



Deploying Information Fiduciaries

LESSONS FROM BIOMEDICAL EXPERIENCE

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August 2019



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ABSTRACT

New tools for governance and oversight are needed to handle the furious pace of innovation, transformation, and expansion in the digital economy to assure future economic growth and improved quality of life. One proposed solution is to create information fiduciaries for personal data with the responsibility to protect end-user interests. In the biomedical economy a fiduciary responsibility is well established and can provide useful lessons for decision-makers when applying the fiduciary concept to the digital economy. The biomedical experience also highlights several challenges including: overlapping legal requirements, building an effective guild, managing informed consent, and determining subjective best interests. Overall, the lessons from the biomedical experience suggest that the concept of information fiduciaries has the potential to address critical governance issues in the digital economy. The potential, however, will be limited unless those in the digital profession truly get behind building trust with users through self-enforcement, professional standards, addressing informed consent, and managing the best interests of users.

I. INTRODUCTION

Rapid change in the digital economy is forcing many industries to adapt to new economic and social pressures. New technological tools have created novel ways of doing business that stress old ways of governing technology. While these changes are touching almost all areas of society much focus has fallen on the early entrants to the digital market place who operate lucrative platforms that consumers struggle to do without. The pace of change in the digital economy has already outpaced regulators ability to keep up and there is no sign of slowing down. This accelerating rate of change requires new policy tools for defining rights, responsibility, and obligations in order to create a balanced ecosystem where all stakeholders can thrive.

Old economy tools to resolve users' concerns, settle disputes, and regulate behavior appear inadequate and misaligned in the digital economy. New tools for governance and oversight are needed to handle the furious pace of innovation, transformation, and expansion to assure future economic growth and improved quality of life. A number of inventive policy solutions are beginning to emerge often borrowing from different sectors where governance strategies have accommodated change while also better protecting the rights of users.

One proposed solution is to create a fiduciary responsibility for those who handle personal data with an early focus on online service providers (OSP). The fiduciary concept confers legal responsibility to an individual or entity who is accountable if they abuse a trusted relationship with end-users. This positive obligation to protect end-user interests results in "three basic duties: a duty of care, a duty of confidentiality, and a duty of loyalty."¹² As introduced by Professors Jack Balkin³⁴ and Jonathan Zittrain⁵, the concept of information fiduciaries asserts that since end-users experience an asymmetry of access to information and since users have difficulty verifying, understanding, or monitoring use, OSPs should be viewed as possessing a fiduciary relationship with end-users.⁶ For specific types of sensitive information such as health data, the fiduciary relationship has been proposed as a way of managing privacy tensions.⁷ Momentum is building around the idea with inclusion in policy proposals such as India's Personal Data Protection Bill, 2018⁸⁹ and the

¹ Mike Godwin, "It's Time to Reframe Our Relationship With Facebook," Slate, November, 2018. Retrieved from: <https://slate.com/technology/2018/11/information-fiduciaries-facebook-google-jack-balkin-data-privacy.html>

² Jack Balkin, "The First Amendment in the Second Gilded Age," Buffalo Law Review, 2019 (forthcoming). Retrieved from: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3253939##

³ Jack Balkin, "Information fiduciaries and the first amendment," UC Davis Law Review. Vol. 49 No. 4, April, 2016. Retrieved from: https://lawreview.law.ucdavis.edu/issues/49/4/Lecture/49-4_Balkin.pdf

⁴ Balkin, 2019.

⁵ Jonathan Zittrain, "How to Exercise the Power you Didn't Ask For," Harvard Business Review, September 2018 Retrieved from: <https://hbr.org/2018/09/how-to-exercise-the-power-you-didntask-for>

⁶ See Balkin, 2016 for discussion of information fiduciaries.

