

## ***THE ETHICAL STARTUP? Lessons from DNA Marketplaces***

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### **Abstract**

Emerging DNA marketplace startups aim to empower individuals with greater control and potential profit-sharing over their genetic data, but they face ethical tensions in navigating uncertain technological and commercial environments. Drawing on ethnographic research and ELSI scholarship, this piece uses the lens of bounded ethicality to show how limits in information, consent, and decision-making call for distributed “ethics supports” beyond individual users and firms. Focusing on cases such as LunaDNA, it outlines strategies, such as decision-support tools, transparent communication, and collaborative ethics infrastructures, to strengthen collective responsibility and ethical capacity in genomics and related fields.

Keywords: DNA Marketplace, Genomics, Consent, Data Privacy, Private Sector, Health Data

### **Introduction**

With universities in much of the world placing more emphasis on entrepreneurship and technology transfer,<sup>1</sup> the private sector is depicted as a key to advancing both basic and applied sciences. At the same time, widely publicized data breaches and stories of fraud have fueled skepticism about whether private sector innovation serves the public good.<sup>2</sup> In response, some biotech startups have begun to position themselves as ethical alternatives to traditional research and business models.

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<sup>1</sup> Robert E. Litan, Lesa Mitchell, and E.J. Reedy, “The University As Innovator: Bumps in the Road,” *Issues in Science and Technology* 23.4 (2007); Jordan Eidlisz, Isabelle von Simson, and Gabrielle Gold-von Simson, “Exploring the current state of technology transfer in the United States: perspectives and improvement strategies from the experts,” *Frontiers* 9 (2024): [doi.org/10.3389/frma.2024.1376185](https://doi.org/10.3389/frma.2024.1376185); William R. Meek and Peter T. Gianiodis, “The Death and Rebirth of the Entrepreneurial University Model,” *Academy of Management Perspectives* 37.1 (2023): [doi.org/10.5465/amp.2020.0180](https://doi.org/10.5465/amp.2020.0180).

<sup>2</sup> Cathy Hwang et al., “The Lost Promise of Private Ordering,” *Cornell L. Rev.* 109 (2023-2025): 1-61. <https://publications.lawschool.cornell.edu/lawreview/2024/01/30/the-lost-promise-of-private-ordering/>

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This paper examines the ethical and institutional burdens that accompany corporate promises to empower consumers in managing their own health data, using emerging DNA marketplaces as a case study. Unlike earlier biobanking models, which relied on broad consent to data use and offered little direct benefit to individual participants, the profit-sharing approach promises more consumer control. These companies let individuals decide how their data can be used and share in the financial benefits when companies sell access to that data. But even companies that think carefully about these dynamics face challenges as they create technologies for a future that is difficult to anticipate. Startups can respond to the ethics challenges that come along with such uncertainty; this paper provides guidance on some key pathways. My interviews, surveys, and focus groups with employees and leadership confirm that many companies are searching for guidance on how to embed ethics into their operations.<sup>3</sup>

DNA marketplaces offer a compelling site for examining ethical challenges that arise when companies promise to empower individuals with control over their health data, in part because companies, such as LunaDNA and EncrypGen, explicitly frame their platforms as “empowering” users.<sup>4</sup> Yet, these companies blur the boundaries between consumer platforms, research intermediaries, and data brokers, placing particularly complex ethical demands on users and institutions alike. This paper argues that such models reveal not only the limits of individual decision-making under conditions of complexity and uncertainty but also the ethical shortcomings of systems that shift responsibility onto consumers without sufficiently engaging the broader obligations of companies, platforms, and institutional actors.

