

Open Source Platforms Beyond Software: From ICT to Biotechnology

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Abstract

Theories of platform strategy and adoption have been largely derived from studies of their application in the information and communications technology (ICT) sector. These platforms vary in openness, with the model of open source software providing the best-known exemplar for open platforms.

This exploratory field study examines the degree to which nine attributes of ICT platforms are applicable to open platforms in biotechnology. Using a combination of interview and secondary data, it identifies three patterns of such biotechnology platforms — IP commons, hackerspaces and crowdsourced patient registries — and the degree to which these nine attributes apply. It shows the impact of ICT platforms and open source software on open source approaches to biotechnology, and how the latter are affected by the technical, legal and institutional differences between information technology and biotechnology.

Instead of open source software platforms organized around modular interfaces, complements, ecosystems and two-sided markets, this study instead suggest a model of open source knowledge platforms which benefit from economies of scale but not indirect network effects. From this, it discusses the generalizability of the ICT-derived models of open source platforms and offers suggestions for future research.

Keywords: ICT platforms, communities, crowdsourcing, openness, biotechnology

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1. Introduction

The growth of technology-based industries often depends on orchestrating a diverse network of firms, suppliers and complementors to produce a complex innovation. Managing the cooperative and competing interests in such innovation ecosystems is the essential task for the success of many classes of complex innovations (Vanhaverbeke & Cloudt, 2006; Rohrbeck et al 2009; Adner & Kapoor, 2010)

In the information-communications technologies (ICT) sector, the dominant form of such ecosystems is the concept of a *platform*, which combines technical and business interfaces to enable firm and industry growth (Baldwin & Woodard, 2009; Gawer, 2014). For 50 years, such platforms have played a crucial role in enabling ICT firms to introduce new products and families of products (Bresnahan & Greenstein, 1999; Gawer & Cusumano, 2002, 2014). More recently, firms have cautiously leveraged existing and created new open source platforms (Dahlander & Magnusson, 2008; Economides & Katsamakos 2006; West & Gallagher, 2006). ICT firms that sponsor platforms wrestle with openness tradeoffs between proprietary control to appropriate profits against sharing control to attract usage and participation (Gabel, 1987; Grove, 1996; Eisenmann, Parker & Van Alstyne, 2009, 2011; West, 2003, 2007). Theories of platforms are not only important to the ICT sector, but these theories have been mainly derived from research in this sector.

A major technology-based sector that has been largely unaffected by platforms are the life science industries, such as medical devices, biotechnology- and chemistry-based pharmaceuticals, and agricultural biotechnology. Entrepreneurs in these two sectors face similar pressures — including educating the market (Teece, 1986), diffusing innovation (Rogers, 1995) and the need for risk capital to scale quickly (Gompers & Lerner, 2001). However, biomedical (especially pharmaceutical) industries have important differences, including the dependence on solving science-based technical risks (Pisano, 2006) and the increased importance of formal IP (Cohen et 2002; Dutfield, 2009).

Until recently, shared platforms were unheard of in the pharmaceutical industry or the broader life science sector. The industry is marked by a tension between the norms of open science and the proprietary goals of strong intellectual property protection (Eisenberg & Nelson, 2002). However, more recently firms have created and joined open platforms for knowledge sharing, particularly for pre-competitive pharmaceutical research (Perkmann & Schildt, 2015; West, 2016).

Biological platforms thus give us a unique opportunity to explore the extent to which insights from platform theory apply beyond ICT. In particular, given the influence of the processes and norms of openness from open science (Merton, 1973; David, 1998) upon biological research, this paper looks at the applicability of ICT-derived ideas of an open platform, specifically the oft-studied open source model. It does so through an exploratory study of communities and other collaborations organized around the idea of “open source biology,” which are modeled (directly or indirectly) on open source ICT platforms.

This study explores the application of open source processes to biotechnology, and is driven by two related questions. First, what has prompted and enabled the recent application of these processes to biotechnology and related life science industries? Second, what do the similarities and differences between the ICT and biotechnology models tell us about the generalizability of the open source model and open platforms more generally?

Using a series of exploratory interviews, it identifies three distinct archetypes of open collaborations in biotechnology: the IP commons, the patient registry and the hackerspace. It then contrasts them to key elements of prior open platforms, including the provision of complements, technical modularity, ecosystems, two-sided markets, IP openness and modularity, community production and governance, and the use of knowledge platforms. Most of the collaborations studied lack the first four elements, but instead they combine the remaining elements of open source processes with attributes of knowledge platforms (Kogut & Zander, 1992; Nonaka & Konno, 1998).

The paper begins with a review of theories of open platforms as they apply to ICT and other contexts, including a discussion of open source software and other open platforms. It then discusses the findings from the field study, and concludes with a discussion of the broader implications for open platforms and open source.

2. Prior Research on ICT Platforms

The platform concept emerged from analysis of competition between computing systems such as the IBM S/360 family (Bresnahan & Greenstein, 1999). It has been used in the ICT sector — computers, software, communications and internet services — and most of the platform research has been derived from the study of this sector, while the study of open platforms has been driven by a particular form of open platform associated with open source software.

This section reviews key elements of the platform concept as they might apply to other industries beyond ICT.

Attributes of ICT Platforms

The concept of an ICT platform begins with the third-party provision of *complements* as part of the “hardware-software paradigm” that fuels adoption through a pattern of indirect network effects (Katz & Shapiro, 1985; Teece, 1986; Gallagher & West, 2009). At the same time, the supply of these complements depends on the well-defined interfaces that enable *technical modularity* and a division of labor both within and between organizations (Baldwin & Clark, 2000; West & Dedrick, 2000; Baldwin 2008; Colfer & Baldwin, 2016). A platform is an architecture for products where some parts stay the same and some change (Baldwin & Woodard, 2009). These standardized technical interfaces and the third party provision of complements provide both a constraint and an ongoing source of competitive advantage as platform sponsors routinely fight for the loyalty of customers and complementors (Morris & Ferguson, 1993; Bresnahan & Greenstein, 1999; Gawer & Cusumano, 2002).

Beyond its origins in computer systems, the application of the platform concept has been applied to a wide range of software architectures, including graphical user interfaces (West & Dedrick, 2000), Java (Egyedi, 2001), databases (Gawer, 2009) and enterprise resource planning software (Ceccagnoli et al 2012). It has also been used to study communications equipment, such as local area networks (von Burg & Kenney, 2003), network routers (Gawer & Cusumano, 2002) and cellular telephony standards (Gawer & Cusumano, 2008), as well as those combined communications and computing devices known as smartphones (West & Mace, 2010; Pon et al, 2014). No matter what the segment, ICT industry research on the dynamics of platform competition and evolution has implicitly (or explicitly) assumed the strategic flexibility provided by malleable software-defined interfaces and implementations.

At the same time, the platform concept has been made more rich and explanatory by linking it to two related concepts.