⁷ Chirag Arora, "Digital health fiduciaries: protecting user privacy when sharing health data," Ethics and Information Technology, 2019. pp. 1-16. Retrieved from: <https://link.springer.com/content/pdf/10.1007%2Fs10676-019-09499-x.pdf>

⁸ Vasant Dhar, "Who controls your data? India may pass a law ensuring that you do," Washington Post, September, 2018. Retrieved from: https://www.washingtonpost.com/news/monkey-cage/wp/2018/09/25/who-controls-your-data-india-may-pass-a-law-ensuring-that-you-do/?utm_term=.bf7d85993a55

⁹ Ahalya Chalasani, "Data Principal and Data Fiduciary in the Personal Data Protection Bill, 2018," Lakshmikumar & Sridharan Attorneys, 2018. Retrieved from: <https://www.lexology.com/library/detail.aspx?g=f0522766-30c6-4c07-ab5a-fb924a74f5cc>

Data Care Act of 2018 in the United States Senate.¹⁰¹¹ The Data Cares Act focuses the fiduciary obligation on OSPs with enforcement resting on Federal Trade Commission and states attorney generals. India's Personal Data Protection Bill, however, applies the data fiduciary responsibility more broadly to include any entity that "determines the purpose and means of processing of personal data."¹² Ultimately, implementation of any information fiduciary obligation will likely require a combination of legal mandates, voluntary commitments, and potentially international harmonization. The information fiduciary concept is not without critics who highlight that meeting expectations related to the duty of care, confidentiality, and loyalty will be challenging in practice and may come into conflict with other legal obligations.¹³

¹⁰Brian Schatz, "S.3744 – Data Care Act of 2018," U.S. Senate, December, 2018. Retrieved from: <https://www.documentcloud.org/documents/5547713-Data-Care-Act-of-2018.html>

¹¹"Senators propose privacy bill establishing fiduciary duties for online companies," International Association of Privacy Professionals, December, 2018. Retrieved from: <https://iapp.org/news/a/senators-propose-privacy-bill-establishing-fiduciary-duties-for-online-companies/>

¹²Ahalya Chalasani, 2018.

¹³Lina Khan and David Pozen, "A Skeptical View of Information Fiduciaries," Harvard Law Review. Vol. 133, 2019 (forthcoming). Retrieved from: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3341661

THE BIOMEDICAL EXPERIENCE

The potential and limitations of a fiduciary concept applied in the digital economy can be observed by looking at sectors with similar challenges. In the biomedical economy a fiduciary responsibility is well established and can provide useful lessons when applying the concept to the digital economy. The biomedical economy has many stakeholders who must rapidly adapt to changing technology while also simultaneously providing services. The biomedical economy is complex with many different specialized communities that often operate in silos but must integrate to offer products and services. The biomedical economy is also lucrative and highly regulated in response to products and services that are critical to life and must work every time. The biomedical economy has also evolved around a deep appreciation for the importance of health information, which remains an important factor in shaping the legal and ethical landscape. Finally, personal data shares many characteristics with health data¹⁴ making experiences from the biomedical economy useful for navigating many of the challenges that personal data creates for the digital economy.

The biomedical economy has experienced many of the same kind of tensions between stakeholders evident in the digital economy. As technology advances, it becomes difficult for regulators and end-users to keep up, leading to an ever more rapid co-evolution. Regulators and end-users seek to assert greater control. At the same time, the pace and complexity of technology continues to advance with innovators pushing even further ahead. Despite making some progress, regulators and end-users feel further behind and seek even greater control. In time, those leading technological innovation will concentrate power as regulators and end-users are unable to keep up. This power imbalance creates dissonance with end-users who distrust technology providers while also embracing the benefits the technology brings to their daily lives. In the biomedical economy, there have been similar imbalances of power between technological innovators and users that resulted in efforts to shift power back to users that were critical to creating a resilient ecosystem. There are also parallels between key constituencies in the digital and biomedical economies:

- **Service Providers.**

Similar to their digital service providers, doctors and other biomedical experts have access to a significant amount of information and can control access to care. As new products and services become available, power concentrates.

- **Technology Developers.**

Both the digital and biomedical sectors rely on those who create new products and services. A drive to rapidly innovate can overlook the implications new products and services have on the end-user.

- **Regulators.**

The biomedical regulatory infrastructure is more mature than the digital sector but must still continually adapt. In the United States, the Food and Drug Administration and the Federal Trade Commission cultivate a system that incentivizes innovation but protects consumers from products whose safety and effectiveness are difficult to determine.

¹⁴Ahalya Chalasani, 2018.

- **End-Users.**

In the biomedical sector these are patients who struggle to make fully informed decisions in the face of asymmetric information and often an urgent need for care.

