

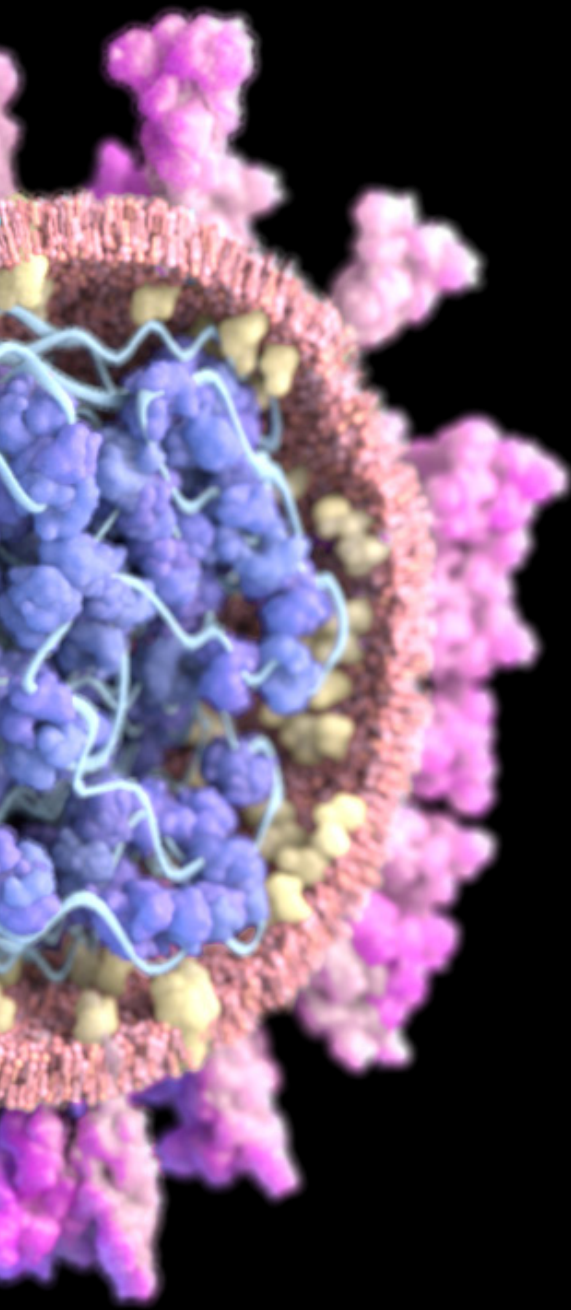
LIFE
(SCIENCES)
AFTER
COVID-19



The Value of Patient-Generated Health Data in a Post-Pandemic World

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The piece you're about to read is from Klick Health's Life (Sciences) After COVID-19 series, a collection of expert perspectives designed to inform and inspire the life sciences community for the coming changes and opportunities we anticipate as a result of this global health crisis.

We invite you to engage with a multitude of these viewpoints by seeking out other pieces from this series, including *Lessons From COVID-19: Improving Health Behavior and Reducing Disparities and Sometimes It's What You Can't See* at **covid19.klick.com**.

THE INSIGHT

Ever since the first wearables emerged onto the healthcare scene, the chatter about the impact and utility of patient-generated health data (PGHD) has persisted. The promise of PGHD has remained both elusive and immense in its potential. PGHD has unlocked opportunities in enhancing self-awareness and self-management of our behavioral or biological patterns. It enables the tracking or aggregation of PGHD across cohorts within the population. And it has demonstrated an ability to elevate the value of interactions between patients and their physicians.

However, the ongoing COVID-19 pandemic has delivered a seismic jolt to the importance of patient-generated health data and the need to define its role in shaping how we function as a society. How might PGHD help us build a bridge to a world beyond where we stand today? In the race to get ahead of the virus, PGHD has been touted as a mission-critical component in promoting population health.

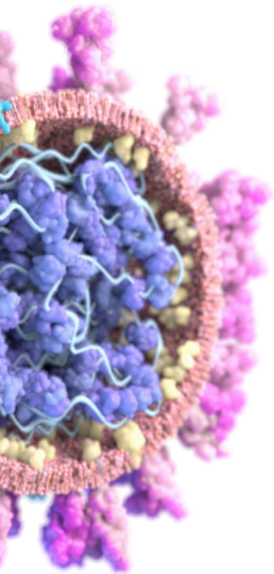
But where do we go from here? What are we learning about the true value of PGHD? How are behaviors changing relative to the adoption of PGHD by sizable portions of the population? What changes do we anticipate in how we utilize the data, and has that data set expanded as a result of COVID-19?