Innovation Ecosystems. The metaphor of the ecosystem captures the interdependence of platform sponsors and complementors on the health of each other and that of the platform, although (as in environmental ecosystems) these ecosystems are marked by constant competition for overall leadership and dominance of specific niches (Iansiti & Levien, 2004a; Moore, 1993). The success of an ecosystem in jointly creating value through innovation depends not just on the ecosystem leader, but also the efforts of the member firms in overcoming their own technical challenges (Adner & Kapoor, 2010; Iansiti & Levien, 2004b). Thus, firms that sponsor platforms have a strong incentive to maintain a healthy ecosystem by focusing on the success of the complementors (Gawer, 2010; Gawer & Cusumano, 2002, 2014; Thomas et al, 2014); if they ignore that success the ecosystem may collapse (West & Wood, 2013).

Two-sided markets. The need for the platform sponsor to court both buyers and complementors corresponds to the two-sided network concept of Parker & Van Alstyne (2000), which more recently has been referred to as the multi-sided market (Eisenmann et al, 2006; Evans, Hagiu and Schmalensee, 2006; Rochet & Tirole 2003, 2006).² As with the ecosystem literature, this research originally examined the complementarity and interdependence of the value creation by the two (or more) categories of actors, but has since focused on market sponsors fine-tuning the cross-subsidies and other incentives to optimize the cost and value creation they obtain from these actors.

A final example (not specific to the ICT industry) is the creation of *knowledge platforms*, which are internal platforms for knowledge management. While they lack external complements or ecosystems, they allow a firm to gather and organize its internal knowledge to provide an infrastructure for future firm innovation (Kogut & Zander, 1992; Ciborra, 1996; Nonaka & Konno, 1998).

The sponsor of a platform faces key tradeoffs in the degree of openness of a platform, in terms of their ability to attract adopters and complementors while capturing private rents (West, 2003; Simcoe, 2006; West & O'Mahony, 2008). At one extreme, a proprietary platform allows one or more firms to both control the platform and capture the largest share of value, while for an open platform the sponsoring organizations seek greater participation by sharing control and access to technology across a wide range of participants (Gawer & Cusumano, 2002; West, 2003; West & O'Mahony, 2008; Baldwin & Woodard, 2009; Eisenmann et al 2009).

Many of these open platforms are produced by collaborative efforts between two or more actors. These multilateral collaborations are not an organization governed by a managerial hierarchy, but a network of relationships between participating organizations (Oliver, 1990; Powell, 1990). In some cases, there may be an organization at the center of the network such as an open source foundation or a standards setting organization (O'Mahony, 2003; Simcoe, 2012). However, much (if not most) of the work is done by the employees of these member organizations, meaning that that the central organization has less control over these members' employees than it would over its own employees (cf. O'Mahony, 2007).

Two examples of such network collaborations are consortia and communities (West, 2014). Consortia are often used to coordinate firm efforts to standardize open platforms, and are typically managed on behalf of member firms by a central nonprofit organization (cf. Leiponen, 2008; Simcoe, 2012). By contrast, communities are a voluntary association of actors (O'Mahony

² Increasingly these researchers have used "platform" as a synonym for "two-sided market" (or more generally "multi-sided network"), but here we follow Gawer & Cusumano (2014) and limit the term to those two-sided markets that share the attributes of one or more of the other definitions of platforms described herein.

& Lakhani, 2011) that may include both organizational and individual members (West & Lakhani, 2008) and may or may not have an organizational sponsor or manager (West & O'Mahony, 2008). For open ICT platforms, this community form is best known from the research and practice of open source software (OSS) communities.

Open Source Platforms

In the ICT sector, there are numerous examples of open platforms that built around open compatibility standards. The openness of these platforms may be defined by the control (or conversely, competition) for various elements or layers of the platform architecture, as well as the costs that platform users, complementors, or implementers or other stakeholders must pay to utilize the platform (West, 2003, 2007; Eisenmann et al, 2009)

Within open ICT platforms, there are important similarities between those defined around open standards and those around OSS. However, a crucial difference is that participants in standards consortia produce a shared platform specification but create their own separate implementations — while open source communities produced a shared implementation of a platform available to all (West, 2003).

OSS platforms are characterized by a community used for producing that shared technology and for governing that production process. Thus, these OSS platforms are distinguished by three attributes of openness: an IP approach represented by open source licenses, as well as community production and governance (West & O'Mahony, 2008).

The best known attribute of OSS Platforms is *IP openness*, proscribing a specific form of software license that guarantees that the software and its source code are freely available and distributed to all parties, and that allows the creation of derivative works (West, 2003; Rosen, 2004). Like other nonproprietary information goods, open source software has attributes of a pure public good in that possession by one party does not diminish the value held by other parties (Zeitlyn, 2003). This form of openness also means that the implementations tend to be free, with firms generating revenues by offering proprietary software and services that build on the open platform, and selectively allocating their efforts between open and proprietary technologies (Dahlander & Magnusson, 2008; Watson et al, 2008; West & Gallagher, 2006).

A second attribute is a decentralized *community production* model, likened to a “bazaar”, in which a large number of participants donate their labor to create the shared good (Dafermos, 2001; West, 2003; Zeitlyn, 2003). While open source communities originally emphasized individual contributors, today many open source communities are built around the contributions of corporate or a mix of corporate and individual members (West & Lakhani, 2008). By crowdsourcing both the production and quality control of this good, there is a belief by open source participants that this produces code quality that is superior to proprietary software (cf. Stewart & Gosain, 2006).³ Motivating, integrating and organizing such community production is key to the success of this model (Crowston et al 2007; von Krogh et al 2003).

Finally, a distinctive form of *community governance* applies to OSS communities. These are a particular form of online communities which are virtual collaborations that may or may not be affiliated with an organization such as a sponsoring foundation (O'Mahony, 2003; West & Sims, 2017). In their original form, a community is independent of any organizational control, is permeable to new contributors and embraces a pluralistic decision process; however, other

³ The security vulnerabilities of the ubiquitous OpenSSL internet security middleware — developed as open source by one full-time employee (Stokel-Walker, 2014) — suggest that the quality effects are driven by the number of participants rather than the open process *per se*.

hybrid forms of community have been created, sponsored and controlled by firms (O'Mahony, 2007; West & O'Mahony, 2008).

Firms working with open source communities face a number of tradeoffs between their private goals and the community goals, including selectively opening their technology to competitors and other firms (West, 2003; Eisenmann et al 2009). An important element of such a strategy is maintaining *IP modularity* that parallels the technical modularity, so that firm owned proprietary modules can be combined with the open modules that are available to all including competitors (Henkel et al, 2013).

3. Open vs. Proprietary Tensions in Biotechnology

The ideas of open source biology are a reaction to tensions between open and proprietary philosophies, tensions that have been intensified by three waves of biotechnology breakthroughs over the past 40 years.