Exploring the fiduciary concept in the biomedical economy provides lessons that decision-makers can use when applying the concept in the digital economy. It will also reveal some likely limitations of the information fiduciary concept. As the subsequent section will demonstrate, the medical fiduciary obligation on its own is not sufficient to shift the balance of power back to the end-user, which will also likely be true in the digital economy. Anticipating challenges allows for more careful design and implementation of the information fiduciary concept, increasing the likelihood of achieving the intended policy goals. The biomedical experience highlights several challenges an information fiduciary concept must tackle either head on, or through other governance mechanisms. These core challenges include:

- Overlapping legal requirements
- Building an effective guild
- Managing informed consent
- Determining subjective best interests.

OVERLAPPING LEGAL REQUIREMENTS

A fiduciary relationship can be a tool to balance power in the face of a dynamic technological change but will not fully replace the need for regulatory oversight or other policy interventions. The medical fiduciary relationship has been constructive for re-balancing power more toward the patient, but egregious injustices have occurred that required regulatory intervention to accommodate new technologies, services, and changing ethical norms. A notable example is the Tuskegee Study¹⁵ where the United States Public Health Service conducted unethical experiments for decades on a population that was unaware of the true nature of the research. When the situation came to light in 1972, public outrage resulted in regulatory action that substantially changed how human subjects are treated in research¹⁶ providing the foundation for the human subject protections that persists to this day.

The medical fiduciary responsibility also overlaps with other important legal obligations including malpractice suggesting additional legal mandates may be necessary to achieve better balance of power. Several US states have no additional legal cause of action for breaches of the medical fiduciary responsibility as they are viewed as being covered by medical malpractice.¹⁷ This raises the question of whether the fiduciary obligation or the threat of legal action for malpractice that compels the desired behavior among medical professionals.

Further, the entity with the fiduciary obligation has legal responsibility for actions of third parties who are not covered, requiring additional policy tools that extend beyond the covered entities. In both the biomedical and digital economies, many of the greatest imbalances of power emerge around research and development, often with the goal of creating novel products and services. Biomedical researchers who do not have a formal fiduciary obligation rely heavily on self-governance and greater oversight as a product is nearing clinical application.

In the digital economy many of the greatest privacy challenges also concentrate around the most innovative uses of data and technology. The boundary between research and application in the digital economy is more fluid as research is often performed in parallel to the delivery of services. There are many researchers outside of large companies who are unlikely to be directly obligated to uphold an information fiduciary responsibility but will be actively engaged in product development or data use. An entity with an information fiduciary responsibility would likely be accountable for the actions of third parties, which would require close and ongoing oversight. The Facebook–Cambridge Analytica scandal¹⁸ is an example where an information fiduciary obligation may have incentivized Facebook to reconsider third party access to end-user data. Even if the data had been given to Cambridge Analytica in the first instance, an information fiduciary responsibility might have required Facebook to get assurances that future use of the data by Cambridge Analytica was in the best interests of the end-user. If inappropriate use by Cambridge Analytica was discovered, Facebook would need

¹⁵ Wayne LaMorte, "The Syphilis Study at Tuskegee," Boston University School of Public Health. Retrieved from: http://sphweb.bumc.bu.edu/otlt/MPH-Modules/EP/EP713_ResearchEthics/EP713_ResearchEthics3.html

¹⁶ U.S. Department of Health & Human Services, "The Belmont Report," The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, April, 1979. Retrieved from: <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html>

¹⁷ Maxwell Mehlman, "Why physicians are fiduciaries for their patients," *Indiana Health Law Review*. Vol. 12 No. 1, 2015. p. 23 Retrieved from: <https://journals.iupui.edu/index.php/iHLR/article/view/18959/18860>

¹⁸ Carole Cadwalladr and Emma Graham-Harrison, "Revealed: 50 million Facebook profiles harvested for Cambridge Analytica in major data breach," *The Guardian*, March, 2018. Retrieved from: <https://www.theguardian.com/news/2018/mar/17/cambridge-analytica-facebook-influence-us-election>

mechanisms to hold the third party accountable for violating their trust and the trust of Facebook end-users. Shaping an information fiduciary obligation that aligns incentives of non-covered entities in the ecosystem will likely be necessary to regain the trust of end-users. Careless actions by researchers could easily frustrate efforts to build trust and shift the balance of power back toward end-users.

As the biomedical experience suggests, an information fiduciary obligation may contribute to balancing interests, it is unlikely to serve as a silver bullet that addresses all power imbalances.