What benefits or opportunities will evolve or emerge in the years to come?

While the focus of mainstream discussion has been on its efficacy for the “track and trace” mandate to mitigate the spread of the coronavirus and its accompanying data privacy considerations, the current debate overlooks intriguing possibilities that may emerge in the wake of the pandemic. If current data-driven efforts are successful at scaling use and achieving their goals while being conducted responsibly in the eyes of the public, the model could have wider applicability in population health.

Whether put into the service of helping manage chronic conditions such as diabetes, issues that resonate across our society such as opioid addiction, or the treatment of diseases such as widespread cancers that remain elusive to our gaining a comprehensive understanding, could the population-level embrace of patient-generated health data unlock new opportunities for insight and action by health sciences leaders?




THE EVIDENCE

Historically, the application of PGHD has been forced to navigate a number of obstacles to play a role in the healthcare narrative—from defining its role or value to medical professionals, to the question of how to integrate with traditional methods of keeping medical records, to the questions of privacy and security.

PGHD has been missing a critical ingredient to drive adoption and utility at scale, a seminal event to give it purpose and galvanize interest at a population level.

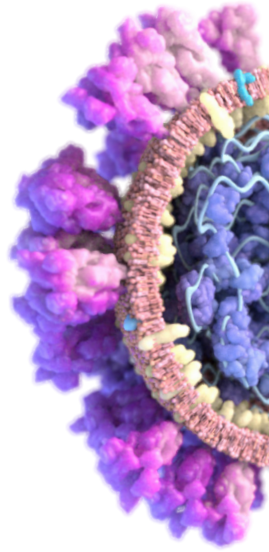
The demands of our current global situation are shaping up to be a turning point.



“The shared experience of COVID-19 is likely to create massive, intersecting reference groups inclusive of relationships in family, community, workplace, faith, and social domains.”

COVID-19 is likely to further accelerate the adoption of wearables that provide users with deeper insights beyond activity, diet, and sleep.

According to a recent report¹, the market for wearable technology with artificial intelligence (AI) is expected to increase 20% per year, supported by the penetration of 5G and smartphone technology that allows PGHD to be stored and used more effortlessly. However, wearables specific to health have lagged the overall market for wearable technology. Researchers at NIH² have suggested that the market has largely focused on technological capabilities while ignoring the influence of patient health beliefs tied to specific concerns. In essence, wearables have been “preaching to the choir” with most adoption occurring among a population of “health seekers.” However, the pandemic has the potential to create a much larger cohort of “health watchers” who have a compelling interest or desire to keep tabs on their health versus optimizing it. Additionally, research has supported the hypothesis that adoption requires significant influence from a reference group of peers. The shared experience of COVID-19 is likely to create massive, intersecting reference groups inclusive of relationships in family, community, workplace, faith, and social domains. The compounding effect of this influence is likely to fuel increased interest in possessing actionable insight on one’s health status.



The value of spatial data is reaching an inflection point in the wake of COVID-19.

Spatial data, or information about physical objects and how they relate to the broader context of the environment surrounding them, has been used effectively in prior epidemics occurring on a more regionalized basis with examples including cholera and Ebola. Since the beginning of the current COVID-19 outbreak, the value of understanding the concentration of confirmed cases, patterns of movement of individuals, and other forms of location-based data have been essential in the management of our global response.

However, what has been unique within the current pandemic has been the enlistment of the individual to opt-in as a willing participant.³ Using readily available technology embedded within their phones, PGHD is expanding the data available to describe patterns of consumption, movement, and interactions with places or people.

Public health officials are able to monitor traffic volume to evaluate the efficacy of stay-at-home policies. Australia has been at the forefront in using Bluetooth technology, and self-reporting of symptoms and testing outcomes is allowing citizens to be alerted if they've been in proximity to other individuals who may have been infected.



The debate over whether data should be centralized or decentralized, meaning stored on the device itself, and whether to entrust PGHD with public versus private players will continue to play out even as solutions are rushed to the marketplace in the hopes of combating the spread of the virus.⁴

The state of Utah has been a leader in the enlistment of its own citizens to propagate PGHD as a key tool in their response to the outbreak. The *Healthy Together* mobile application being rolled out in Utah uses a platform originally developed as a proximity-based social meet-up tool called *FriendFinder*.⁵ For the purposes of population health management, it leverages the same geo-fencing algorithms to map the locations and movements of those who test positive for COVID-19 in relation to others using the application.