Modern biotechnology began with the recombinant DNA technique that made it possible to combine the genes of two organisms via “gene splicing” to make a new organism. In contrast to the dominant paradigm of the preceding century — small molecule pharmaceuticals synthesized via organic chemistry — biotechnology products are large molecule proteins that more directly block disease mechanisms (Morrow, 2004). Following the success of the first biotechnology product in 1982 — Genentech’s synthetic insulin — the first wave of startup companies launched products and went public in the early 1980s, including Amgen, Chiron, Genzyme, Hybritech, Immunex, and were followed by more than 100 other firms in the late 20th century (Robbins-Roth, 2000; Pisano, 2006). These companies depended heavily on the research created and licensed from university researchers (McMillan et al, 2000). As with other pharmaceutical companies, the high failure rate and large R&D costs meant these firms would not invest without the temporary monopoly provided by a patent on the therapeutic compound (Pisano, 2006).

The second wave came with genomic medicine, which through its understanding of the human genome promised an increased understanding of the genetic basis of disease. It was enabled by the application of information technologies to studying genetic data, including software that facilitated comparison of partial gene sequences (Altschul et al, 1990), public and private efforts to sequence the human genome from 1990-2001 (Eisenberg & Nelson, 2002), and subsequent drops in sequencing costs (Collins, 2010). This knowledge has since enabled new classes of genetically targeted therapies for cancer and other diseases (Dalton & Friend, 2006).

The latest wave is the field of synthetic biology, which is driven by vision of biological engineering that applies principles of ICT systems engineering such as abstraction, well-defined interfaces, and standardized components. By allowing component reuse, advocates hope to make the process of engineering new complex organisms more efficient and reliable (Endy, 2005; Canton et al, 2008; Torrance & Kahl, 2014). However, beyond student experiments (Shetty et al, 2008), the potential of synthetic biology remains largely unrealized because direct fabrication of organisms thus far has proven more difficult than originally predicted.

These new technologies made possible new products, new companies and new industry segments. However, they also created new tensions between academic research and private commercialization, as the private monopolies slowed the norms of dissemination and openness associated with the academic process of open science (Nelson, 2001; Fabrizio, 2006; Murray et al, 2009).

In response to these tensions, some scientists, clinical researchers, patient advocates and entrepreneurs sought to create new models of IP sharing in biotechnology that emulate elements of open source software. Such models are the subject of this study.

4. Research Design

Unlike for open source software, there is no central definition of open source biology (as in the Open Source Definition), no central nonprofit (such as the Open Source Initiative or the Free Software Foundation), and no central repository such as SourceForge. For background information, we searched for “open source biology” on the World Wide Web (and specifically Google Scholar) of published articles and research; for historical trends, we also consulted Lexis-Nexis. For published articles, the term was most often used in *Wired* magazine and the Xconomy online website. The search terms “biohacking” and “DIY bio”⁴ were more popular than “open source biology”, but upon further investigation applied to a narrower range of phenomena.

We were confronted with a welter of efforts seeking to apply the “open source” principles (and mantra) to issues of applied life sciences. Lexis-Nexis reports that the earliest occurrences of the phrase “open source biology” came with a 2001 article on the Molecular Sciences Institute near UC Berkeley (Weege 2001). Cambia, an Australian agricultural biotechnology nonprofit, was profiled in 2003 by *Wired* about “open source” in the context of biology (Goetz 2003). A third early effort came with the BioBricks Foundation, launched at MIT in 2006, which sought to build a library of synthetic biology components through submissions to its annual International Genetically Engineered Machine (iGEM) conference (Shetty et al, 2008). The BioBricks components were an analog to the software libraries of the Free Software Foundation, formed as an MIT spinoff more than 20 years earlier.

After our preliminary research and initial interviews, we decided to focus on those activities that related to biotechnology, defined by the OECD (2001) as “the application of science and technology to living organisms ... to alter living or non-living materials for the production of knowledge, goods and services.”

Because of the limited research on the nature of the open source biology phenomenon, we chose a qualitative exploratory case study approach; such an approach offers the richness of detail and allows answers to “how and “why” questions.

The data collection included visits to five related conferences or workshops from 2011-2015: two visits to the annual Open Science Summit in Silicon Valley, online and face to face participation in two synthetic biology workshops, and an online webinar on patient registries. It also included written accounts, both primary data (such as published interviews, position papers and other articles written by open source biology participants) and secondary data such as news accounts and web sites.

To answer questions not addressed by these sources, we sought interviews with individuals who by their previous comments or experience appeared to be knowledgeable about the subject of open source biology. This included people found from Internet searches, published articles, conference speakers and experts identified or recommended in earlier interviews.

The primary data included 26 interviews with 23 individuals. Of the 26 interviews, 20 were recorded, and 15 were conducted in person, with the remainder conducted via phone or Skype. Of the 23 subjects, 15 were based in the Bay Area, a major center for biohacking, the home of Silicon Valley, as well as two of the major universities for synthetic biology (Berkeley, Stanford).

⁴ The phrase “do it yourself biology” was about 6x less popular on Google than “DIY bio”, while “do it yourself bio” was even less popular.

Another major synthetic biology center (MIT) was represented by two interviews with founders of an MIT spinoff, while four interview subjects were located elsewhere in the U.S. and two outside the U.S. As part of these interviews, the data collection also included multiple visits to two California hackerspaces from 2012-2013.

As recommended by Eisenhardt (1989), during the interviews we wrote detailed field notes, and after each interview summarized key insights and impressions. The interviews were transcribed, either entirely or selectively to bring out quotations identified by the field notes. As the interviews progressed, we looked for patterns: the author and research assistants discussed similarities and differences in the collaborations being studied.

5. Three Platform Archetypes

While our exploratory sample could not capture all possible manifestations of open source biology, our field data suggested at least three models of open source collaboration in biology: an IP commons, “hacker” oriented community, and a patient registry for crowdsourcing patient data (Table 2). These archetypes differed in the nature of their participants, their goals, aspects of open source that they emulate, and their stage in the biomedical value chain (Figure 1). Each form had distinct policies and economic logics, while at the same time holding overlapping goals of encouraging research and reducing the entry barriers for new biotechnology inventions.

Based on analysis of this exploratory data, we discuss these three archetypes, their origins, motives and activities. Using this data, we map their technical designs, policies and activities against the possible attributes of a platform described by prior research.

Explicit and Implicit Conception of Platforms

Of the 23 subjects interviewed, eight subjects explicitly mentioned the “platform” concept. Consistent with the definition of “product family platform” (Thomas et al, 2014), five referred to “platforms” in the context of a family of related products produced by a company participating in one of the collaborations. Three from hackerspaces referred to instrument platforms, one about the hackerspace working with the platform of a well-known sequencing company (cf. Quail et al, 2012), and two referring to the instruments of a company spawned by a hackerspace. One referred to a platform for discovering a series of new drugs (cf. Goldstein et al, 2008). One entrepreneur referred to their own intended platform of synthetic biology products — which by their nature would be analogous to ICT product platforms.

The remaining three interview subjects (and the webinar on patient registries) used “platform” to refer to shared knowledge platforms maintained by either a IP commons or patient registry collaboration. Because of the limited explicit use of the term, a more complete picture is provided by the implicit use of platform attributes by these three categories of collaborations. Data from these three archetypes were mapped against the nine attributes of open platforms identified by earlier platform research (Table 3).