BUILDING AN EFFECTIVE GUILD

Most people are familiar with the Hippocratic oath obligating a medical professional to first do no harm but the biomedical fiduciary relationship is more complex in theory and practice.¹⁹ Historically, medical practitioners were not well respected by society due to frequent abuses of power leaving patients unable to differentiate quality practitioners from quacks.²⁰ Controlling the self-interests of medical professionals evolved less from an enlightened policy goal than as a pragmatic need to increase patient trust and professionalize the medical community.

The American Medical Association (AMA) founded in 1847²¹ initially behaved more like a guild to standardize professional standards that were seen as critical to protecting the legitimate members of the profession. The AMA increased its power not only over its membership but also its influence over policy, sometimes advancing controversial positions. Today, the AMA strongly influences the medical profession through tight control over education, accreditations, and professional resources. Deviation from the professional and ethical norms of the AMA can impede a medical professional's ability to seek future employment, career advancement, or prestige in their field. These community norms and sanctions are a powerful tool for compelling professional and ethical behavior and reinforce the fiduciary obligation.

Professional norms allow for rapid adaptation as technology and society evolve enabling standards to address new challenges. Even strongly held norms, however, are subject to interpretation especially in sectors with high rates of innovation and outcomes that can be difficult to predict. Professional norms are not legally binding and organizations such as the AMA often lack sufficient resources to investigate alleged grievances.²² Professional norms can serve as a foundation for legal obligations such as a fiduciary responsibility²³ but can conflict with other legal responsibilities such as the need to protect public health, which can be used as justification to breach patient confidentiality.^{24,25}

An organization such as the AMA that cultivates and enforces professional and ethical standards on practitioners who control access to the end-users has been an important element of self-governance across the biomedical economy. The AMA Codes of Medical Ethics²⁶ serve to clarify professional expectations allowing individuals to better understand and apply standards in a specific context. Biomedical communities beyond medical doctors have also created codes of conduct appropriate for the professional and ethical challenges of other areas of the biomedical enterprise and result in

¹⁹ Maxwell Mehlman, 2015. p. 1-64.

²⁰ Ibid, p. 57.

²¹ "AMA history," American Medical Association. Retrieved from: <https://www.ama-assn.org/about/ama-history/ama-history>

²² "Frequently asked questions on ethics," American Medical Association. Retrieved from: <https://www.ama-assn.org/about/publications-newsletters/frequently-asked-questions-ethics>

²³ Maxwell Mehlman, 2015. p. 33

²⁴ Chirag Arora, 2019.

²⁵ Maxwell Mehlman, 2015. p. 33

²⁶ "AMA Principles of Medical Ethics," American Medical Association. Retrieved from: <https://www.ama-assn.org/about/publications-newsletters/ama-principles-medical-ethics>

standards that are also largely self-enforced.²⁷²⁸ Medical associations in other nations²⁹ and at a global level³⁰ have created mechanisms for international self-governance of professional standards.

There are early efforts to cultivate organizations that serve this function in the digital economy. Groups such as the Developers Alliance,³¹ the Data Guild,³² and the Association of Software Professionals³³ touch upon aspects of the professional guild concept. Digital stakeholders have tended to engage these guild-like efforts through corporate responsibility initiatives such as the Global Network Initiative, a multi-stakeholder alliance that “helps companies respect freedom of expression and privacy rights when faced with government pressure to hand over user data, remove content, or restrict communications.”³⁴ These early efforts remain fragmented and it is unclear if these efforts are seen as critical to the core business of digital professionals as would likely be necessary for a digital guild to be effective.

²⁷ “ASM Code of Ethics,” Ethics Codes Collection, Illinois Institute for Technology. Retrieved from: <http://ethicscodescollection.org/detail/d8c612e4-da21-4d14-b1e2-39536e798252>

²⁸ Chia-Yi Hou, “National Academy of Sciences Votes to Change Its Bylaws,” *The Scientist*, May, 2019. Retrieved from: <https://www.the-scientist.com/news-opinion/national-academy-of-sciences-votes-to-change-its-code-of-conduct-65826>

²⁹ See the British Medical Association, retrieved from: <https://www.bma.org.uk/>; the Chinese Medical Association, retrieved from: <http://en.cma.org.cn/>; the India Medical Association, retrieved from: <http://www.ima-india.org/ima/>; and the Associação Médica Brasileira, retrieved from: <http://www.amb.org.br/>

³⁰ World Medical Association. Retrieved from: <https://www.wma.net/>

³¹ Developers Alliance. Retrieved from: <https://www.developersalliance.org/>

³² “Principles,” The Data Guild, August, 2018. Retrieved from: <https://www.thedataguild.com/principles>

³³ Association of Software Professionals. Retrieved from: <https://asp-software.org/www/>

³⁴ GNI helps companies respect freedom of expression and privacy rights when faced with government pressure to hand over user data, remove content, or restrict communications.

