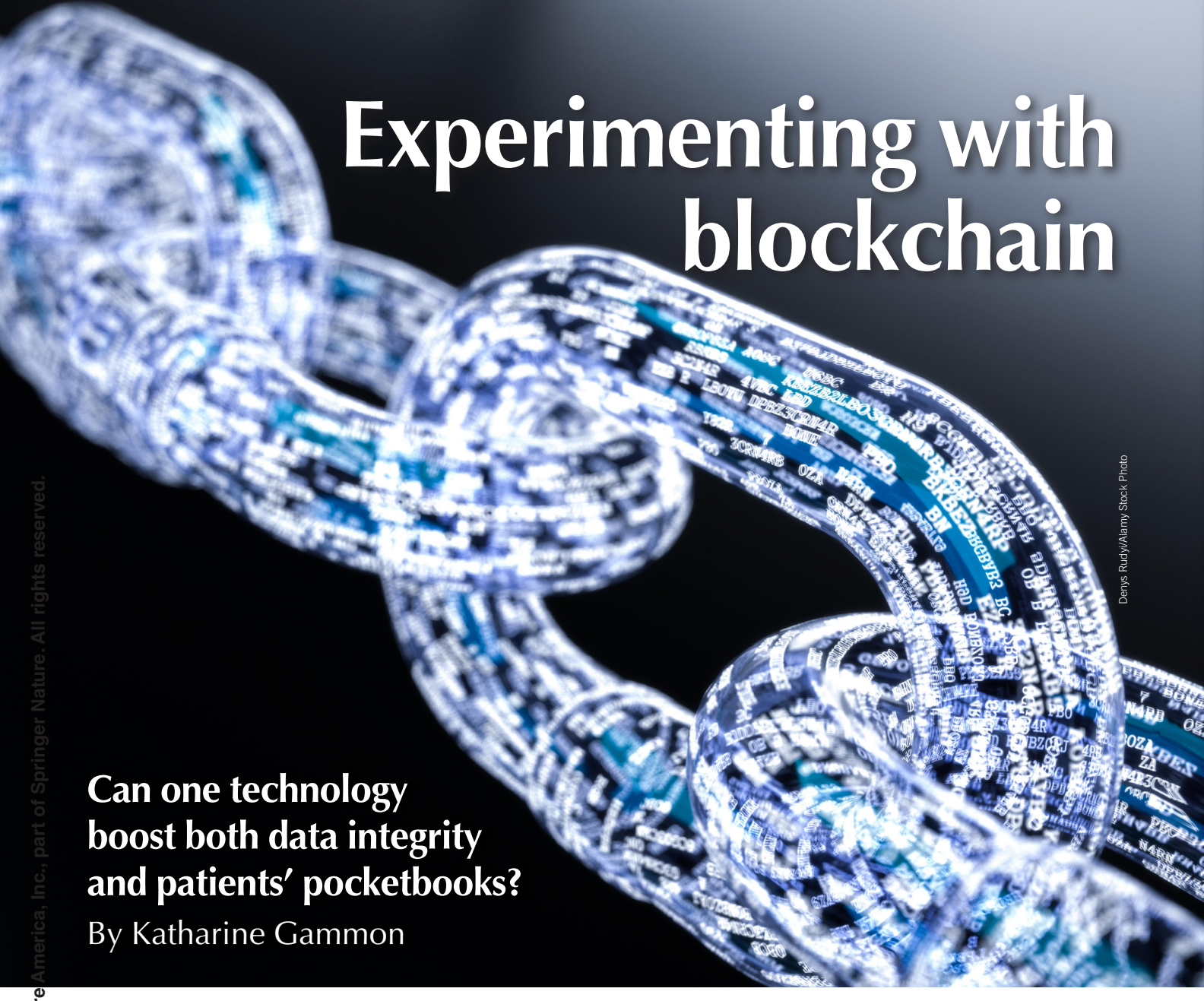
Experimenting with blockchain



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Can one technology boost both data integrity and patients' pocketbooks?

