these use cases all focus on the patient and the shortcomings that need to be addressed for them. Specific to this year's fellowship program, the CARIN IG for Blue Button, CARIN Real Time Pharmacy Benefit Check (RTPBC) and Digital Insurance Card were chosen by project leads as key topics of focus.

The Centers for Medicare & Medicaid Services (CMS) finalized Interoperability and Patient Access Final Rule required health plans (payers) to make consumer data available via API's. The regulatory requirement was critical in advancing the adoption of FHIR standards to allow patients to access their healthcare data. In speaking with Use Case implementers, fellows noted the level of Use Case implementation ranged from initial concept phases to fully built. Despite differences in use case maturity, key themes emerged across all three IGs.

Initial phases of development

At the time of the interviews, many use case implementers were still in the initial phases of rolling out their FHIR APIs and programs. Several noted the challenge associated with measuring the value, given how new the technology was, but acknowledged its potential in helping providers and payers reimagine how patients can use healthcare data. The regulatory requirement was important in encouraging organizations to implement FHIR interoperability standards.

As one implementer noted, the work in this space will follow a "crawl, walk, and run" timeline, where the crawl phase involves getting everything into a FHIR format. Once FHIR is standardized across the entire ecosystem, the potential to do innovative things with the data becomes more interesting and widespread.

Improved patient care and decisions
Providing healthcare information that is real-time, curated, and actionable is important in allowing patients to manage their health as they see fit. In the current state, patient information is housed across different data systems within various healthcare organizations. Patient care is often reactive, which is costly. By giving patients a complete 360-degree view of their own health status and insights that are meaningful, they and their caregivers can be more proactive in managing their health. Fellows spoke with implementers ranging from large technology companies to start-ups and noted growing interest in applying machine learning (ML) and artificial intelligence (AI) to healthcare data. For example, through APIs, third party applications can use patient data to create trend lines and sparklines of a patient's labs which provides tailored insights based on their lab history. Allowing them to receive tailored information based on their current and historical health status.

Individual control
Allowing patients to take their data and have it "travel" with them throughout their life and healthcare journey has significant clinical and administrative benefits. For example, when a patient changes a health insurance carrier, instead of having to reapply for prior authorization, the processes can be streamlined using FHIR standards. FHIR has the potential to allow payer to payer exchange prior-authorization information, preventing patients and providers from having to start the process over, every time a patient or their employer changes an insurance carrier. This could prevent delays in access to care by removing administrative inefficiencies. *Improved patient care and decisions*
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Potential Barriers
Although the CARIN implementations are patient-centered, the cost of these implementations necessarily need to be paid by the organizations who serve these patients. In other words, much of the direct value from these use cases does not go to the organization (although it probably benefits them in the long run). This gap puts these implementation efforts at some risk of being abandoned or ignored by the organizations that are necessary to implement them.

Other points of Interest
The patient-centered nature of the CARIN IGs creates a lot of tangible value to big tech companies due to their direct impact on consumers. Historically, there has been a large void between healthcare and technology companies due to healthcare being slow to adopt technology, but this gap has quickly closed over the last several years and the reliance on technology in healthcare continues to grow. One additional advantage of big tech participation in FHIR standards is it allows third party apps to scale faster, by removing the hurdle of directly contracting with large health systems to gain access to the data. The alignment between tech and healthcare is accelerating the adoption of FHIR standards.

Recommendations
The CARIN Alliance should be thoughtful and intentional about marketing the benefits of their implementation guides to the implementers, especially if those benefits are somewhat indirect.

The demand for CARIN Use Cases will only grow as more patients request access to their data and demand new ways of using it. Fellows assigned to the CARIN IGs did not speak with patients to assess their interest and thoughts. Future Innovator Fellows should consider interviewing patients to gain their perspectives on how the technology can positively impact their lives and the potential hurdles in limiting adoption.