Lastly, the integration of contextual information to augment PGHD has accelerated in the wake of COVID-19.

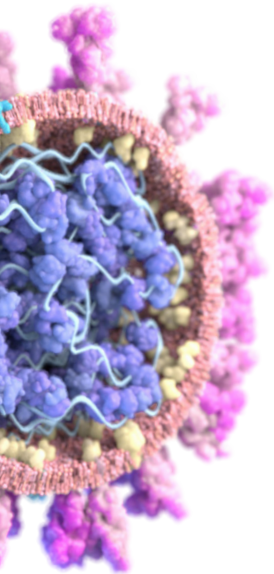
With much of society sheltering in place, people are generating sizable amounts of data that could enhance the utility of PGHD. Data signals are being generated by Internet of Things (IoT) devices that describe their environment, streaming devices that assess time spent consuming content, e-commerce purchase patterns that surface needs states, and home assistants that capture queries including those involving symptoms or concerns.



Each of these data points, when combined with implicit and explicit health data, hold the potential to paint a more comprehensive picture of tomorrow's patients.

The use of social determinants, the notion that your zip code is a primary predictor of your health status, is acutely accurate in the context of infectious disease. Demographics and socioeconomic variables have proven to be highly descriptive of COVID-19 risk, as well as impact among those infected. Therefore, when combined with location, PGHD provides additional context for appropriate, targeted interventions and support efforts.

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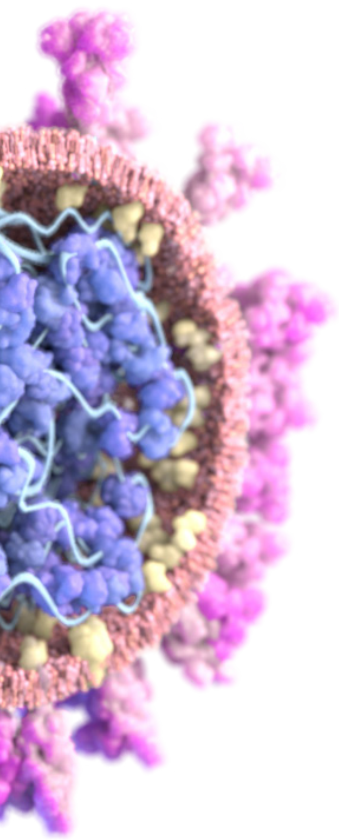
THE POSSIBLE FUTURES

In light of this evidence demonstrating both the value and expanding applications of PGHD, how might this shape our world beyond the pandemic? Which of these trends will continue on their current trajectory and what are the implications?

The real estate industry has long relied on identifying patterns of data arising from consumer behavior, such as traffic patterns and housing trends, to identify which corner to open another McDonald's or Starbucks. If PGHD could provide policymakers and health science leaders with insights that could help direct more targeted actions by geography and be equipped to evaluate and adapt the impact of those actions, what futures might that unlock?

A new dawn for population health management?

Clearly, mitigating the spread of COVID-19 has been highly dependent on real-time patient level data that can be quickly aggregated to enable snapshots of a rapidly evolving healthcare picture at the population level. In the pending wake of the pandemic, the channels and mechanisms that are being mobilized for our immediate environment could potentially be maintained and redirected to the management of large-scale population health concerns that have long vexed health science leaders.



One example includes improving the timeliness and targeted distribution of efforts to mitigate chronic diseases such as Type 2 diabetes. Leveraging similar applications and aggregating data from devices (such as wearable blood glucose monitors, daily outreach surveys, activity sensors, web-enabled scales, and location tracking when de-identified, contextualized and aggregated among a geographic sample of T2D patients) could help target the delivery of resources that align with identifiable patterns of behavior. Insights could also enable in-market experimentation to assess the impact of interventions at a population level involving many of the same key players that are actively collaborating to combat the current coronavirus outbreak.

Marking the rise of the “enlightened” patient?

While adoption of PGHD during the pandemic has been varied state-to-state, a recurring thread among the populace and health care innovators has been the recognition that information is the centerpiece in the fight. Much of what we learn about how the virus spreads and how it affects people exposed to it is derived from data being collected on the ground, oftentimes via PGHD.

Successful efforts to enlist healthy individuals to participate in the capture of PGHD herald the possible emergence of a type of healthcare consumer who is somewhat different from the traditional “empowered” patient that we might call the “enlightened” patient.