### A Framework for Ethics Supports

Among the many genomics products launched in recent years, a series of companies has emerged that offer a means for individuals to “rent” their DNA to companies and universities for research and product development. These DNA marketplaces have promised compensation in exchange for personal data, as well as privacy and transparency through novel technologies. Nebula Genomics, co-founded in 2016 by George Church, offered free genome sequencing in exchange for data-sharing on their blockchain-secured platform, or redeemable Nebula tokens for sharing genomic data sequenced elsewhere.<sup>5</sup> The following year, EncrypGen launched a blockchain marketplace which uses proprietary cryptocurrency to pay individuals for de-identified data,<sup>6</sup> and LunaDNA launched an offering of non-voting shares in the company in exchange for data use—e.g., 300 shares for a whole genome shared, a \$21

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<sup>3</sup> Alexis Walker, “Diversity, Privacy, Profit: An Empirical Study of Industry Employees’ Views on Ethics in Private Sector Genomics,” *AJOB Empirical Bioethics* 13(2022):166-178. <https://doi.org/10.1080/23294515.2022.206399>; Elizabeth Adetiba and Alexis Walker, “‘Forget the Age of HIPAA and Lean Into The Age of Consumer Privacy’: Exploring Ethics and Responsibility among Private Sector Genomics Leaders Using Group Interviews.” *New Genetics & Society*. *Forthcoming*.

<sup>4</sup> LunaPBC, “LunaPBC Raises \$4.6 Million to Accelerate Company Growth and Drive Health Breakthroughs,” *PR Newswire* (2019), <https://www.prnewswire.com/news-releases/lunapbc-raises-4-6-million-to-accelerate-company-growth-and-drive-health-breakthroughs-300846139.html>; Innovations of the World, “LunaDNA: The World’s First People-Powered Health Data Platform,” *Innovations of the World* (n.d.), <https://innovationsoftheworld.com/lunadna/>; LunaPBC and Genetic Alliance, “Genetic Alliance and LunaPBC Partner to Support Personal Health and Accelerate Medical Breakthroughs,” *PR Newswire* (2018), <https://www.prnewswire.com/news-releases/genetic-alliance-and-lunapbc-partner-to-support-personal-health-and-accelerate-medical-breakthroughs-300781275.html>.

<sup>5</sup> Molteni, Megan. “These DNA Startups Want to Put All of You on the Blockchain.” *Wired* (2018), <https://www.wired.com/story/these-dna-startups-want-to-put-all-of-you-on-the-blockchain>.

<sup>6</sup> Ben Herschler, “Cashing in on DNA: Race on to Unlock Value in Genetic Data.” *Reuters* (2018), <https://www.reuters.com/article/us-health-genomics-blockchain/cashing-in-on-dna-race-on-to-unlock-value-in-genetic-data-idUSKBN1KO143>

value according to the company's preliminary offering circular.<sup>7</sup> The marketplace model also allows participants to specify which types of studies their data would support, enabling them to opt in or out of research domains based on topic, perceived risk, or institutional or corporate affiliation of the research team. LunaDNA regularly invites participants to review and approve data use for new studies, including those with different levels of data access or revised shared offers.

In addition to the challenges faced under prior models of consumer genetic data sharing (e.g., through Ancestry.com, 23andMe), these companies have struggled to meet the expectations they set around user control, data ownership, and financial benefit. LunaDNA was founded as a public benefit corporation, with the premise that by receiving shares, participants would benefit financially from any proceeds LunaDNA earned from that data. The company failed to build a steady revenue stream and eventually closed in early 2024, without issuing payouts to contributors, as the company reported no cash reserves.<sup>8</sup> Ethical, legal, and social implications (ELSI) researchers have noted the challenges that these *DNA marketplaces* face as data brokers that must gather ongoing consent and manage data privacy.<sup>9</sup> In this piece, I highlight the broader ethical challenges that such marketplaces face, considering the startup sector's demand for continual innovation and often grandiose speculation, even in the face of frequent organizational change and evolution.