MANAGING INFORMED CONSENT

Informed consent is an important tool for balancing power in the biomedical economy and has an important role to play in the digital economy. As discussed in the report, “Meaningful Consent in the Digital Economy,” the concept of consent “is well-established in many areas of law and ethics. Intuitively, consent provides people with the opportunity to exercise control over important aspects of their life or personhood, for instance when undergoing medical procedures. Consent is now recognised [as an important element of privacy and data protection, notably in the European Union’s General Data Protection Regulation (GDPR)].”³⁵

In the biomedical economy, a medical professional is required to present a patient with understandable information that explains the complexity around potential treatment options or research at a level that allows a patient to make an informed decision before agreeing to proceed. When a subject agrees to participate in research, the design of the research is described and any expected research results that will be shared with the subject are identified.

In biomedical research, informed consent can also impede information flow back to a subject. For example, initial results from the Resilience Project that used existing genetic data from consenting subjects in datasets such as those held by 23&me identified 13 individuals who survived into adulthood despite possessing what previously had been considered genetic mutations that were lethal in childhood.^{36,37} The type of consent received for the research prevented re-contacting these “genetic superheroes”³⁸ or approaching them about further study to better understand the unexpected results. While it is possible to create consent agreements that allow for re-contact, it can be difficult to structure consent agreements that imagine all situations requiring re-contact *a priori*. One can also imagine scenarios where researchers’ discoveries would be unwelcome or not in the best interest of a research subject to know because of the potential for significant impact, leaving the fiduciary to determine about whether to share information even with an existing re-contact clause.

Knowledge generated in the digital economy may run into similar challenges around the limits and interpretation of consent. As in the genomic context, it is difficult to predict in advance the most innovative applications or insights from data in order to get informed consent at the time data is gathered.³⁹ A user could consent to have research performed using their personal data but may not reasonably be able to predict the resulting knowledge that will be generated making it difficult for them to give *informed* consent. For example, research performed on consenting subjects revealed that social media posts can be used to help predict subsequent manifestation of depression⁴⁰ and Facebook has acknowledged

³⁵ “Building a Consentful Economy,” University of Southampton, 2017. Retrieved from: <http://www.meaningfulconsent.org/reports/2017/>

³⁶ Sarah Zhang, “Genetic Superheroes Walk Among Us, But Shhh! No One Can Tell ‘Em,” *Wired*, April, 2016. Retrieved from: <https://www.wired.com/2016/04/scientists-find-genetic-superheroes-cant-tell/>

³⁷ Rong Chen, Lisong Shi, Jörg Hakenberg, Brian Naughton et al., “Analysis of 539, 306 genomes identifies individuals resilient to severe Mendelian childhood diseases,” *Nature biotechnology*. Volume 34 No. 5, May, 2016. Retrieved from: <https://www.nature.com/articles/nbt.3514.pdf>

³⁸ Sarah Zhang, 2016.

³⁹ Solon Barocas and Helen Nissenbaum, “On Notice: The Trouble with Notice and Consent,” *Proceedings of the Engaging Data Forum: The First International Forum on the Application and Management of Personal Electronic Information*, October, 2019. Retrieved from: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2567409

⁴⁰ Johannes Eichstaedt, Robert Smith, Raina Merchant, Lyle Ungar et al., “Facebook language predicts depression medical records,” *Proceedings of the National Academy of Sciences*. Vol. 115 No. 44. October, 2018. Retrieved from: <https://www.pnas.org/content/115/44/11203>

tracking users posts with a suicide prevention algorithm⁴¹ that has already raised questions about consent. Consider, for example, if a suicide prevention algorithm identified likely sexual orientation, which neural networks have demonstrated an ability to do from visual images,⁴² as a potential risk factor in depression or suicidal ideation? An individual who provides consent to a study of social media and depression or suicide might not be prepared for research results indicating their sexual orientation. Knowledge generated outside the scope of the initial expectation can be impactful to how an individual views themselves or their place in the world. The type of information collected would need to be weighed when determining whether an individual consented for that information to be shared, stored, or even provided back to themselves.