Whereas the “empowered” patient seeks out information from third-party sources so that they are equipped to self-advocate for healthcare decisions in their own best interest, the “enlightened” patient instead seeks to enhance their awareness of their own health state—focusing on tracking homeostasis—to direct behaviors that best preserve their current state of health.

There is always the concern that those who adopt this type of behavior—the first to buy a FitBit or spend the money on a Peloton bike—are those who are already inclined to do so. These trends tend to decelerate once this cohort of health seekers has been served and satiated.

However, COVID-19 has engendered a concern that is more universal to us all, which ironically might be the catalyst to unlock motivation at the individual level even among those without that inherent spark. This isn't to suggest that every person will embrace the use of PGHD with a similar degree of interest, but rather that certain types of information captured as PGHD could emerge as ubiquitous alongside concepts, such as temperature, weight, and blood sugar, that help patients assess their health status at a point in time and on a longitudinal basis.

It becomes less aspirational and more informational. More about maintaining health status than achieving a health outcome. With COVID-19, people are more interested in knowing where they stand and the degree of risk to which they may be exposed.

If this desire evolves into a stable health belief among patients post-pandemic, this would usher in an increase in the use of PGHD to “know thyself” at a deeper level than counting steps, hours of sleep, or calories consumed. This “enlightenment” would be focused more on defining a desired state of health and the metrics that correspond with it as opposed to measuring the actions that lead to it. The pandemic has surfaced a significant population of patients whose primary interest is knowing where they stand and monitoring shifts in their homeostasis that could signal potential health issues.

These “enlightened” patients would invite AI into their daily lives through the use of conversational, chat-based exchanges to effortlessly query for implicit and explicit cues that could signal shifts in mood, behavior or overall wellness. While the utility to the individual is one of self-awareness, the value at the population level could be substantial.

Might this be a catalyst in creating a marketplace for PGHD?

Personal data has tremendous financial value, yet patients themselves have no standing to share in it. In a post-pandemic environment where the scalable promise of PGHD is laid out with greater clarity, ubiquitous adoption might require an accelerant in the form of monetary incentives derived from a patient’s participation.

Many have imagined the creation of a data exchange that enables patients to both manage and monetize their personal health data,

albeit along with the adoption of clear guardrails in how it’s used and digital rights management considerations.

Perhaps the coronavirus has fast-forwarded us much closer to that future.

But is this future worth pursuing?

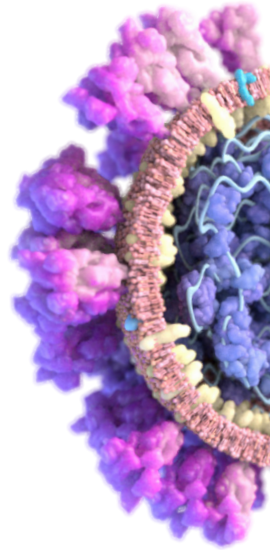
Let’s explore that question further.

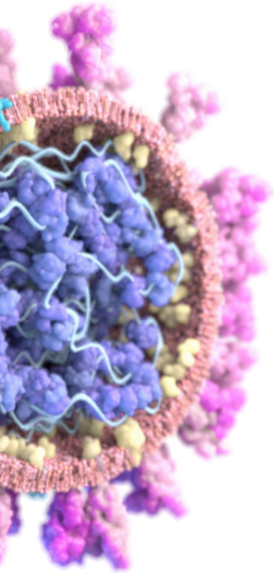
Making the case for...

The pandemic has thrust our healthcare system into the center of the storm and challenged whether we have the data and tools we need. Absent a crisis, what have we learned about the utility of PGHD in our approaches to managing population level health concerns?

One of the most exciting arrivals on the healthcare scene has been the advent of digital therapeutics that deliver clinical value through software and the resulting digital interactions with patients. These treatments represent the types of breakthroughs that could be delivered through the analysis of millions of signals captured directly from patients themselves.

Scaling and sustaining our attempts at using AI and advanced analytics to surface behavioral patterns would be unobservable in normal context. PGHD has typically focused on a single individual, however even in its infancy we’ve seen the power that comes from aggregating critical masses of data.





Additionally, this insight enables policy-making that would apply more targeted and appropriate marketplace interventions based on behavioral principles that “nudge” individuals or restructure environments in service of population health outcomes on an informed basis—rooted in data as opposed to instinct.

At the individual level, the synthesis of PGHD would allow for development of predictive algorithms that trigger preemptive engagement at the individual level with the hope of heading off the emergent risk of complications, including shifts in activity, mood, or biometric readings that suggest “below the surface” issues forming, such as microvascular complications of diabetes. When it comes to infectious diseases like COVID-19, PGHD could extend into digital certifications for immunity or vaccination.

