Portable Genomics Pursuing Patient-Profit Model for New Consumer Genomics Mobile App

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Premium

NEW YORK (GenomeWeb) – Portable Genomics is preparing to launch a new consumer genomics mobile application and exploring an unusual business model that it believes will generate significant revenue but also let patients profit from the use of their datasets.

The San Diego-based company builds apps that help users collect and browse their genomic and other healthcare information on mobile devices like iPhones and iPads. Portable is currently beta testing a new app, internally called NuMe, that lets patients aggregate genotype and phenotype results as well as health and lifestyle information on mobile devices.

In addition, the company will broker revenue-sharing arrangements with for-profit and non-profit companies and research organizations who want access to app data for research studies. Prospective research clients will pay a prescribed fee for data from consenting app customers and Portable will split the check with the data contributors.

It is an uncommon business model but not entirely unheard of. At least one other company compensates patients for their research contributions:DNAsimple matches genetic researchers to data donors who have consented to part of the company's database of potential research subjects. Consenting donors can provide samples for as many different research studies as they want and the firm compensates donors at a rate of $30 per sample shared.

There are multiple mechanisms for patients to voluntarily share their health data. GenomeConnect, for example, has an online portal where patients with rare diseases can contribute de-identified genotypic and phenotypic information to publicly available genomic databases such as the National Center for Biotechnology Information's ClinVar. Also, DNA.Land, a non-profit jointly launched by Columbia University and the New York Genome Center, provides a forum for participants to submit genomic results from direct-to-consumer companies such as 23andMe for research purposes. In return, donors receive ancestry, relationship, and other information not currently provided by the genotyping companies. As of this month, more than 20,000 participants had signed up to submit their data, according to the site.

But pharma and biotech companies place high premiums on these datasets, especially those from patients with rare and chronic diseases, Portable Genomics Founder and CEO Patrick Merel noted. "Why not share this value with patients who are sharing data with industry?" he said.

There are markets for high-value items such as cars and property and people profit from these in everyday life, yet there are no good mechanisms that let people monetize equally valuable health data, Merel noted. "We want to change that" and bring "a fair business model to the personal health data space," he added.

Portable's new app uses much of the same technology as an earlier app called Portable Genomics 23, or PG23, that the company launched in 2012. PG23 let users visualize and explore their 23andMe genotyping results. Portable launched a second app that year called GeneGroove that creates personal musical tunes for users based on their 23andMe data; and a third app in 2014 called SaveMy23 that lets users store copies of their 23andMe data. It also began testing an initial NuMe prototype that year for browsing genomic data only.

Merel, a molecular biologist by training, was interested in correlations between genotype and phenotype and wanted to design a platform that could help study those relationships, he told GenomeWeb. That meant expanding the original platform to capture clinical, lifestyle, behavioral, and other kinds of data in addition to genotype, he said. Also, for patients' data to retain value, it needs to remain private. That meant that the Portable app had to aggregate data on users' devices only and not on any external servers or systems.

"I had to completely restart the NuMe development," he said. "[I] was [fortunate] to meet Rafi Krikorian, former vice president of engineering at Twitter, who helped me to build this new architecture and who still is an advisor to Portable Genomics." Krikorian is now engineering lead at Uber's Advanced Technologies Group.

What Portable now offers is a generic platform that it can customize to capture disease-specific information. In January, Portable began testing a bespoke version of NuMe — which could eventually be named the Portable Genomics app — with cystic fibrosis patients, clinicians, and disease foundations, Merel said. More recently, the company has discussed the app with at least one unnamed cancer foundation and it hopes to begin testing an oncology-specific version later this year.

Portable has also discussed its business model with patients, foundations, and pharmaceutical companies, Merel said. For instance, if a pharma company that develops treatments for high cholesterol wants data from people who are predisposed to higher cholesterol levels, that company could reach out to Portable Genomics and ask for access to data from the app. In addition to genetic data, that might include access to information on statin metabolism, for example.

Portable Genomics does not access patients' data directly but it does monitor the types of data that users gather and it has mechanisms for capturing information that patients have consented to share, Merel told GenomeWeb. When patients download the app, they use it to tell Portable that they are willing to share their data with third parties for pay.

When the request for information comes in to Portable, the company will then reach out to the participating foundation whose patients have agreed to contribute to ongoing research. Portable might say something like "we have a company X willing to collect your genomic profile and cholesterol levels over three months and they are willing to pay $20,000 for this," Merel said. "Portable Genomics will take X percent of this money and you will get Y percent of this money. Are you still in?"

Once patients confirm their interest in contributing to the project, Portable negotiates a price with the requesting pharma company that depends on the type of data it is interested in, the duration of data collection, and other factors. Merel said that the company is exploring algorithms that companies in

the financial and other industries use to share revenues to see if these could work for genomic and health data sharing. Once they have agreed on the price, Portable will extract the data from the individual's mobile device, de-identify and encrypt it, and then send it off to the pharma company. The company pays Portable which in turn shares the revenue with the participating patients based on the previously agreed on percentage split.

Throughout the process, patients retain control of their data and only agree to share with third parties if they are satisfied with the revenue-sharing agreement. Otherwise, the data never leaves their mobile phones. Customers can also withdraw consent at any time in this process. The aforementioned example focused on industry but the same principle also applies to non-profits including academic institutions, Merel told GenomeWeb. Basically, any group that monetizes data extracted from Portable's app will have to agree to share those revenues with contributors, he said.