While firms may have ethics infrastructures, such as ethics committees or institutional ethics policies, ethical issues today increasingly cluster beyond the confines of an individual company. Many problems emerge in the complex landscape of angel investors, venture capital firms, private wealth management entities, crowdfunding, accelerators, incubators, co-branded partnerships, tech transfer offices, service providers, and industry networks. While ethical approaches, such as anticipatory ethics, have been developed to predict and address ethical challenges early in the development of emerging technologies,<sup>10</sup> many issues today arise in spaces that lie beyond the control of a single platform, ranging from downstream data sharing by a DNA platform customer to further data use by unknown subsequent parties, to company acquisition, bankruptcy, breaches by partners, and other challenges.<sup>11</sup>

To analyze these challenges, this paper applies the theory of *bounded ethicality*. Bounded ethicality suggests that social, psychological, and practical pressures limit people's ability to make ethical decisions. For example, limits on

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<sup>7</sup> U.S. Securities and Exchange Commission, "Offering Circular: LunaDNA, LLC," Form 253G2 (2018), <https://www.sec.gov/Archives/edgar/data/1741687/000119312518340286/d631377dpartiandiii.htm>.

<sup>8</sup> Jonathan D. Grinstein, "Total Eclipse of LunaDNA: Once Touted Genome Data Sharing Platform Goes Dark," Inside Precision Medicine, January 18, 2024, <https://www.insideprecisionmedicine.com/topics/precision-medicine/total-eclipse-of-lunadna-once-touted-genome-data-sharing-platform-goes-dark/>.

<sup>9</sup> Eman Ahmed and Mahsa Shabani, "DNA data marketplace: an analysis of the ethical concerns regarding the participation of the individuals," *Frontiers in Genetics* 10 (2019): 10.3389/fgene.2019.01107.

<sup>10</sup> Philip A.E. Brey, "Anticipatory ethics for emerging technologies," *NanoEthics* 6 (2012): 1-13, <https://doi.org/10.1007/s11569-012-0141-7>.

<sup>11</sup> Donna M. Gitter, "Informed consent and privacy of non-identified bio-specimens and estimated data: lessons from Iceland and the United States in an era of computational genomics," *Cardozo Law Review* 38.4 (2016); Julie Cook Lucas et al., "Donating human samples: who benefits? Cases from Iceland, Kenya and Indonesia," in *Benefit Sharing*, eds. Schroder et al (Springer, 2013), [https://doi.org/10.1007/978-94-007-6205-3\\_5](https://doi.org/10.1007/978-94-007-6205-3_5); Stephen J. O'Brien, "Stewardship of human biospecimens, DNA, genotype, and clinical data in the GWAS era," *Annual Review Of Genomics And Human Genetics* 10 (2009): 193-209, 10.1146/annurev-genom-082908-150133.

available information, time constraints, decisional complexity, and bias contribute to ethical decision-making.<sup>12</sup> These limits point to the importance of moral *supports* to promote ethics and justice. Bounded ethicality recognizes the limits of the individual moral agent, instead spreading moral labor across platforms, collectives, supportive technologies, and contingencies. As shown below, combining this lens with a focus on downstream thinking can help companies and individuals establish well-designed ethical supports.

### Ethics Challenges for DNA Marketplace Platforms

DNA marketplaces risk overpromising the degree to which they can protect data. In response to criticisms of earlier genomics companies that sold user data to pharmaceutical and other companies, including data brokers, without sharing benefits, these companies have created data use policies and means to allow participants to benefit.<sup>13</sup> But even so, substantial risks to data privacy remain. Data breaches, government or law enforcement demands that override privacy protections, and within the limits of both users' and technologists' capacity to anticipate abstract future scenarios.<sup>14</sup> The bounded ethicality lens draws attention to the importance of caution in companies' framings of their offerings, recognizing the limits even with our best efforts for ethical practice, thus guiding us toward hedging the zeal with which companies advertise privacy protections, untraceability, and individuals' control over their data's use.