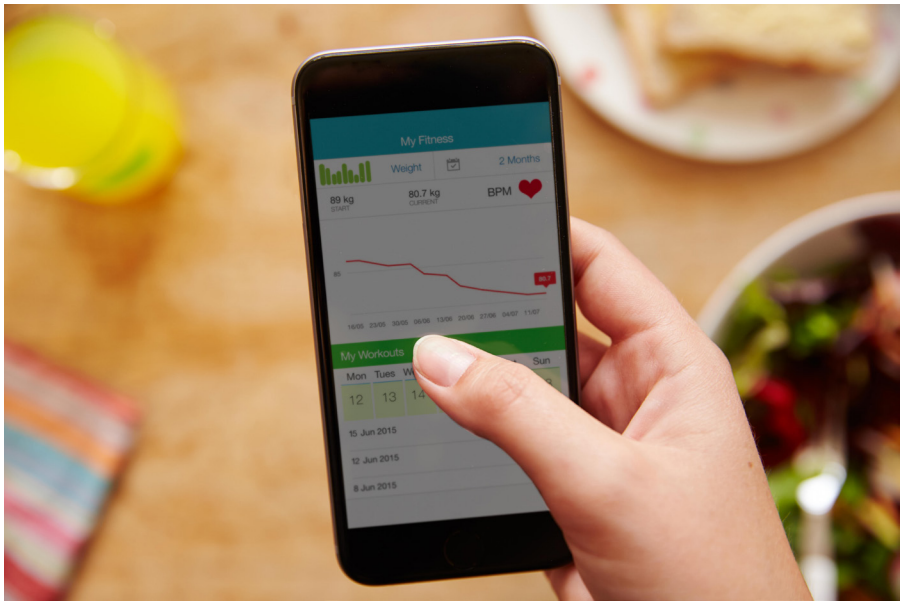
By Katharine Gammon

Lucy Ojomoko eyes her selfie. She is young, tall and slender, and her dark hair is pulled back in a ponytail. She clicks 'upload' and waits. Her picture is soon accepted to the system she helped to create, and five LifePounds are deposited in her online account.

While she waits for the LifePounds to deposit, she clicks through to add her current health information—height, weight, blood pressure, resting pulse—and adds updated data in these fields. More sensitive information, like blood tests or pictures of her skin, face, back or chest, earn more LifePounds. The company says that their digital currency can eventually be traded for discounts on health tests or products like toothpaste and shampoo—and exchanged for cold, hard cash. The LifePound is a brand of cryptocurrency, a new form of digital currency that operates without a bank. The government, as well as private companies and drug developers aiming to develop drugs and antiaging products, can buy the data linked to the currency through the Longenesis marketplace.

Ojomoko is a Blockchain AI program manager at Longenesis, a decentralized medical record marketplace for life data like medical records and health data. The platform, which is being used by employees and will open to the public in spring 2018, allows individuals to store and monetize their own health data, including blood test results, medical history, genetic profile and other sensitive information, in a blockchain-based marketplace. In the marketplace, people are paid in LifePounds to lease all kinds of information to companies for a certain amount of time.

Longenesis isn't alone in this idea: Nebula Genomics, a Cambridge, Massachusetts–based startup cofounded by George Church, aims to use blockchain to allow individuals to sell access to their entire genome for a cryptocurrency called Nebula tokens. Individuals who do not yet have their genome sequenced can take paid surveys about their health conditions. If companies are interested in their genomic information, those companies can subsidize the cost of genome sequencing. Another system known as MedRec that uses blockchain for sharing health records is slated for testing later this year at Beth Israel Deaconess Medical Center in Boston. Even governments have



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In your hand: We're treasure troves of data.

got on board with the blockchain approach: in 2017, the Estonian e-Health authority implemented a blockchain solution enabling storage of a million health records, letting patients control data access through a special keyless signature infrastructure, making them the first government in the world to do so.

The blockchain technology on which these endeavors rely was created in 2008 for users to buy and sell the cryptocurrency bitcoin, as its public transaction ledger. The technology was the brainchild of Satoshi Nakamoto, a much-debated pseudonym that may stand for a group of people. In recent years, Bitcoin has upended the financial world. But the power of blockchain technology can go far beyond the world of finance.

Part of the power of blockchain rests in the fact that it is a huge, public, secure and decentralized store of ordered records or events. Each of these records, or 'blocks', contains a cryptographic hash of the prior block in the chain, indelibly linking the two. Information cannot be erased. The dataset is owned by no one, is controlled by users and is not ruled by central regulatory instance. Trust is encoded in the protocol through a complex cryptographic algorithm and maintained by the community of users.

As long as everyone agrees on the rules of engagement, participants can choose how much to engage, without having a central authority, says Lucila Ohno-Machado, a professor of biomedical informatics at the University of California, San Diego. "This is a really important new tool in our arsenal," says Ohno-Machado. "If done correctly, derivatives of blockchain technology can solve issues around patient privacy and data sharing."