IP Commons

The concept of an IP commons is intended to share IP (and create new shared IP) to enable life science research. Its IP models are often modeled on licensing and sharing models developed for open source software, as well as related efforts such as Creative Commons or Science Commons. It is oriented towards the concerns of PhD-holding academic and industry scientists, with an emphasis towards early stage, basic research. Examples of such efforts are given by Table 4.

One of the earliest projects to adapt open source to the life sciences came from Cambia (Center for the Application of Molecular Biology to International Agriculture), an Australian nonprofit founded in 1994 to create public access agricultural biotechnology (Boettiger & Wright, 2006). Another was Sage Bionetworks, formed in 2009 by former Merck employees to share data related to human therapeutics (Friend & Norman, 2013).

As might be expected from the open source software inspiration, the IP commons demonstrates four attributes of open platforms:

- *IP Openness*. Commons leaders repeatedly emphasized the central importance of an open IP model to their efforts. For example, the founder of one commons emphasized the difference between his effort and nominally “open” academic approaches to biological research: “The universities themselves want deals with industry that support their building buildings. ... How are they going to build the Amgen building or the Genentech center unless they offer something not freely available?” (Interview, July 11, 2012).
- *Knowledge Platform*. The large amount of open IP must be organized and structured so that it can be shared; as one interview subject said, “the concept of open source biology was used specifically about how data is shared”. Thus, the creation of a shared knowledge platform is the explicit goal of many of these consortia, although these are inter-organizational knowledge platforms rather than the intra-organizational platforms of Nonaka & Konno (1998).
- *IP Modularity*. The consortia expect that this knowledge will be used by corporate sponsors as the basis for their own proprietary research, and thus the organization recognizes IP modularity that allows the open IP of the open platform to be combined with the firm’s own proprietary technologies.
- *Community Governance*. The consortia differ in their governance structure, whether by committee or by a strong central nonprofit organization that acts on the behalf of the members. However, both approaches parallel the community governance models of open source software (O’Mahony, 2007) and standardization consortia (Simcoe, 2012).

Hackerspace

A second form of collaboration — sometimes termed “DIY bio” or “garage biology” (cf. Meyer, 2013) — seeks to empower amateur biohackers to conduct low cost experiments in the life sciences (Table 5). In many ways, this is most similar to the early (pre-corporate) days of the free software and open source movements, in which individuals (such as Linus Torvalds) exploited the suddenly available desktop computing power to collaboratively develop their own software. Of the three archetypes, this one showed the greatest degree of community identity and common purpose as defined by prior research (O’Mahony & Lakhani, 2011; West & Sims, 2017).

Although inspired by open source communities, in many ways the do-it-yourself orientation of these hackerspaces is unlike the cooperative OSS efforts that use community production to build a shared information good (such as the Linux operating system). Instead, they more resemble the earliest do-it-yourself computer hackers 35 years earlier, the amateur inventors of Silicon Valley’s Homebrew Computer Club, comparing experiments and discussing their own individual projects. Like the PC and Linux examples, the DIY bio communities attracted enthusiastic amateurs new to the technology, young scientists seeking to experiment with what they learned in formal education, and occasionally more experienced scientists who worked (or had previously worked) in the field. Leadership seemed to be held by those with enough enthusiasm (i.e. available time) and experience to have a vision of the community’s potential.

The DIY bio efforts — including Biocurious in Silicon Valley — parallel those of the DIY PC generation in another way, in providing a launching pad for individual inventors and their entrepreneurial initiatives.⁵ Some of the hackerspaces explicitly support entrepreneurial efforts by combining shared lab space with a business incubator, sometimes linked to crowdsourced funding of new firms.

As with the Linux hacker examples, these hackerspaces include open IP and open governance from the open source software model:

- *IP Openness.* As with open source software, some of the openness reflected a vision of transforming an industry: as one IT-biology hacker explained, “If you want to start a company, be sure you have a patent; if you want to start an industry, be sure you give it away” (Interview, July 27, 2012). In other cases, the openness was a practical reality to attract individuals and nascent entrepreneurs to learn and pursue potential opportunities.
- *Community Governance.* While most of these hackerspaces had a part- or full-time manager, they had limited resources and relied heavily on donated resources and volunteer labor. Like the YMCA, most provided access to equipment to those who paid a membership subscription; in 2010, Biocurious was launched using \$35,000 raised from 239 donors via crowdfunding. Most were organized as a nonprofit organization with a board of directors.
- *Community Production.* Each of the labs had one or more research projects to engage new members. New York’s Genspace collaborated to discover microorganisms in a local Superfund site and developed an inexpensive anaerobic chamber. Biocurious members worked to isolate bioluminescence genes from existing organisms, and develop a printer for 3D printing live cells. But these projects seemed more to create extended teaching opportunities than to advance the state of the art or results that could be used by others.
- *Knowledge Platforms:* The hackerspaces created a particular type of shared knowledge base, for training new members, which tended to be informal and not shared outside the lab.

As with the open source hackers (cf. Gruber & Henkel, 2006), several of the interview subjects had started their own firms to commercialize ideas they discovered during or after participating in a hackerspace. For example, Biocurious helped spawn OpenPCR — which made a hobbyist-level machine for duplicating DNA samples — and GlowingPlant.com, which raised nearly \$500,000 in crowdfunding to engineer (and sell seeds for) plants that glow in the dark.

These early stage entrepreneurs expressed an ongoing cultural affinity for these communities — particularly those seeking to market their inventions to these audiences — even if their firm’s proprietary technical capabilities had grown far beyond what was available as open IP from the hackerspace. They seemed much more involved than similar 3D printing entrepreneurs studied by Greul and her colleagues (2017), perhaps because the 3D printer product category and market are already well developed while the market for biohacking tools is still very early.

Crowdsourced Patient Data

If the first two collaborations seek to empower research scientists or would-be entrepreneurs, the third category is a community organized for (and sometimes by) the nominal beneficiaries of

⁵ The Homebrew Computer Club is best known for spawning Silicon Valley’s earliest personal computer manufacturers, including Apple Computer, Morrow Design and Osborne Computer Company (Freiberger & Swaine, 1984; Levy, 2001).

biomedical research: the patients. It seeks to leverage their one key asset — control of their own medical data — to catalyze research that will address their medical concerns. These may be organized informally by patients, or through existing patient registries established by disease-specific⁶ nonprofit organizations (Table 6).

On the one hand, the desired output of these communities parallels that of the IP commons: compiling large databases that can be freely shared with researchers seeking to develop a cure. On the other hand, the leadership of all but the largest communities — often led by parents of patients with rare inherited disorders — reflect more the amateur ethos of the biohackers than the professional norms and motives of the professional IP commons scientists.