Much like genomic data, personal data could provide derived knowledge that cannot be unlearned if the subject later decides they do not want to have that type of insight. Prioritizing the best interests of the user could require that an information fiduciary interpret the scope of consent given and weigh the impact derived knowledge could have on the user to determine if it is in the best interest of the user to be informed.

⁴¹ Benjamin Goggin, "Inside Facebook's suicide algorithm: Here's how the company uses artificial intelligence to predict your mental state from your posts," Business Insider, January, 2019. Retrieved from: <https://www.businessinsider.com/facebook-is-using-ai-to-try-to-predict-if-youre-suicidal-2018-12>

⁴² Yilun Wang and Michal Kosinski, "Deep neural networks are more accurate than humans at detecting sexual orientation from facial images," Journal of Personality and Social Psychology. Vol. 114 No 2. February, 2018. Retrieved from: <https://psycnet.apa.org/doiLanding?doi=10.1037%2Fpspa0000098>

DETERMINING SUBJECTIVE BEST INTERESTS

Fiduciaries have the responsibility to act in the best interests of users. In the biomedical economy, a fiduciary can generally assume that it is a patient's preference and in their best interest to stay alive with the minimum amount of pain. However, that may not be true in all circumstances. For example, if an individual altruistically donates a kidney they are choosing to take on greater pain and health risk demonstrating a more complex set of preferences. At other times, determining what is in the best interest of the patient may not be easy due to uncertainty around the cause of disease or the potential outcome of an experimental procedure or technology. Further, the wishes of a patient do not always determine their best interests, leaving the fiduciary empowered to make a decision in the patient's best interest that could run counter to the patient's wishes.

In the digital economy, an information fiduciary would have an obligation to represent user interests but the priorities of each user could be different, difficult to discern, and frequently changing as technology and society change. Acting in the best interest of a user requires a fiduciary to have a shared understanding of the user's values and preferences. Determining what is in the best interest of a user can be subjective and based on preferences that may not have been shared with the fiduciary. In a rapidly evolving field, the lack of past precedent could force a fiduciary to extrapolate preferences in situations that are unlike anything previously encountered. Further, user preferences can evolve over time requiring a fiduciary to constantly adapt to changing user preferences as technology continues to advance. For example, the use of genealogy-focused web services by law enforcement to catch criminals is an innovation in the science and the use of digital services. Individuals chose to upload their direct-to-consumer DNA profiles to the genealogy-focused web service GEDmatch, likely because it was a free open-source public aggregator that allowed end-users to search for ancestors across many databases rather than be confined to the customers of a single provider such as 23&me or Ancestry.com.⁴³ The openness of the GEDmatch platform allowed law enforcement to submit genomic profiles from DNA left at crime scenes, which ultimately led in April 2018 to the apprehension of Joseph James DeAngelo, also known as the Golden State Killer. When end-users initially uploaded their genomic profile to GEDmatch they may not have envisaged that law enforcement might use their submission to identify the distant relatives of criminals. Apprehending serial killers, however, is generally seen as a socially desirable outcome. Different end-users are likely to have different preferences around the appropriateness of genealogy-based forensics. Those preferences would likely also be influenced by the types of criminals being sought and additional actions taken by law enforcement, making it difficult for a digital service providers to made decisions that align with all users' preferences.

