Chapter 2
Ecosystems in Precision Medicine:
The Need for Good Governance

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ABSTRACT

Emerging technology requires participating members to intensely collaborate in fundamentally novel ways. This participation includes established and start-up firms, health professionals, standards bodies, regulatory agencies, and of course, patients. But how to design, implement, and manage emerging technology that cuts across shifting zones? With firm and global boundaries increasingly blurred, uneven regulatory treatment, and evolving standards, how can ecosystem partners collaborate to mitigate the risks to consumers as their data becomes ever more precise and identifiable? This chapter explores the relationships and decisions that ecosystem partners must collaboratively take together in the context of precision medicine and the challenges of working effectively – and ethically - with consumers.

INTRODUCTION

The aim of Precision Medicine[1] is to improve health care outcomes for patients using tailored treatments, often based on innovative health information technology. These tailored treatments depend on diverse stakeholders who must collaboratively build ecosystem relationships while innovating within their entities. Ecosystem coordination is complex; it is like upgrading the navigation system of one's in-

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flight aircraft while attempting to fly in tandem with aircraft conducting their own upgrades. History provides a stark reminder of costly ecosystem disconnects. For example, Pfizer's inhalable insulin was technologically sound, but the ecosystem coordination was not. Members of the ecosystem were not prepared for the changes in the value chain due to FDA regulatory requirements. The $12 million in actual sales vastly underperformed original projections of $1.5b (Adner, 2013).

Ecosystem coordination is especially vital for sharing patient data, considered a necessary lynchpin to precision medicine. Some believe that the data in research databases is the core of the ecosystem and crucial to advancing precision medicine (Aronson & Rehm, 2015). This coordinated sharing remains a distant promise, as health data is currently non-standardized, often inaccessible, located across systems, and is challenging to understand, use, and share (Attaran, 2020). It is not for lack of trying; for over two decades, numerous policy guidelines have been produced, with the explicit aim to improve data sharing to address privacy, data security, and interoperability in precision medicine (Blasimme, Fadda, Schneider, & Vayena, 2018; Sansone et al., 2012). Indeed, some believe that the future of healthcare depends upon fully connected ecosystems for cohesive patient journeys (Wray, 2017).

With better ecosystem coordination in mind, this chapter describes innovative and precision medicine ecosystems. Types of precision medicine ecosystems, and their challenges, are discussed. Recommendations to increase the chances of ecosystem success are explored, emphasizing governance principles that underpin collaborative and innovative ecosystems in the context of Precision Medicine. The chapter concludes with future research opportunities for patient-centered ecosystems. After all, if Precision Medicine becomes truly patient-centric medicine, then surely the health of these ecosystems matters.

BACKGROUND

What do we mean by innovative ecosystems? Broadly defined, innovative ecosystems are collaborative arrangements that allow firms to combine offerings into a customer-facing solution (Adner, 2006). Usually made up of diverse stakeholders, innovative ecosystems use technology to enable development (Jackson, 2011; Oh, Phillips, Park, & Lee, 2016). In addition to technology, innovative ecosystems can include new products, business models, behavioral changes, and policies (Gong, 2020).

Some believe that innovative ecosystems focus on the partnership arrangements necessary to deploy new solutions, requiring a balance of proprietary and strategic interests (Silva, Schaibley, & Ramos, 2018). Others believe that innovation is more closely tied to inter-firm knowledge transfer that can accelerate research and development efforts (Chesbrough, 2003; Silva et al., 2018). Regardless of the