There are two distinct types of patient registries: firm controlled and non-profit controlled. In both cases the sponsoring organization provides the necessary resources, but in the former case it comes from firm profits and in the latter case it comes from donations to the nonprofit to support its mission. They also differ in terms of the access to the knowledge in the registry — whether to benefit one firm (usually with an existing product to diagnose or treat that disease) or a broader range of academic or industry researchers.

Both forms suggest the applicability of four attributes of open ICT platforms:

- *Community Production.* As with open source, these patient registries utilize a crowdsourced community production model; in this case, the user-patients are contributing their own patient data that is aggregated by the community for the efforts of researchers.
- *Two-sided Market.* These registries demonstrate the two-sided markets seen in ICT platforms. In this case, one class of stakeholder is the patient, and the other is the researcher or health professional (or their respective employers). At the same time, while their motivations are congruent, their time horizons are not; as one collaboration manager explained:

Patients are not thinking “I want to participate in this experiment for the sake of getting more science done.” [They are thinking] “Is this going to provide me the best chance I have?” (Interview, Aug 21, 2013)

- *Innovation Ecosystem:* as with other two-sided markets, the registries are only successful if there is adequate participation of multiple stakeholders: researchers without patients generate no data, while patients without researchers generate no cures.
- *IP Modularity.* While the patient registry provides access to its IP to one or more researchers, those researchers seek to keep that IP separate from the IP they might generate through their own scientific discoveries — corresponding to the process of IP modularity identified by Henkel and his colleagues (2013).

While the goal of these projects was to generate data for biomedical researchers, most did not use an open IP process for sharing that data. At the same time, nonprofit organizations are increasingly facing competition in seeking donations and thus differentiation from rival organizations (Barman, 2002); for patient registries, their access to patients and patient data are their major source of differentiation, and thus not surrendered lightly.

⁶ Not all efforts are limited to a single disease, but instead may be grouped to address a category of related conditions (such as muscular dystrophy or cardiovascular diseases.)

6. Adaptation of Open Source Concepts

Our research identified different interpretations, motivations and implementation of the open source concept for biomedical products. However, respondents repeatedly identified three key drivers of this trend: the rapidly declining costs of biotechnology research and production, the exemplar of open source processes in software production, and the challenges of applying open source IP principles despite important differences in the law and practice of intellectual property between software and biotechnology.

Digitalization and Democratization of Biotechnology

Just as making inorganic objects has shifted from machine shop prototypes to computer aided design software, so the understanding and fabrication of biological organisms is shifting from a lab to digital research process. This means that biotechnology is looking more like information and communications technologies while also leading to ongoing cost reductions and the more widespread accessibility of biotechnology research tools and projects.

With improved imaging techniques (that, for example, allow analyzing the structure of human proteins) and the sequencing of the human genome, biological research over the past 25 years has been informed by an exploding volume of scientific data about human health and pathologies. Such data — most of it archived and freely distributed over the Internet by government agencies — has allowed biologists to do research *in silico* rather than the traditional *in vitro* or *in vivo*.

In turn, this has helped lead to the rapidly declining prices of conducting biotechnology research and production, and expectations of even further declines. Aided by Moore's Law, the cost of DNA sequencing has dropped dramatically; for example, the price of sequencing the human genome has fallen from \$1+ billion to less than \$1,000 in about 15 years, and is expected to fall even further (Hayden, 2014). Declining costs have made possible an explosion of publicly available genomic data such as offered by the National Center for Biotechnology Information of the US National Institutes of Health or the Sequence Read Archive hosted by Google.

Together, cheaper tools and more data have brought an increasing shift away from expensive wet labs towards virtual drug discovery (Augen, 2001). Such digital discovery techniques have leveraged new and potential methods of production, whether through contract manufacturing, short-run production labs, or desktop printing of new organisms. Together, these have brought closer the dreams of synthetic biologists who – intentionally emulating computer engineering — hope for the first time to separate the design of new biological organisms from their production (Endy, 2005; Purnick & Weiss, 2009).

These trends combine to enable for biomedical products the sort of “democratizing innovation” trends observed by von Hippel in information goods and a handful of consumer goods: “When I say that innovation is being democratized, I mean that users of products and services—both firms and individual consumers—are increasingly able to innovate for themselves (von Hippel, 2005: 1). However, while von Hippel emphasizes innovation by users meeting their own needs, thus far the role of users (e.g. patients) in open source biology seems to have been mostly limited to providing information to innovators.

At the same time, the decentralized production of novel biological organisms by biohackers raises issues parallel to those for cyberhackers. Pessimists worry that strict laws are needed to prevent an outbreak of bioterrorism. Optimists argue that the experiments of DIY biologists will help policymakers understand the implications and regulation of new forms of genetic engineering (Kuiken, 2016).

Impact of the Open Source Exemplar

In the interviews, many of the founders of open source biology efforts were aware of the success of open source software and articulated a desire to explicitly emulate one or more aspects of its success. In particular, they expressed an interest in two specific attributes of the open source model:

- The IP model that enables open sharing and reuse of knowledge.
- A collaborative community production model enabled by that openness — often enabled by the democratization of the technology.

For those that had an IT background, the analogy to open source software —and the way that enable participation — was salient:

Any time I hear open source, I go to the computer model — which has always meant code libraries that are not proprietary. You don't have to buy, rent, and break into a building to use [it]. ... How does this work in biotechnology? People are taking their tools and techniques and trying to make them accessible in the same way. Free as in beer⁷ means I can give away a procedure. (Interview, July 10, 2012).

Those from the traditional background were more skeptical. When asked to define open source biology, a former pharma executive now trying to share data replied:

Originally the concept of open source biology was used specifically about how data is shared and then it turned into the concept of non-expert ... those that want to do biology that are not certified [experts]. Then it shifted to another concept, along the Michael Nielsen⁸ [model of] network team approaches [to science]. (Interview, July 11, 2012).

Technical, Legal and Institutional Limits on Openness

When interviewed about open source biology, the most common response of our subjects was to emphasize the importance of the efforts as a response to an increasingly proprietary approach to intellectual property.

Applying the principles of open source software to biotechnology are complicated by the differences between the three major forms of intellectual property: copyrights, patents, trade secrets, and in fact interview subjects mentioned all three. Software has traditionally been protected by copyright, pharmaceutical compounds by patent, while open science makes use of trade secrets. In addition to legal issues, interviews suggested that the use of both proprietary and open strategies is also influenced by the technology, institutions and cultural practices.

Copyright. For open source software, some approaches enforce openness through an adaptation of software copyright dubbed “copyleft” (West, 2003). However, several respondents were familiar enough with open source software — and its reliance on copyright law — to note that such an approach would not work with biotechnology.

⁷ This refers the longstanding debate on open source whether free beer (no price) is more important than free speech (freedom to modify). Some evidence suggests that the former is more valued in practice, at least by organizational users (e.g. Dedrick & West, 2004).

⁸ This was one of two informants to mention Nielsen (2012) and his model for professional scientists to harness the contribution of amateur contributors via crowdsourcing; see also Franzoni & Sauermaun (2014).

