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PatientsLikeMe Builds Multi-Omic Longitudinal Program to Track Biology of Disease and Wellness

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Premium

NEW YORK (GenomeWeb) – Health information-sharing firm PatientsLikeMe is about six months into a new program called DigitalMe, which departs from the company's initial focus on self-reported health information, attempting now to bridge phenotypic measurements or perceptions of health and disease with a broad variety of genomic and other molecular data.

Essentially a longitudinal registry, the goal of DigitalMe is to link the evolution of patients' experience of wellness and unwellness — and especially the shifts from one to another — with the concurrent evolution of whatever biological minutia the company can get its hands on.

"This has been historically what PatientsLikeMe has always been about, although the focus for many years was in digitizing the experience of health — things like patient reported outcomes, symptoms, and treatments. ... The goal now is to figure out how to take that ... and couple it with a measurement of what is happening inside the body," said Renee Deehan-Kenney, PatientsLikeMe's vice president of biocomputing.

The DigitalMe program, which has consented more than 5,000 individuals so far, involves a baseline blood draw for DNA and RNA sequencing, and a variety of other molecular analyses, including protein assays, measurement of metabolites, and analysis of patients' immune repertoires.

Deehan-Kenney said that the team is also researching additional inclusions like methylation analysis, T- and B-cell sequencing, and microbiome measurements.

To help harmonize and utilize the different analytes that are being assessed, Deehan-Kenney said that DigitalMe is using a tool called Biological Expression Language (BEL), which allows the representation of scientific findings in the life sciences in a computable form.

Currently, the effort is focused on a handful of conditions, which cluster into four therapeutic areas: Neurologic diseases (ALS, Parkinson's, and multiple sclerosis), autoimmune disorders (rheumatoid arthritis and lupus), fatigue disorders (chronic fatigue syndrome and fibromyalgia), and mental health conditions (major depressive disorder, post-traumatic stress, and bipolar disorder).

Since the goal of the program is to track patients' biology longitudinally, additional blood samples are scheduled every four months, and patients are surveyed for their PatientsLikeMe self-reported health status monthly.

Importantly, Deehan-Kenney said, the program also uses algorithms to detect when participants may be experiencing a change in health status — suffering a new symptom, for example, or trying a new drug. Such changes can then prompt added blood sampling outside of the four-month schedule.

Even if the algorithms don't catch anything, patients themselves can also alert the program that they think they are seeing a change that merits a biological recheck. "Participants can flag us, and say 'I'm having a change now,' and if warranted we will go collect another blood draw," Deehan-Kenney explained.

So far, the DigitalMe analyses are free for the subjects that participate, funded by a more-than-\$100 million investment from iCarbonX, whose "Digital Life Alliance" PatientsLikeMe joined last January.

Other companies [in the Alliance](#) include proteomics firm SomaLogic, microbiome therapeutics firm AOBiome, microbiome diagnostics firm General Automation Lab Technologies, health modeling firm (and iCarbonX acquisition) Imagu, recombinant enzyme and cosmetics firm Robustinique, and immune system diagnostics firm HealthTell, which Deehan-Kenney said is conducting the immune repertoire analyses for DigitalMe.

But the company's description of its goals suggests that there might be plans to use the DigitalMe study as it stands now to eventually develop commercial services for a broader customer base. "We want to invest and partner with you, to help make this more affordable and available to everyone in the future," the firm wrote on its website describing the current registry program.

DigitalMe also reflects some of the commercial services that have been launched over the last several years that purport to help individuals optimize their own health. Arivale's [health coaching program](#), for example, offers customers a combination of baseline genomic analyses, close monitoring of various blood biomarkers, and more experimental tracking of things like the microbiome.

Unlike these commercial offerings, DigitalMe participants do not, at least right now, have access to the data or the potential insights gleaned, though the company is working to make that possible.

According to Deehan-Kenney, the task at hand is to make sure that if and when DigitalMe does return findings back to participants, the science behind what it is reporting is solid.

"We want to make sure that the integrity of the science we are doing is iron clad ... and we don't want to do anything that could cause any kind of harm to a patient, so we have to investigate every ethical angle we can," she said.

In the meantime, patients in the program aren't seeing direct benefit to themselves, but that may not be much of a deterrent, at least not to some of the communities that have evolved within the forum of PatientsLikeMe.

Cris Simon, who was diagnosed with ALS several years ago, is a long-time participant in the PatientsLikeMe interface, and said that she joined DigitalMe enthusiastically as soon as she heard about it. "I participate in any clinical trial or study I can," Simon explained, "only because in 75 years ... nothing has been accomplished [for my disease]."

Not everybody in the PatientsLikeMe population is gung-ho to do studies the way she is, she added, but many are, especially among individuals with ALS. "To see a cure, or even a slowing of progression will be a miracle ... [And] I know in my lifetime I'm probably not going to see that ... but at some point, it's going to help somebody," she added.

Meanwhile, that DigitalMe continues the sense of contribution and participation of the larger PatientsLikeMe environment — by incorporating patients' own perceptions of their disease state into how and when biological analyses are done — is both familiar and encouraging to people like Simon.

"I'm fortunately a slow progresser," she said of her own disease. "However, the last six months I've had more [symptoms], and each time something new happens, I let them know. They are watching my biomarkers, so they will be able to look at what is happening during that progression."

When DigitalMe gets to a point where it can return information, Deehan-Kenney said that the types of things reported would start with results that pertain more to individual health behavior — things like diet and exercise.

Although this data is only preliminary, she said that the DigitalMe group has already seen patterns that might lead in this direction.

"One individual had continually elevated C-reactive protein, which is a blood marker for inflammation ... [and] we were able to ... identify a whole collection of blood metabolites that correlated with that," Deehan-Kenney said. "A hypothesis that could now be tested is if some of these have a dietary source, and if you modulate diet, does that cause CRP to decrease."

PatientsLikeMe is a for-profit company and has organized its business around the provision of the patient data it collects to companies developing and selling anything from drugs, devices, and medical equipment to insurance and medical services. So, presumably, the insights that are developed in terms of these types of health and wellness interventions could be funneled into a commercial product of some kind, though the company did not describe any specific partnerships in this vein.

In the longer term, the DigitalMe data will presumably also be attractive for drugmakers, and the ultimate hope for patients like Simon is that the project's longitudinal analyses may lead not only to optimization of health behaviors, but also to new drugs or potentially even curative discoveries.

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