Difficulties also arise because of the complexity of tasks DNA marketplaces ask of their users. The complexities of these tasks include taking control of their genetic data, assessing scientific risk, postulating future scenarios, quickly learning enough genetic science to become ably informed as part of a consent process, and engaging in ongoing monitoring of developments with the platform. Growing research shows that decision fatigue, readerly limitations, distraction, comprehension and educational factors, momentary mood or energy levels, and more impede sound decision making.<sup>15</sup> Unlike other industries where consent may be a one-time hurdle, DNA marketplaces demand repeated, proactive choices about whether to share their genetic data, opt in or re-consent to new studies, allow certain types of future use, and decline participation in others based on study type, affiliated institutions or companies, or perceived risk. It is crucial that companies describe the terms and conditions to help customers grasp the yet unknown ways in which data could be used, including adverse scenarios. At the same time, lengthy consent

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<sup>12</sup> Dolly Chugh and Mary C Kern, "A dynamic and cyclical model of bounded ethicality," *Research in organizational behavior* 36 (2016): 85-100, <https://doi:10.1016/j.riob.2016.07.002>; Dolly Chugh, Max H. Bazerman, and Mahzarin Banaji, "Bounded ethicality as a psychological barrier to recognizing conflicts of interest," in *Conflicts of interest: Challenges and solutions in business, law, medicine, and public policy*, eds D. Moore, D. Cain, G. Loewenstein, & M. Bazerman (New York: Cambridge University Press, 2005).

<sup>13</sup> Linnea I. Laestadius, Jennifer R. Rich, Paul L. Auer, "All your data (effectively) belong to us: data practices among direct-to-consumer genetic testing firms," *Genetics in Medicine* 19 (2017): 513-520.

<sup>14</sup> Christi J. Guerrini, Jill O. Robinson, Devan Petersen, and Amy L. McGuire, "Should police have access to genetic genealogy databases? Capturing the Golden State Killer and other criminals using a controversial new forensic technique," *PLOS Biology* 16 (2018): 10, [doi.org/10.1371/journal.pbio.2006906](https://doi.org/10.1371/journal.pbio.2006906).

<sup>15</sup> Laura M. Beskow and Kevin P. Weinfurt, "Exploring understanding of 'understanding': the paradigm case of biobank consent comprehension," *The American Journal of Bioethics* 19.5 (2019): 6-18, [10.1080/15265161.2019.1587031](https://doi.org/10.1080/15265161.2019.1587031).

documents cannot fill this need, as they overwhelm participants and do not invite deep engagement with the issues at hand.<sup>16</sup>

Another ethical issue is that significant debate persists about the risks of re-identification of ostensibly de-identified genomic data, which is possible with limited public information.<sup>17</sup> While some argue that little incentive exists for re-identification, there is insufficient evidence to support this claim.

Companies must remain responsible for protecting users, rather than placing responsibility on consumers for protecting themselves via consent procedures.<sup>18</sup> Many ethical frameworks acknowledge that consent alone does not waive organizational obligations. But in practice, many organizations have consent procedures and documents that resemble legal contracts more than tools for participant understanding, designed more to limit liability than to foster meaningful participant engagement.<sup>19</sup> Beyond these legal shields, companies owe participants real efforts to support truly informed consent, given the substantial asymmetries in expertise and control that make meaningful consent difficult without institutional support, and the broader ethical imperative to build public trust in data systems where risks are often collective, long-term, and structurally mediated. Companies can implement insights from the robust consent literature, including offering decision support tools such as interactive or pre-highlighted written information, digitally enhanced user support tools, and re-consent cues at key moments, such as when a company is acquired or when scientific developments enable new unanticipated uses of genetic data.<sup>20</sup> If DNA marketplaces have models that presume ongoing user engagement, support to sustain such engagement is essential.

This discussion makes it clear that platforms cannot reasonably suggest to users that they will maintain the privacy that many companies tout. A more ethically grounded approach could include planning for and explaining to users recourses for when a site is hacked, compromised, or down, etc. Privacy is more than a platform security issue. The future contains new kinds of capabilities that can "de-privatize" previously privatized data by way of future datasets that we never predicted, IT capacities that we cannot yet envision, and other difficult-to-predict circumstances.