One respondent said that the copyright used for protecting software won't work with biotechnology because "DNA sequences cannot be copyrighted", citing research by two Duke law professors on how this difference makes it harder to create an IP commons for synthetic biology (Rai & Boyle, 2007). Another pointed to the practical difference between protecting software and organisms: "biology is inherently open source in that the source code is readable."

Finally, this difference makes it difficult to adapt the cumulative process of open source software to biotechnology (Boettiger & Burk, 2004). When asked to comment on the difference between open source using copyright and patents, a former IT engineer turned biohacker said "copyright is less worrisome and for commercial entities less useful," while patents would pose more of a barrier to experimentation.

Patents. Most often mentioned—in interviews, white papers and websites about open source biology—was the impact of universities patenting biological discoveries. While once university research in biology—as with the other natural sciences—was developed and disseminated through a government-sponsored model of open science (Merton, 1973; David, 1998), today such research is often patented by the university and licensed to and sold by a for-profit entity. Such commercialization of university research by U.S. universities—accelerated by the 1980 Bayh-Dole Act that provided universities an incentive for patenting and commercializing their discoveries—is normally thought of as a success story to be emulated by other countries around the world (Mowery et al, 2001; Mowery, 2011). The policy helped lead to a dramatic rise in the rate of life science patenting by universities (Nelson, 2001).

The oft-cited exemplar of such success is the recombinant DNA patent of Stan Cohen and Herb Boyer, which allowed researchers to combine the DNA of two existing organisms to make a new organism that didn't exist in nature. The patent was licensed to some 200 young biotechnology companies, and overall generated \$254 million in royalties on sales of more than \$35 billion by some 2,400 products. In response, other universities sought to augment operating revenues through biomedical licensing, as when NYU received more than \$600 million in royalties for a single arthritis drug (Feldman et al, 2007; Bera, 2009).

At the same time, the rise in university patenting—and the secrecy associated with efforts to commercialize these patents—reduced the access to knowledge by individuals and organizations that don't (or can't) pay for a license either to patents or unpatented know-how (Fabrizio 2006). As one interview subject said

The universities themselves want deals with industry that support their building buildings, that gives them unrestricted funds they can't get from the government. How are they going to build the Amgen building or the Genentech center unless they offer something not freely available? (Interview, July 11, 2012).

In response to a dramatic increase in university patenting, promoters of open source biology sought to forestall patent oligopolies to allow greater freedom to innovate by some combination of academic researchers, existing firms, new entrants, or enthusiastic amateurs. Their solutions included a combination of identifying existing IP, weakening or working around those IP rights, and creating new IP unencumbered by proprietary restrictions.

In other cases, efforts to change practice were heavily constrained or even useless. The founder of one IP commons was forced to drop his original approach as his effort to create open source IP "was about 10 years too late": American universities had fully embraced patenting and licensing as a revenue source, and thus had no incentive to cooperate in open source efforts.

Overall, patents hinder open source biology by increasing transaction costs, limiting experimentation, creating patent thickets that make it expensive to commercialize a technology,

and create an anti-commons — problems that are only partly ameliorated for firms that can afford to pay for a license (Nolan-Stevaux, 2007).

Trade Secrets. The concerns about secrecy requirements imposed by firms on academic researchers are well known (e.g., Moses et al, 2002). At the same time, advocates of knowledge sharing in IP commons and patient registries noted the obstacles posed by the secrecy of traditional academic science. While the final results of biological research are disseminated via open science, researchers often keep secret intermediate data and materials to protect against academic competitors. As one respondent said

Sharing is punished in academia. For you to get tenure, you have to show you're irreplaceable. How can you get to that unique status [necessary for tenure], if every time you have a discovery everyone knows what you know? (Interview, July 11, 2012).

Or as another respondent said, “they’re all hoarding their own data — they’re all waiting to publish their high impact papers” (Interview, August 1, 2013).

Such hoarding was not limited to academics, but also include disease foundations, including those that run patient registries. As one former pharma executive said, “Pharma companies are more willing to share data than some patient foundations.” In response, IP commons have sought to find ways within existing patient privacy regulations to allow patients to donate their (anonymized) data to open research databases (Terry & Terry, 2011; Friend & Norman, 2013).

7. Conclusions

Based on exploratory data on open source biology, the paper shows how differences between the life sciences and ICT have led to a different implementation of open platforms in this context. Below we briefly summarize these findings and the implications for open source and platform theory.

Adapting Open Source from ICT to Biology

After reviewing the attributes of open ICT platforms, this study sought to see the degree to which they apply to open platforms in the life sciences — specifically those cooperative efforts that fall under the rubric of “open source biology”. These life science platforms parallel the development of ICT platforms in important ways, particularly since the rise of genomic medicine has brought a digitalization of life science research.

It identified three broad classes (or archetypes) of open source biology collaboration: an IP commons, a hackerspace and a crowdsourced patient registry. These archetypes were classified using the nine attributes of open platforms from the earlier platform literature, and they differ on several attributes from the earlier open ICT platforms — whether OSS platforms or open ICT platforms more generally (Table 3).

Among the key similarities and differences:

- Pre-competitive collaboration for knowledge in the IP commons resembles the pre-competitive cooperation observed by Simcoe in standardization, in that the (often temporary) cooperation in creating shared value is an antecedent to inevitable competition in private efforts to capture value (Simcoe, 2006, 2012). In fact, some of these biological collaborations are directly modeled on standardization consortia (Wagner et al, 2010) and also the industry-funded open source consortia such as Eclipse (cf. West & Gallagher 2006).

- The IP commons and crowdsourced patient data resemble the intra-organizational knowledge platforms of Nonaka and Konno (1998), except that they span organizational boundaries.
- Crowdsourced patient registries and hackerspaces resemble the user innovation of early open source (cf. von Krogh et al, 2003). They also make use of the community production model, although the community production tends to be the aggregation of individual data points rather than (as in open source software or hardware) a carefully coordinated interdependent production process to create a complex system (cf. O'Mahony & Ferraro, 2007; Balka et al, 2010).

Overall, the collaborations demonstrated pre-competitive collaboration for shared knowledge (as when defining standards) but not shared implementations (which would correspond to implementing standards). This is an inherent problem of extending openness for information goods into tangible goods, as noted by Balka and her colleagues (2010).

This study of open source biology did not identify a complements (“software”) element to these open platforms. Pharmaceutical products don’t have complementary goods in the sense of the Katz & Shapiro (1985) or the hardware-software model (applications, videogames etc.), where the platform sponsor seeks to maximize the number of suppliers of such complements.⁹ While the ecosystem model of third-party suppliers was not evident, the patient registries demonstrated elements of an ecosystem dynamics with the interdependence of a multi-sided market, in this case of patients and medical researchers. In this case, the platforms correspond loosely to the “audience makers” of Evans (2003), except that the firms are seeking information from the audience rather than to push advertising on the audience.

