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#### FORESIGHT BRIEF

## **Commercialization of Biological Data**

Personal biological data (e.g., information about one's genetics, facial features, and gut biome) is a growing commodity that can be captured, bought, sold, traded, and turned into other products and services.

A variety of strategies are emerging to generate profits from human biological data. These strategies include using biological data to offer hyper-personalized products and services, manipulate consumer behaviour through bio-informed marketing, and provide genetic sequencing and surveillance services. Buying, holding, and selling valuable biological datasets is also becoming an investment strategy.

These trends could have far-reaching policy implications in terms of privacy, ethics, equity, and consumer protection. For example, access to biodata may accelerate both the emergence of powerful new therapies and the drive to privatize healthcare as new profit models develop. In addition, informed consent to use one's data today may not take into account all future use cases. Current genetic privacy laws may be ill-equipped to protect consumers if market forces encourage firms to maximize the collection and use of biodata. Lastly, massive biosurveillance databases raise the stakes of biocrime and state abuse.

This brief aims to deepen readers' understanding of the commercialization of biodata and its implications for a range of policy areas, including some that may be unexpected. Anyone who engages with the following areas might find this brief relevant to their work: security, industry, research and development, trade, international, energy, environment, identification and privacy, rights and social justice, and governance. Thinking about the changes shaping the future of the commercialization of biodata can help decision-makers understand some of the forces already influencing their policy environment. Considering the potential implications of such changes can also help policymakers identify opportunities to make decisions today that may benefit Canada in the future.

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# Commercialization of Biological Data

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## Introduction

Today, individuals leave behind a vast trove of personal digital information as they browse the Internet, order lunch, message friends, or scan a concert ticket. Companies have long exploited these datasets, seeking to profile, predict, and manipulate consumer behaviour with the help of artificial intelligence (AI) tools that can extract key behavioural patterns from them.

But the exploitation of personal data extends far beyond our online clicks and likes: our physical bodies leave digital traces all around us. Smart watches capture users' heartrates throughout the day, and facial recognition software can identify individuals on a crowded city sidewalk.

Thanks to rapid advances in sensing and AI analysis tools, biological data are providing an increasingly intimate window into an individual's preferences, needs, characteristics, and behaviours. Human biological data—the information obtained from the human body and its physical activities—are becoming a valuable commodity that can be bought, sold, and traded like any other. This could influence power dynamics between different groups, while raising new ethical and policy concerns.

## What is changing?

New strategies are emerging to generate profit from human biological data. These include using biological data to offer hyper-personalized products and services, manipulate consumer behaviour through bioinformed marketing, and provide genetic sequencing and surveillance services. Buying, holding, and selling valuable biological datasets is also becoming an investment strategy.

#### Personalized product offerings and precision bioindustries

Companies are increasingly using biological data to offer products and services tailored to an individual's unique biological makeup.

Al tools are allowing for leaps in the research sciences, including the synthesis of new biomaterials. A range of sub-disciplines within the biological sciences (e.g. genomics, transcriptomics, proteomics, metabolomics, and microbiomics) generate vast amounts of data about individuals' genetic information, protein profiles, metabolism, and gut health. However, these fields have historically been limited by analysis tools. Now, AI can rapidly integrate large quantities of data to generate meaningful insights and results.<sup>1</sup> For instance, it can predict the shape of proteins much faster and almost as reliably as laboratory techniques, with the potential to produce novel protein therapies for cancer, autoimmune disorders, and more.<sup>2</sup> The same goes for generative AI tools which may help decode protein patterns, making it easier for researchers to synthesize proteins not normally found in nature. These technologies may lead to new proteins for targeted therapeutics, with potential implications for the treatment of cancer, autoimmune disease, diabetes, and neurodegenerative disorders.<sup>3</sup>

Sensors are seamlessly integrated into wearables that capture detailed physical data about an individual. Smart fabrics actively respond to changes in heat, light, or humidity to better serve their users, while capturing both personal health and environmental data.<sup>4</sup> AI-powered shoes<sup>5</sup> and other wearable movement-enhancing technologies<sup>6</sup> adjust physical properties in real time. Ultrasound sensors for deep-tissue and cardiac monitoring are now wearable as well.<sup>7</sup> Especially when linked to sources of behavioural data, these sensors can help develop precision health interventions, predictive insurance products, or targeted advertising.

**Miniature sensors and microbiome testing are providing new gut health insights.** Smart pills, which combine genetically engineered bacteria and tiny electronic sensors, may make it possible to track internal biological markers in minimally invasive ways.<sup>8</sup> Similarly, microbiome testing companies have become increasingly popular in recent years.<sup>9</sup> These companies claim to provide insight into one's epigenetic age, optimal diet, and disease risk, based on stool analyses that profile gut bacteria. Many companies claim to provide targeted products as well as lifestyle and diet advice based on these personalized analyses.