Making the case against...

However, there are tradeoffs and risks associated with extending the use of PGHD to the lengths described above.

Any application of PGHD would require voluntary participation, a clear, understandable value prop that benefits the individual and does not subject the individual to the potential for government overreach. A mandatory model would not garner the engagement needed—we cannot endorse healthcare conscription to fight battles such as COVID-19 in the years ahead.

Privacy has been a primary discussion topic and once ceded or diminished, it is difficult to claw back.

When combined with notable breaches in data security, there remains an embedded skepticism of public and policy makers when it comes to promises of propriety in the handling of personal health information.

Data ownership is another key issue that remains unresolved though current law favors the individual. Even still, as PGHD becomes de-identified and used in aggregate form, the rights of the individual to control how their personal data is utilized becomes less favorable. With no remuneration to the individual and ambiguity hovering over the roles of public versus private, for-profit players, there remains a delicate balance.

We must be able to ensure that PGHD is used to foster insight and education versus used punitively as a tool of enforcement. Any misappropriation, mishandling or misuse will further breed distrust that could infect and undermine faith in other domains of data utility.

And importantly, technology cannot solve this on its own. We must prioritize the human being who is providing the data. The human interface is critical. Enabling PGHD and the tools that capture it to fit into our lives, to be intuitive and useful, and to be present yet unintrusive. Today, there is a premium placed on urgency and we are moving fast to find the mechanisms we need to solve our current challenges. Yet we must not lose sight of how we craft the experience in ways that will sustain behaviors supporting PGHD when the crisis mentality wanes.

THE ACTION PLAN FOR LIFE SCIENCES LEADERS

Today's health science leaders should use their voice to help shape the role of PGHD so that it has a place to contribute on a wider scale.

Data-driven decision making remains in the early innings—now is the time to make game-changing investments in your capabilities to incorporate PGHD:

We will continue to launch brands in a post-pandemic world. PGHD offers a gateway to tap into real-world evidence that might support brand value propositions and associated pricing and access considerations. But the institutional utility of PGHD relies on investing in several key areas, such as the tools that can bring together disparate data sources and make sense of it, the analytical talent to transform the data into actionable insight, and the right mix of partners to develop the in-market interventions to engage the patient in a meaningful way.



Don't lose focus on the patient:

It's critical that health science leaders keep their focus where it has always belonged: on the patient. We must be vigilant in the wake of dealing with a foe with the reach of COVID-19 that we don't lose sight that we must deliver value to the individual in order to foster engagement necessary to harness PGHD. This means any strategy to leverage PGHD requires defining clear use cases and eliciting input from all stakeholders, including patients themselves in the form of feedback loops or advisory boards.

Good governance is a prerequisite for leveraging PGHD:

Crisis may be what is driving urgency at this moment but sustaining trust will build or derail momentum beyond the crisis. Once lost, trust is near impossible to restore. Therefore, in the days that follow the pandemic, efforts to expand the use of PGHD should not move too far too fast nor push ahead without full transparency.

This should include the development of rules of ownership for personal data and clearly defined responsibilities for public and private players. Perhaps embracing the concept of creating a pool of PGHD that can be shared by all to serve the public good would build momentum for the goodwill needed to achieve universal adoption.

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Brian has a wealth of experience developing solutions for brands in the healthcare space over the past 20 years, from both the agency and client perspectives.

His focus has been on helping brands grow from market shaping to maturity while cultivating meaningful customer engagement.

Prior to joining Klick, Brian provided senior leadership for the healthcare practice at Targetbase, a leading relationship-marketing agency, delivering solutions for clients such as GlaxoSmithKline, Bristol Myers Squibb, Astellas, and Abbott across a wide range of therapeutic areas.

On the client side, Brian was a founding member of the Global e-Marketing Center of Excellence at Eli Lilly. In this role, he pioneered digital marketing capabilities that fueled successful brand launches. Additionally, Brian leveraged the emerging digital space to more productively engage key opinion leaders and managed care organizations as a means of maximizing commercialization potential prior to launch.

Brian received his MBA from the University of Georgia with a focus on integrated marketing and technology and a BA in Communication from the University of Pennsylvania.



While change can create challenges, it also opens the door to new opportunities. Join us as we explore the many imaginable paths to post-pandemic growth. We welcome you to start a dialogue with the author of this piece:

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