Finally, consistent with the stated goals, those promoting open source biology embraced many of the same IP policy and ethical positions of open source software. The push for openness by hobbyists (hackers) and academics (university employees) is consistent with the pattern of open source software. Similarly, the limited corporate support for pre-competitive openness in the IP consortia is consistent with the corporate-sponsored open source model by which firms share IP to reduce costs in a model that West & Gallagher (2006) term “pooled R&D.” At the same time, firms sought to partition their IP through the process of IP modularity (as defined by Henkel et al, 2013), so that the open (or shared) IP that they access from the open platform is not commingled with the proprietary IP generated by the firm after utilizing that platform.

As might be expected from our sampling procedure, all three archetypes thus have elements of open source software. All three also have elements of the knowledge platform of Kogut & Zander (1992) — which normally would correspond to an “internal platform” in the Gawer & Cusumano (2014) typology.

Finally, both the IP commons and patient registry combine some of the elements of both the “internal” and “external” platforms of Gawer & Cusumano (2014). Just as Chesbrough (2006) argues that innovative firms need to manage inbound and outbound flows of knowledge, so these suggest the need for some platform sponsors to create knowledge platforms that span firm boundaries to maximize the pool of knowledge available for the firm’s innovation strategy. However, further research is required to characterize and establish the generalizability of this style of inter-organizational knowledge platforms.

⁹ Pharmaceutical products have complements such as manufacturing, support and distribution — other complements in the sense of Teece (1986). Some also combine a therapeutic compound with a diagnostic for testing for that condition, or specialized delivery hardware (such as drug-eluting stents).

Implications for Platform Theory

The success of a typical ICT platform enables and is fueled by the complement-mediated demand-side economies of scale provided by indirect network effects (Gallagher & West, 2009). This study shows a pattern of interorganizational knowledge platforms without complements or modular interfaces, and (in most cases) lacking two-sided markets or ecosystems of complement providers.

Lacking these network effects, the IP commons model suggested more conventional supply-side scale economies: if enough big firms sponsor an effort, it will have enough resources to achieve its goals. And while the patient registries correspond to a two-sided market, it does not follow the complement-mediated indirect network model of (for example) videogame console; in fact, most of these disease-specific consortia are competing with non-adoption (rather than rival adoption), suggesting that the model is the uncontested adoption of a new technology (such as ATM machines) rather than the familiar platform war fighting for complementors' loyalty.

This study supports earlier research (e.g. Balka et al, 2010) suggesting that IP models of open source software have been highly influential beyond software, providing an exemplar that is often emulated (even in those cases where IP model does not follow the copyright-enabled software industry). The open biotechnology collaborations also show elements of community production and governance of Internet-enabled virtual collaborations, again supporting the generalizability of open source exemplar.

However, as with open source software (e.g. West & Gallagher, 2006), firms seeking to make a business off of open platforms — available to all rivals — need to add their own unique value creation to attract revenues. The biotechnology platforms suggest that the provision of a shared implementation in open source software is not inherent to all open source processes, which instead may use the shared knowledge as the antecedent to an implementation as with open standardization (West, 2003, 2007; Simcoe, 2012). In such cases, platforms are antecedents to private value creation rather than providing some portion of that value creation.

More generally, the nature of biotechnology open platforms suggests the crucial difference between complex and discrete products, the difference between products “comprised of numerous separately patentable elements versus relatively few” (Cohen et al, 2002: 1356). For complex systems that are modularized into many small components “make it relatively easy for capital-constrained firms and entrepreneurs to gain a foothold with a modular innovation that is limited in scope” (Baldwin & Woodard, 2007: 37). For open ICT platforms, firms can make a new system by combining (shared) open components with new proprietary components: the shared value creation from the open components reduces entry barriers to entrepreneurs while allowing them to create unique combinations of components at relatively low cost (Gruber & Henkel, 2006; West & Gallagher, 2006). A few of the hackerspace projects suggested early aspects of such collaboration to allow entrepreneurial entry based on shared open platforms.

However, many other life science products (human therapeutics, diagnostics and agricultural biotechnology) correspond to the discrete IP model of a firm-developed innovation. This discrete model means both higher barrier to entry and also a stronger ability to exclude rivals (Hall et al, 2005). As such, in discrete (rather than complex) product industries, open platforms provide less benefit to new firms, replacing the role of the open platform providing a modular component of a firm's complex offering with a mere input to the firm's own proprietary innovation efforts.

Overall, this study suggests opportunities for future research on the role of platforms in other natural sciences, for discrete (rather than complex) products, and for industries that lack the interface/complement model of network-driven adoption and platform competition.

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9. Tables and Figures

Platform Attribute	Key Finding	Prior Research
<i>Complements</i>	Value of core product increased by complementary product	Katz & Shapiro 1985; Teece 1986
<i>Technical Modularity</i>	Well-defined interfaces allow division of labor and separate evolution of technical design	Baldwin & Clark, 2000; Baldwin 2008; Colfer & Baldwin, 2016
<i>Innovation Ecosystems</i>	Interdependence of key stakeholders in health of ecosystem	Iansiti & Levien 2004a,2004b; Adner & Kapoor 2010
<i>Two-Sided Market</i>	Two (or more) different audiences create value for each other	Parker & Van Alstyne 2000; Rochet & Tirole 2003, 2006
<i>IP Openness</i>	Open IP encourages participation and cumulative innovation	West, 2003; Rosen 2004
<i>Community Production</i>	Community members can be harnessed to produce knowledge	von Krogh et al 2003, 2012; Crowston et al 2007
<i>Community Governance</i>	Allowing shared governance encourages participation	O'Mahony 2003, 2007; West & O'Mahony 2008
<i>IP Modularity</i>	Different degrees of IP openness need to be partitioned along technical interfaces	Henkel et al 2013
<i>Knowledge Platform</i>	Pooled knowledge provides an infrastructure for future research	Ciborra, 1996; Nonaka & Konno 1998

Table 1: Key attributes of open platforms

Archetype	Participants	Main Focus	Desired Outcome	Examples
IP commons	Scientists and other professionals	IP rights	Ability of many players to practice cumulative innovation	Cambia BiOS, SageBase,
Patient Registry	Patients and patient advocates	User empowerment	Leverage self-reported user data to accelerate cures	PatientsLikeMe, Pompe Registry
Hackerspace	Individuals and entrepreneurs	Amateur (“hacker”) science	Enable experimentation by individual hackers	Biocurious, DIY Bio

Table 2: Three archetypes of open source biology collaborations

	Biotechnology			ICT	
<i>Attributes</i>	IP commons	Hackerspace	Patient Registry	Open Platform	Open Source Platform
<i>Members</i>	Established firms	Individuals, new firms	Individual patients	Firms	Firms, individuals
<i>Technical Modularity</i>				X	X
<i>Complements</i>				X	X
<i>Innovation Ecosystems</i>			X	X	X
<i>Two-Sided Market</i>			X	X	X
<i>IP Openness</i>	X	X			X
<i>IP Modularity</i>	X		X	X	X
<i>Community Production</i>		X	X		X
<i>Community Governance</i>	X	X			X
<i>Knowledge Platform</i>	X	X	X		