#### Biologically informed marketing and advertising

New technologies use biological measures such as eye movement, pupil dilation, or heartrate to predict or influence consumer preferences.

Increasingly, firms use eye-tracking data and other physiological metrics collected in on- and offline spaces to anticipate consumer preferences and refine advertising strategies. While many companies already offer advertising insights services using eye-tracking data,<sup>10</sup> some social media companies are investing in novel eye gaze-tracking techniques for augmented reality (AR) and virtual reality (VR) environments,<sup>11</sup> allowing insight generation in both online and offline spaces. When combined with high-throughput AI analysis tools, these techniques can monitor and optimize an individual's engagement with advertising content.

Health service apps may integrate new types of behavioural data to sell health products and services. Amazon recently launched Amazon Clinic,<sup>12</sup> a virtual care service for common healthcare conditions; meanwhile, Amazon Pharmacy now offers prescription filling and delivery services through a subscription membership model.<sup>13</sup> In the future, e-pharmaceutical, e-commerce, and health tracking devices may offer prediction products and integrated services based on prescription history, doctors' assessments, and consumer behaviour.

#### Genome sequencing and genetic surveillance services

Genomic surveillance is an increasingly profitable sector, often relying on large, user-provided commercial genetic databases that were originally collected for other purposes.

**Commercial deoxyribonucleic acid (DNA)-testing companies are repurposing genetic information for product development and forensic science.** Since 23andMe debuted in 2006, it has built one of the largest private genetic datasets in the world (5 million people).<sup>14</sup> The company recently launched a pharmaceutical division and a new partnership with GlaxoSmithKline,<sup>15</sup> selling the rights to develop a drug based on its users' DNA.<sup>16</sup> Beyond personalized medicine, genetic testing companies could sell the data they collect to marketing and insurance firms, or even firms eager to influence the social or political preferences of individuals using AI-powered analysis.

As large genetic databases continue to change hands through acquisitions, and as AI analysis tools become more powerful, customers' initial consent for the generic use of their data may become less meaningful. For instance, genealogical site GEDmatch (which helped catch the Golden State Killer)<sup>17</sup> was sold in 2019 to forensic science company Verogen,<sup>18</sup> transforming the database from a popular, user-sourced genealogy tool into one used primarily for law enforcement purposes.

State security services are increasingly purchasing direct-to-consumer DNA testing services from private companies. The Canada Border Services Agency uses private, direct-to-customer DNA-testing companies and ancestry websites to help establish the nationality of migrants,<sup>19</sup> validate familial ties,<sup>20</sup> and determine the identity of longer-term detainees. It has previously used these direct-to-consumer services in deportation cases.<sup>21,22</sup> The United States (U.S.) similarly employs DNA relationship testing for some immigrant VISA applications.<sup>23</sup> U.S. Immigration and Customs Enforcement and Customs and Border Protection agents<sup>24</sup> may request rapid DNA testing from suspected fraudulent family units.<sup>25</sup> Refusal to submit a rapid DNA test may be considered when assessing family relationships.

Environmental DNA (eDNA) sampling techniques could become a powerful tool for human biosurveillance. eDNA sampling techniques allow researchers to sample and analyze plant, animal, and human DNA from air, water, soil, or wastewater samples.<sup>26</sup> The use of eDNA for human biosurveillance may facilitate tracking transmittable diseases.<sup>27</sup> However, even when sampling targets plant and animal DNA, it may be difficult to avoid the unintentional capture of personal human genetic data.<sup>28</sup>

Genomic sequencing technology is becoming cheaper, faster, and more accessible, accelerating the above trends. Easy-to-access software can turn an iPhone into a mobile sequencer using a handheld tool.<sup>29</sup> Scientists can also access much more powerful sequencing technologies, including long-read machines, which sequence larger segments of genetic material.<sup>30</sup> These tools may rapidly reduce the time and cost of performing consumer genetic analyses, making it easier for companies to sell direct-to-consumer sequencing services that are available anytime, anywhere.

#### Biological data trading and speculation

As biological data is increasingly treated as a commodity, buying, holding, and selling this data has become an investment strategy separate from its practical value.

As the utility and demand for genetic databases grow, companies may acquire large datasets as commercial investment assets. A database's commercial value is likely to keep rising as machine learning becomes more powerful and helps companies extract ever more valuable insights from the data. The DNA testing company Ancestry sold the largest consumer DNA database in the world to private equity firm Blackstone for \$4.7 billion in 2020,<sup>31</sup> despite Blackstone claiming to have no intention of accessing user DNA data directly.<sup>32</sup> This may be an early indication of data holding and speculation as a profit mechanism. In the future, it may be more and more profitable for firms to buy datasets low, hold them until they gain value, and sell high.