Pharma's chain reaction

The potential for blockchain to change biomedical research is not lost on the pharmaceutical industry, and companies are already starting to use blockchain. In February, the Institute of Electrical and Electronics Engineers (IEEE) held the first international conference on blockchain and clinical trials, with sessions focused on topics such as increasing clinical research integrity and integrating blockchain into medical records. Meanwhile, a study from IBM published in 2016 showed that 16% of healthcare executives planned to put a commercial blockchain solution in place by last year, and 56% expect to do so by 2020 (ref. 1). IBM's own Watson Health artificial intelligence (AI) unit recently signed a two-year joint-development agreement with the US Food and Drug Administration to explore using blockchain tech to securely share patient data for medical research and other purposes.

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Blockchain could help pharma companies discover patients with the right profile for a clinical trial, even if those patients were not actively searching to participate in a clinical trial for a product from which they might benefit. Patients could be prompted based on their data (which are anonymized) to join the trial, thereby also accelerating the process and accuracy of trial recruitment, says Milind Kamkolkar, chief data officer at Sanofi. If they decline, no personal information has been shared and the person's identity remains private. If they agree, the overall process would move faster by abolishing the need for intermediaries.

For pharma companies, better inclusion in clinical trials and better reproducibility for studies can reduce the time and money needed to develop new drugs. Part of the challenge that these companies face is that health information is scattered across multiple systems, paper or digital, creating huge data silos, Kamkolkar says.

Additionally, pharmaceutical companies, including Pfizer, Amgen and Sanofi, have expressed interest in blockchain's qualities for ensuring the accuracy of and safeguarding data. Companies are looking for ways to improve pharmaceutical supply chain management, tracking, for example, the provenance of pharmaceuticals. Counterfeit drugs cost pharmaceutical companies $200 billion each year. Blockchain could track the chain of custody for drugs through the supply chain and establish new ways to maintain drug integrity and veracity.

Patient protection

Because health data managed with blockchain startups are stored on a decentralized network, there is no single institution that can be robbed or hacked to obtain a large number of patient records. That is important because, when researchers are dealing with institutions that might compete for patients to include in studies, it might not be easy to cede authority to one institution over another, Ohno-Machado says. This built-in security is a way a blockchain-backed health information marketplace has the potential to change clinical science, she adds.

Blockchain companies are cropping up everywhere. In addition to Nebula Genomics, there is also Luna DNA, a company that asks people to upload genetic information and receive Luna Coins when

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File sharing: Tracking medical records blockchain might improve research quality.

they allow researchers to have access. Another company, EncrypGen, has a similar plan to use metadata about the actual genome.

"This is the Wild West, and a lot of new efforts will fail," says Alex Zhavoronkov, CEO of medical AI company Insilico Medicine, which together with blockchain tech company BitFury, created Longenesis. "It's very much like the dot-com boom of 2000 and 2001 in this area."

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These companies are all using a simple tool to help people control their data: smart contracts. A smart contract is an automated way to get something done—the idea calls to mind technology as straightforward as a vending machine or thermostat. In the future, doctors can prescribe the use of devices like Fitbit for improving personal health. Smart contracts can be implemented on personal fitness data: if you walk so many steps and your health improves, you could get an automatic reward after a visit to the doctor.

Within Longenesis, Ojomoko says users will be able to create smart contracts for leasing out data—say, to a company—and getting them back after a certain amount of time. Users could choose to re-up their contract with the same company or lease out the data to a new firm. As a result, when Ojomoko uploads her photos and blood work into the Longenesis system, she ultimately has control over who can access the data.

The Longenesis vision is a collaboration between the AI-based drug development company Insilico Medicine and the blockchain mining company the Bitfury Group. Their plan is to pay people to hand over their data—everything from pictures to height, weight, bloodwork, diseases, MRIs and CT scans, and the marketplace for others to lease the data is set to open in spring of 2018, with a full launch in 2020. The company is starting by working with healthcare providers. Pictures can carry enormous amounts of information, says Zhavoronkov. "People think their genomes carry a lot of info," he says. "But with a picture, you can predict someone's age—you can't do that with a genome." Longenesis will charge a fee to guarantee the data are valid and annotated, which they will do using AI.

"Simply put, blockchain is a software that enables value transfer," says Hilary Carter, director of faculty at the Blockchain Research Institute, a Toronto-based nonprofit think tank that researches the impact of blockchain technology on government, business and society.

Ojomoko echoes this notion that blockchain upends the flow of patient data, putting patients, who can financially profit directly, in the driver's seat. "It's an ecosystem built around the individual," Ojomoko says.

Selling your data

Personal and health data are already being collected, sold and used in ways patients probably don't even know about, says Bonnie Kaplan, a bioethicist at the Yale Center for Medical Informatics. "What's different in initiatives like Longenesis and other similar marketplaces is that the data sale is explicit and you at least have some control and could get some financial benefit from data about you."

Kaplan adds that health data marketplaces give some autonomy: they let patients curate data about themselves and decide which of those data to sell and where to sell them. "Having this control and financial benefit is good but comes with taking on responsibility for making decisions and assessing risks," she says.