Table 3: Contrasting platform attributes between ICT and biotechnology archetypes

Founding Date	Organization/Colaboration	Location	Initial Sponsor	Financial Support	Focus
2006	BioBricks Foundation	Cambridge, Mass	MIT		Synthetic biology building blocks
2006	Biomarkers Consortium	Bethesda, MD	FDA	7 major pharma companies and 1 trade association	Finding proxy indications for clinical outcomes
1994	Cambia	Canberra†			Agricultural biotech
2009	Coalition Against Major Diseases	Phoenix		9 major pharma companies	Develop disease models for neurodegenerative diseases
2007	Infectious Disease Research Institute	Seattle		7 major pharma companies	Research on developing country infectious diseases
2009	Innovative Medicines Initiative	Brussels	EU	European trade association and the EU	Funding biomedical open science
1996	Molecular Sciences Institute	Berkeley		US government agencies, corporations, foundations	Synthetic biology research
2009	Sage Bionetworks	Seattle†	Merck		Computational biology data
2004	Structural Genomics Consortium	Toronto†		4 major pharma companies	Determine structure of medical proteins

† Also has other locations

Table 4: Efforts to build IP commons in biology

Hacker Space	City	Founding Date
Bio, Tech and Beyond	San Diego area	2013
Biocurious	San Francisco Bay Area	2009
BOSSLab	Boston	2009
Genspace	New York City	2009
Hivebio	Seattle	2012
LA Biohackers	Los Angeles	2010
La Pallaise	Paris	2011
portLAB	Portland	2013

Table 5: Examples of biotechnology hacker spaces

Condition	Disease Registry Name	Sponsor	Collaborator	Start Date
Acid Maltase Deficiency	Pompe Registry	Genzyme		2006
Amyotrophic Lateral Sclerosis	National Registry of Veterans With Amyotrophic Lateral Sclerosis	US Department of Veteran Affairs	ALS Association	2003
	PatientsLikeMe	<i>Started by a patient family</i>	Numerous academic and industry partners	2004
	Pseudobulbar Affect Registry Series	Avanir Pharmaceuticals		2011
	Amyotrophic Lateral Sclerosis Web Based Patient Care Database	Forbes Norris MDA/ALS Research Center	Muscular Dystrophy Association	2006
Becker's Muscular Dystrophy	Pediatric Cardiomyopathy Registry	National Heart, Lung and Blood Institute		1994
Bethlem Myopathy	Congenital Muscle Disease International Registry (CMDIR)	Many countries		2008
Central Core Disease	Congenital Muscle Disease International Registry (CMDIR)	Many countries		2008
Cystic Fibrosis	Cystic Fibrosis Patient Registry	Cystic Fibrosis Foundation		1970s
Deuchene Muscular Dystrophy	The United Dystrophinopathy Project	University of Utah		
	Deuchene Connect Patient Registry	Deuchene Connect		2007
Myotonic Dystrophy	Myotubular Trust Patient Registry	Myotubular Trust		2013
Spinal and bulbar muscular atrophy	Kennedy's Disease Association	Kennedy's Disease Association		2000

Table 6: Select crowdsourced patient registries

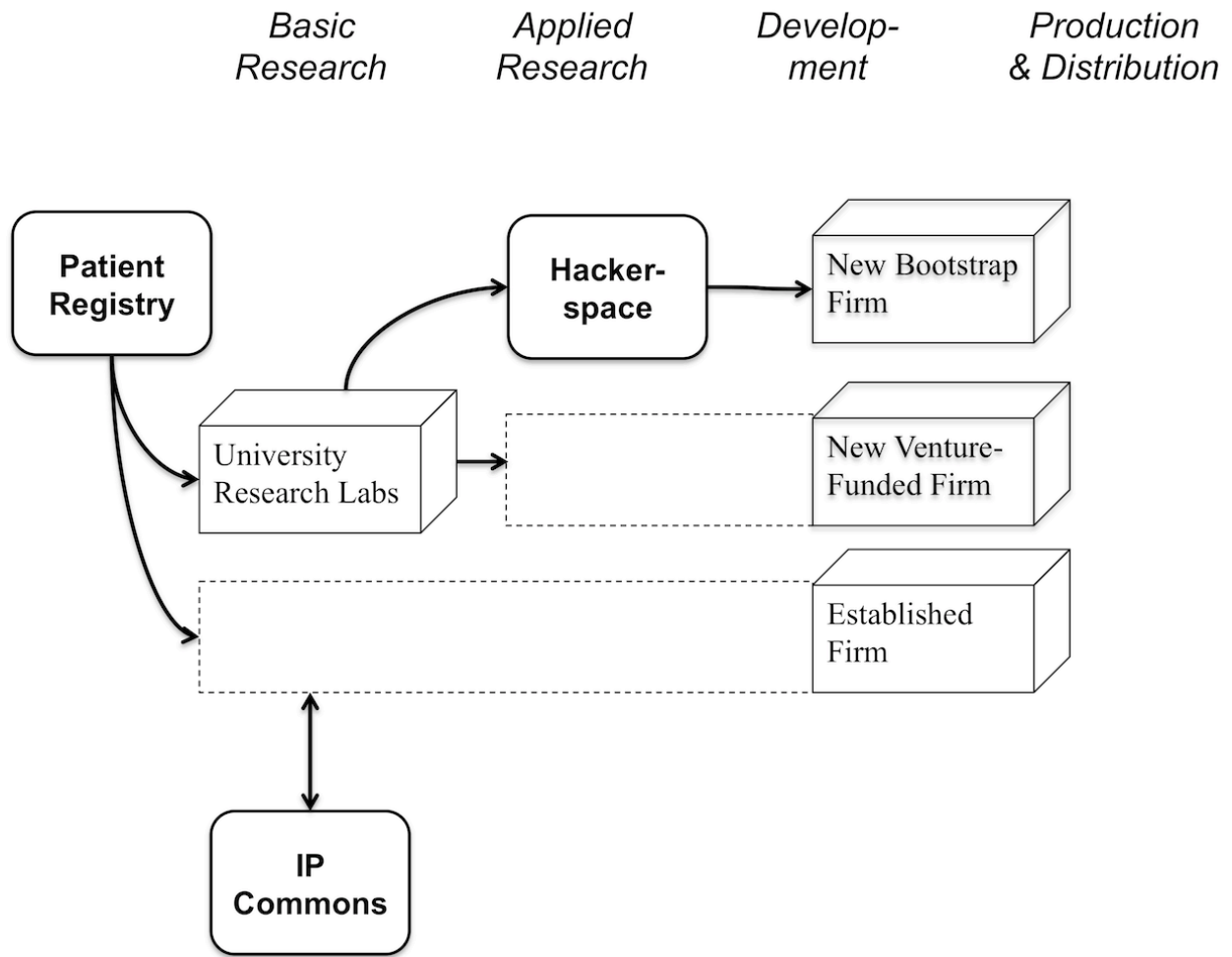


Figure 1: Role of each archetype in industry value chain