### **The Way Forward: Expanding Moral Capacity**

Actionable strategies include tools to help consumers make informed decisions. Again, using the lens of bounded ethicality, I propose possible areas of intervention, but such strategies cannot completely solve moral problems or guarantee "right" moral choices; rather, they can support ethical action by redirecting attention and resources, including personal, organizational, institutional, and even technological, to spaces of moral risk, and expand capacity in those areas.

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<sup>16</sup> Lydia O'Sullivan et al., "An evaluation of the process of informed consent: views from research participants and staff," *Trials* 22.544 (2021): <https://doi.org/10.1186/s13063-021-05493-1>.

<sup>17</sup> Muhammad Naveed et al., "Privacy in the Genomic Era," *ACM Computing Surveys* 48 (2015): 1-44. [doi.org/10.1145/2767007](https://doi.org/10.1145/2767007).

<sup>18</sup> Ella Corren, "The Consent Burden in Consumer and Digital Markets," *Harvard Journal of Law & Technology* 36.2 (2023).

<sup>19</sup> David B. Resnik, "Do Informed Consent Documents Matter?" *Contemporary Clinical Trials* 30, no. 2 (2009): 114-115. (2009), doi:10.1016/j.cct.2008.10.004; Keith Porcaro, "It's Time to Burn Medical Consent Forms," *Wired* (June 16, 2022), <https://www.wired.com/story/health-data-consent-forms/>.

<sup>20</sup> Holly K. Tabor, "My46: a Web-based tool for self-guided management of genomic test results in research and clinical settings," *Genetics in Medicine* 19 (2017): 467-475, <https://doi.org/10.1038/gim.2016.133>.

### ***Innovate in Comprehension and Decision Support***

Since DNA marketplaces ask users to perform complex mental tasks, including analytic, abstraction, anticipatory, and calculative work in decisions about sharing, privacy, future risks, and personal benefit. Bounded ethicality points to the need for more assistance so that consumers are not too limited when making important decisions. Significant research discusses the challenges of consent as well as possibilities for addressing them.<sup>21</sup> And while I advocate the use of decisional, visualization, and simulation tools to support consumers at crucial moral moments, literature in the social sciences and humanities make the dangers of expecting technology to solve all challenges clear.<sup>22</sup> Instead, I am advancing a vision of how today's technologies can be designed to support the structural interventions needed to advance justice and equity.<sup>23</sup>

### ***Lead with Limitations***

Substantial empirical data show that in the face of goals that we, as moral agents, really want to achieve, we enact what many refer to as “willful blindness,” sidelining moral considerations.<sup>24</sup> Ethics supports would then involve *leading* by introducing potential limitations through marketing, communication, explanations, consent processes, etc. Leading with limitations may be the only way that users cognitively “register” the downsides of given options. Companies need to *overstate* the limitations of their platform's security, the exceptional vulnerability of all digital data, the prospect that sharing their data may not lead to potential, specific cures, and the possibility that market demands may impact the company's future practices or unravel its present policies. While this may seem counterproductive to current business goals, the very emergence of DNA marketplaces selling themselves as equitable and just alternatives to older models suggests that ethical practice can increasingly be seen as a selling point for some companies.

While bounded ethicality supports enhancing the capacity of users (say, overemphasizing that which data shows we are psychologically prone to tune out), the model also requires migration away from an ethics powered mostly by sole subjects. Ethics strategies that load most of the moral risk onto individuals via the consent process, the self-report, or “honor systems” discharge too much moral labor onto a single subject, often imagined to have indefatigable capacities. Instead, the view proposed here would ask companies to do more to prevent or decrease the risk of a breach of privacy, unexpected later use of data, and reidentification. Companies should use more systems, personnel, practices, and tools to help shoulder the risks. Regulatory frameworks such as the California Consumer Privacy Act (CCPA), the General Data Protection Regulation (GDPR), and the Genetic Information Nondiscrimination Act (GINA)