Some of the ideas for the future of blockchain in healthcare are controversial. Zhavoronkov suggests that, in resource-poor countries, leasing out health data could serve as a way to introduce a 'universal basic income', which describes the idea of giving a basic living stipend to all members of a society. "People could take medical tests [and] license their data" for this steady income, he says.

Mark Rothstein, director of the Institute for Bioethics, Health Policy and Law at the University of Louisville School of Medicine, says that could be problematic. "In many low-income countries the health records are of poor quality and not suitable for research and therefore the main asset would be biospecimens in a national or federated biobank," he says, adding that in many countries it's unlawful to export information about specimens without the involvement of a local investigator in the research.

Iraneus Obioma Ogu, a researcher with the Africa Blockchain Artificial Intelligence for Healthcare Initiative (Ogu consults for Longenesis), looks to Africa when he talks about the future of blockchain. In many regions of the continent, Ogu says, people don't realize the value of data, especially personal data. "It's a continent with a large, young population and a rate of internet penetration that is increasing exponentially," he says. That makes Africa a potentially huge market for mining data and paying participants to use their information.

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Fitness test: Is blockchain a good fit for the clinical research enterprise?

In addition to providing income to people who let the system know everything from their food intake to their sun exposure, Ogu suggests the Longenesis marketplace could also be a way to open doors to drug development in parts of Africa and other places companies may not consider first. Mining the data will make it easier for companies to develop medications that help groups of people who are sometimes overlooked, Ogu suggests.

Sifting through people's data, companies can put together more effective drug trials because they can find the exact people they're looking for. Blockchain is yet another way to personalize medicine, Ojomoko adds.

In some low- and middle-income countries, however, participaton in clinical trials is the only opportunity for gaining access to medical care[2]. The question of whether payment for personal health data from populations for clinical trials with blockchain would be a form of economic coercion to become research participants remains an open question[3].

The promise of traceability

Pharmaceutical companies are interested in automating more trials through blockchain because it can help them show the exact, inviolable history of the data. "Big companies have to protect themselves—when they are accused of this or that, they have a strong way to say, no, these are the data," says Mehdi Benchoufi, a medical researcher at the Hospital Hôtel Dieu in Paris, who published a paper last year on blockchain and clinical trials[4] and is leading the IEEE workstream on blockchain and clinical trial consent.

Using blockchain, a researcher can track each piece of data, with a cryptographic validation of each transaction. In addition, each bit of data is recorded in chronological order, and this information is publicly available to anyone with access to the chain. Benchoufi says that this feature can help prevent typical issues related to clinical trial protocols, such as selective reporting of outcomes related to harm, under-reporting of nonsignificant outcomes and mismatches between planned outcomes in the protocol and final publication.

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"When you publish your paper, a publisher could take the whole trial and compile it, just like software," he says. "And they could confirm all data were recorded in the correct order, every event happened in the way the authors said."

The immutability of blockchain may also be a novel way to get around one of science's most thorny problems: reproducibility. In 2005, Stanford researcher John Ioannidis estimated that more than 20% of clinical trials are not reproducible[4]. That number has climbed, with a 2014 essay estimating that 85% of research resources are wasted, mostly owing to findings being false or exaggerated[6]. Blockchain could potentially address this, according to Benchoufi, who also imagines a network of clinical trials where results are easily compiled, making meta-analyses simpler to conduct.

Blockchain does have some powerful hurdles to overcome before it gets widely adopted. For one, it is energy intensive to create cryptocurrency and move it around. The Digiconomist, a website that covers cryptocurrency fraud and risk mitigation, estimates that if Bitcoin—the world's most accepted and valued cryptocurrency—were a country it would use about as much energy as Algeria.

One other issue is nagging blockchain in science: user authentication. It's easy to authenticate the user when someone is meeting with their doctor, but there are concerns that people might upload phony data to the system to make money, Benchoufi says. And regulations that govern the ownership of patient health records also may arrest the adoption of blockchain systems by governments.

Because of these regulations, Benchoufi thinks blockchain will benefit scientists trying to increase reproducibility before it benefits patients looking to share health data for profit. Still, people have historically volunteered their data for clinical trials and received nothing in return for it. At least marketplaces allow patients to build a better society and potentially get some cash for doing so. "As we see more jobs taken over by AI, there will be a lot of people who need to rethink their careers and their lives," Zhavoronkov says. He sees society starting to shift from manual labor and generating capital to a new place: "You can't go wrong with advancing society through an economy driven by health."

Katharine Gammon is a freelance science writer based in Santa Monica, California.

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