## **Policy implications**

The implications below emerged through an exploration of plausible futures for the commercialization of biological data and may not reflect its current state. They are not predictions, and they do not represent expected or desired futures — nor is this list exhaustive. These implications were chosen to help policy makers build better models of the future.

Readers should suspend disbelief and imagine that the challenges and opportunities listed below develop. Here are some questions for consideration:

- How might changes in the commercialization of biodata challenge specific policies or programs?
- How would the assumptions built into today's policies and programs fare in the face of challenges and opportunities this future creates?
- What actions could be taken now to maximize opportunities and mitigate challenges related to the commercialization of biodata in the future?

The commercialization of biological data has important implications for privacy, ethics, consumer protection, and security.

New data-driven and platform-based health services<sup>33</sup> may produce novel therapeutics—but may also accelerate privacy and equity challenges in healthcare. Al facilitates the integration of multiple sources of health data, providing the potential for novel healthcare insights, treatments, and breakthroughs. By expanding portable testing and treatment options, new platform-based health services may expand anytime, anywhere access to healthcare. However, if increasingly essential healthcare services depend on individuals providing personal data to governments or private companies, those individuals may lose the practical power to consent to (and opt out of) these services. In addition, if these platforms are privately owned, they may worsen unequal access to healthcare. Competition with public healthcare could intensify as health outcomes and profits become tied to profitable health data collection, targeted advertisements, and new predictive products.

Informed consent for the use of biological data today may not cover the analyses that can be done on biological data in the future, or its use in developing future commercial products. Individuals who purchase DNA testing

hand over their data based on knowledge of how it can be used today. However, they may be forfeiting control over their data to corporations or state actors for many decades to come, and for future use-cases and products that may be difficult to predict. For instance, while the technology remains limited today, advances in DNA phenotyping and generative AI may soon allow researchers to more accurately reconstruct a person's face<sup>34</sup> based on their DNA, paving the way for DNA mugshots.<sup>35</sup> Moreover, while one individual may consent to handing over their genetic information, their genome also contains information about their relatives—in many cases, individual consent to genetic testing may in fact implicate their current and future relatives.

Genetic privacy policies and protections may not be living up to their intended purposes as genetic testing becomes increasingly profitable. Laws enforcing genetic nondiscrimination currently ensure that no one is forced to undergo a genetic test or share genetic testing information with insurance companies and employers.<sup>36</sup> However, businesses could use coercive or manipulative incentives to acquire genetic information.<sup>37</sup> For example, private firms could make access to important new health products and services conditional on obtaining consumers' genetic data, undermining the principles of free, prior, and informed consent.

As biodata breaches become more common, biocrimes may compromise both personal privacy and national security. Armed with AI tools, hackers with social, political, or monetary motivations may increasingly target databases containing sensitive health and genetic information. Personal data may be used against targeted individuals, as in cases of genetic blackmail.<sup>38</sup> At the population scale, a recent breach of 23andMe user data appears to have targeted a particular ethnic or racial group.<sup>39</sup> This highlights the potential national security risks of such datasets and the growing potential for targeted attacks along geographic or racial lines.

eDNA, combined with new AI tools, can help monitor people, creating both new privacy risks and public health opportunities. Sampling human DNA from air, soil, and wastewater already provides new public health intervention opportunities with the early detection and tracking of communicable diseases. However, in the future, eDNA sampling may also be used for human surveillance (either through accidental or intentional DNA capture).<sup>40</sup> Especially when paired with high-performance AI tools, eDNA technology could easily help capture the location, health, and identity of individuals without their consent, raising serious privacy concerns.<sup>41</sup> The risks may increase as eDNA technologies become widespread and readily available for consumer use.

Consumer protection agencies responsible for health-related product verification and quality control may struggle to keep up with new kinds of direct-to-consumer bioproducts and bio-services. Microbiomics companies offer gut bacteria-testing services that claim to determine one's epigenetic age<sup>42</sup> or epigenetic health, even though these claims are difficult to validate. Some have also raised concerns about the validity and ethics of using direct-to-consumer genetic ancestry tests to establish the nationality of migrants detained at borders.<sup>43</sup> At present, it is difficult to assess whether many direct-to-consumer services are valid, raising new consumer protection challenges for regulatory agencies. In the future, the spread of these products and services may outpace institutions' ability to monitor and regulate them, increasing the risk that problematic bioproducts reach the market.

## Conclusion

Technological advances are accelerating companies' ability to obtain and analyze personal biological data—from gut biome profile to genetic risk for specific health challenges. This information can help create personalized products and services, new forms of bio-marketing, genetic surveillance, and data trading and speculation. As new opportunities to generate profits from personal biological data appear, power dynamics between individuals, firms, and governments may shift. These developments carry considerable opportunities, risks, and challenges for policy makers in the privacy, ethics, innovation, and consumer protection.

### Learn more

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