The exact percentage split will vary from one partnership to the next and so will the amount of money that the requesting company agrees to pay. But if Portable can drum up enough interest, especially from industry players, its income from these deals could be substantial.

Merel gave GenomeWeb this example: Portable partners with a cancer foundation that has 500 patients in its database, about half of whom have tumor profile data or exome sequence data that they are willing to share. A pharma company might want to collect the patients' genotype information as well as drug regimen information and lifestyle data over a three- to six-month period. Assuming that a patient's genotype is valued somewhere between $10,000 and $20,000, as speculated in a recent *MIT Technology Review* article, the additional drug regimen and lifestyle datasets could bring the total value of the data to around $25,000 per patient. If all 250 patients agree to share their data with the company, then Portable will have raised a little over $6.2 million in shareable revenue from a single deal.

If Portable can make at least one large deal every three months its business will grow quite rapidly in a single year. If it is able to generate enough revenue from data exchange deals alone, Merel said that Portable could make some of its paid services available for free to app customers. For example, it charges a "minor" fee to develop disease-specific modules for the app but if it is able to generate enough revenue from its business deals, it could make those customizations for free to patient groups, Merel said. The company could even help patients pay for genotyping, he added.

It's also a good investment for pharma because they can recruit the most appropriate patients for their studies and thus mitigate the risks and expense of failed clinical trials. And existing deals in the marketplace have shown that companies are willing to pay for good data, according to Merel. As proof, he pointed to Genetech's deal with 23andMe to sequence 3,000 people from 23andMe's Parkinson's disease community. It's an arrangement that could put up to $60 million in 23andMe's coffers — and that's for just sequence information, he said.

"We are offering ... deep data from medical, lifestyle, behavior to genomics [collected] over months. ... It is a substantial value," Merel said. And patients benefit in more ways than one. They can still contribute to research into their disease condition and at the same time raise funds for their care or they can put the money towards more research. "It's a new field of possibilities," he added.

Merel believes that Portable's stance on protecting patient data privacy and its emphasis on patient ownership will make it attractive to disease foundations. La Jolla, California-based startup Guardiome business is based on the same principles of individual data privacy and ownership. Guardiome's customers get their whole genomes sequenced on a password-protected desktop device called Helixa. These devices never connect to the internet so customers are not at risk of online threats to their data. If unauthorized users try to hack into the device, the data self-destructs.

With Portable's app, users not only pick who to share their data with but they can track where their data goes. "All of this will be very transparent from our platform," Merel said. Also Portable only asks users to indicate their willingness to share data upfront as well as which datasets they feel comfortable sharing. It does not actually touch the customer data until there is an agreement in place, he stressed.

Also unique to Portable is its willingness to customize the app to specific use cases, which Merel believes could distinguish it from Apple's ResearchKit app, which may not be as flexible. "ResearchKit is a fantastic opportunity for patients to monitor their data, but it is … data that [the developers] have decided to monitor," he said. Portable's app is developed in partnership with physician experts, but developments are also, at least in part, driven by patients.

For example, the company worked with a local cystic fibrosis foundation and physicians in the San Diego area to develop modules within the app to capture things like spirometry measurements, genetic mutations, drug regimens, and lung microbiome information from cystic fibrosis patients. But the company could also extend the app to capture additional biometrics that physicians are not necessarily thinking about but are important to patients and possibly crucial to their care, Merel noted. It can also make more fine-grained customizations to the app based on patients' behavior. For example, if Portable sees that many patients are uploading their Pathway Genomics test results to the platform then it could build a unique module for capturing Pathway data, he said.

Merel is now trying to secure venture capital to further develop the Portable platform and pursue partnerships. The company is still small. It has two employees including Merel and he works with external group of developers and consultants on the Portable platform. The company also has a six-person board of directors that includes pharma and biotech experts such as Francois Ferre, co-chairman and co-founder of Althea Dx, and Emile Loria, chairman and co-founder of Ose Pharma.

Portable recently received a notice of allowance from the United States Patent and Trademark Office for a patentfiled in 2010 that covers its methods of organizing and visualizing human genomes on mobile devices. Specifically, the patent covers a carousel-based graphical user interface that uses color-coded tags or thumbnail images to display genes, phenotypic traits, and disease information on mobile devices. It also covers methods of activating genomics-based applications and for combining genome data with geographical location information. Also covered are methods of sharing data with medical professionals, scheduling appointments, and monitoring compliance.

In the last four years, the company has raised $1 million in seed capital from angel investors in the San Diego area, which it has used to build NuMe and prep the app for beta testing, Merel told GenomeWeb. It needs to raise an additional $2 million from investors in the near future to keep

developing its platform and it is hoping that its proposition catches the eye of venture capital firms like the newly launched Illumina Venture, he said.

The company is also trying to reach ovarian and breast cancer foundations with its app. The cystic fibrosis iteration of the app is available to beta testers through Apple's TestFlight platform. Patients can ask to participate in the beta through the NuMe website. Meanwhile, Portable is working on a version of the app for oncology patients, Merel said. He hopes to have signed a partnership with at least one ovarian cancer foundation and to start testing a tailored version of the app with patients this fall.

At the same time, Portable is talking with unnamed pharma companies with ongoing discovery projects in oncology and cystic fibrosis. It hopes to have an agreement with at least one pharmaceutical client in place by the fall, Merel said. "We are really at a stage [where] we need to talk to partners to go to the next step with this company," which means also talking to potential partners such as genomic data providers and healthcare insurance companies, he said.