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<sup>21</sup> R. Jean Cadigan, et al, “Online education and e-consent for GeneScreen, a preventive genomic screening study,” *Public Health Genomics* 20.4 (2017): 235-246, [10.1159/000481359](https://doi.org/10.1159/000481359); T.J. Kasperbauer, et al, “Incorporating biobank consent into a healthcare setting: challenges for patient understanding,” *AJOB Empirical Bioethics* (2020): 113-122, <https://doi.org/10.1080/23294515.2020.1851313>; Michelle M. Langer, et al, “Development and validation of a genomic knowledge scale to advance informed decision making research in genomic sequencing,” 2.1(2017): <https://doi.org/10.1177/2381468317692582>; Megan Prictor, Harriet J.A. Teare, Jane Kaye, “Equitable participation in biobanks: the risks and benefits of a ‘dynamic consent’ approach,” *Front Public Health* 6 (2018): 253, [10.3389/fpubh.2018.00253](https://doi.org/10.3389/fpubh.2018.00253); Harriet J.A. Teare, Megan Prictor, and Jane Kaye, “Reflections on dynamic consent in biomedical research: the story so far,” *European Journal of Human Genetics* 29 (2021): 649-656.

<sup>22</sup> Hamid Ekbia et al., “Big data, bigger dilemmas: A critical review,” *Advances in Information Science* 66.8 (2015): [doi.org/10.1002/asi.23294](https://doi.org/10.1002/asi.23294).

<sup>23</sup> Melissa S. Creary, “Bounded Justice and the Limits of Health Equity,” *Journal of Law, Medicine & Ethics* 49.2 (2021): 241-256, <https://doi.org/10.1017/jme.2021.34>.

<sup>24</sup> Margaret Heffernan, *Willful Blindness: Why We Ignore the Obvious at Our Peril*. (Walker & Company, 2012).

provide important protections and set meaningful legal baselines. But as technologies and data practices evolve, ethics strategies can be a key site for anticipating emerging forms of risk and responsibility that may fall outside current regulatory scope.

### ***Ethics Beyond Individual Platforms***

DNA marketplaces are also subject to concerns that genetic data, accessible through genetic databases of various types, could be used for deleterious purposes – to make claims, for example, about the genetic superiority of certain groups over others. LunaDNA addressed this by creating a data access committee that would grant research rights only to parties engaged in *health research*. Again, solutions have focused on the individual company level. But by requiring us to address and compensate for limits on ethical decision making, the approach described involves thinking *beyond* the self in much the way thinking about accessibility involves thinking about assistance at both technological and structural levels.<sup>25</sup>

There have been increasing efforts to build collaborations across the private sector genomics industry for addressing ethics and policy issues.<sup>26</sup> Such approaches would multiply the power of efforts at the level of individual companies. For example, creating a common database of suspicious or declined data access requests, accessible by all DNA marketplace companies, could help protect against nefarious uses and users and facilitate collective moral problem-solving. Responsibility should be distributed widely and across actors, since relying on individual moral exemplars (who leave), company cultures (which change), or terms of service (which ignore out-platform problems) puts too many of one's ethical eggs in one basket. Thinking beyond individual moral agents in ethics breeds strategies that go beyond individual executives, platforms, policies, and even users.

Applying empirical data about limitations on ethical decision making leads to solutions that empower consumers and individual companies by eliminating the limitations that impede high-quality moral decision making (unbinding the ethicality). Because DNA marketplace platforms like LunaDNA have specifically sold themselves as a more ethical alternative to older models, they are an ideal place from which to build these approaches.

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<sup>25</sup> Elvan Dogan Kumtepe et al., "Design based exploration of medical system adoption: Case of wheelchair ramps," *Technology in Society* 66 (2021): <https://doi.org/10.1016/j.techsoc.2021.101620>.

<sup>26</sup> BLINDED