In the biomedical economy there are policy tools that assist in weighing best interests especially in areas of rapid technological innovation. These tools often provide an opportunity to seek expert guidance – and in some cases binding adjudication – to weigh patient interests and ethical constraints. For example, in the United Kingdom (UK) the Human Fertilization and Embryology Authority (HFEA)⁴⁴ is an independent regulator of fertility treatments and embryo research performed within the UK. HEFA provides a process to seek expert opinion and approval to use cutting edge

⁴³Joseph Zabel, "The Killer Inside Us" Law, Ethics, and the Forensic Use of Family Genetics," *Berkeley Journal of Criminal Law*, 2019 (forthcoming). Retrieved from: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3368705

⁴⁴Human Fertilisation & Embryology Authority. Retrieved from: <https://www.hfea.gov.uk/>

reproductive technologies.⁴⁵ HEFA has the ability to weigh interests and provide doctors, clinics, and patients guidance on what is an acceptable practice considering the state of available technology and ethical constraints. For example, in 2018 HEFA approved the use of mitochondrial replacement therapy designed to avoid severe mitochondrial diseases that effectively creates babies with three parents, which raised ethical concerns.⁴⁶ While not the first time this procedure was performed, HEFA's approval provides guidance as to whether the use of the technology in this instance was ethical and in the participants' best interests. In contrast, also in 2018, the Chinese scientist who announced the birth of the first CRISPR edited babies was roundly rebuked by the scientific community and the Chinese government largely because of ethical concerns that many believe did not properly weigh the interests of the participants.^{47,48}

While protecting life and minimizing pain are generally unifying values in the biomedical context, in the digital economy the priorities of a user may not be as clear and could change over time as new applications of data continue to emerge. A legal obligation to act in a user's best interests may require an information fiduciary develop new methods or technical tools to better determine and update the preferences of users in order to build and uphold their trust.

⁴⁵ Ian Sample, "UK doctors select first women to have 'three-person babies'," *The Guardian*, February, 2018. Retrieved from: <https://www.theguardian.com/science/2018/feb/01/permission-given-to-create-britains-first-three-person-babies>

⁴⁶ Jessica Hamzelou, "First UK three-parent babies could be born this year," *New Scientist*, February, 2018. Retrieved from: <https://www.newscientist.com/article/2160120-first-uk-three-parent-babies-could-be-born-this-year/>

⁴⁷ David Cyranoski, "First CRISPR babies: six questions that remain," *Nature*, November, 2018. Retrieved from: <https://www.nature.com/articles/d41586-018-07607-3>

⁴⁸ David Cyranoski, "The CRISPR-baby scandal: what's next for human gene-editing," *Nature*, February, 2019. Retrieved from: <https://www.nature.com/articles/d41586-019-00673-1>

IMPLEMENTING INFORMATION FIDUCIARIES

The concept of information fiduciaries is a tool for protecting consumers from asymmetries of information and the potential for a provider to benefit at the expense of the user. However, as the biomedical experience demonstrates, there still remain challenges for implementation of the information fiduciary in the digital economy that require additional consideration. The success of a fiduciary obligation in the medical field is not the result of an imposed legal requirement on the sector, but rather grew out of the medical community's desire to increase professionalism and trust with patients. It is not obvious that imposing an information fiduciary responsibility on the technology community will achieve the same outcome unless responsibility to effectively self-govern is embraced by those in the digital technology profession. A legal mandate for information fiduciaries on its own is unlikely to be sufficient without supporting organizations that cultivate a professional culture in recognition that it is in the best interest of the industry to build and keep the users' trust. These supporting organizations will also need methods to enforce professional standards and norms across the sector while also likely being active participants in seeking any needed regulatory constraints.

Complexity around consent and subjectivity of determining user best interests could leave a well-intended information fiduciary struggling to identify what action to take in the best interest of the user. Additional mechanisms such as external advisory groups where information fiduciaries can seek guidance on how best to navigate user interests especially in the face of rapidly changing technological landscape could be useful. New technological tools that enable information fiduciaries to better understand the nuances around user privacy preferences and more rapidly adapt to personal changes rather than a one size fits all policy on data privacy may also be needed.

The digital economy will continue to create products that integrate into every facet of consumer lives in ways that create even greater dependencies and more closely resemble a patient's reliance on biomedical products. As consumers continue to rely on data driven technologies, there will be a need for policies that cultivate a healthy balance of power and trust between each of the digital economies constituencies. Exploring policy ideas from the biomedical economy can illuminate opportunities for experimentation while also assisting in envisaging unintended consequences that may need to be accommodated in policy design and signal that a theoretical policy might not actually work in practice as it was intended.

Overall, the lessons from the biomedical economy suggest that the concept of information fiduciaries has the potential to address critical governance issues in the digital economy. However, this potential will be limited unless those in the digital profession truly get behind building trust with users through self-enforcement, professional standards, addressing informed consent, and managing the best interests of users.