languages do not have words for DNA or gene, which makes it difficult to inform every research participant about the goals and results of genomics research. H3Africa's bioethics consultant Paulina Tindana, who is also Tsey's doctoral advisor at the University of Ghana, stresses that proactive community engagement should be "part of the conceptualization" of every genomics project. One sensitivity in some African communities, Tindana notes, is a reluctance to donate blood for genomic studies. This is an example of the local knowledge genomics researchers should appreciate in order to gain community support, Tindana suggests.

New insights

The collection of data since H3Africa's inception is yielding results, says Rotimi. "We are beginning to identify some genetic variation that could not have been identified in Europeans because they were not there or were not variant enough," he says.

One H3Africa project focuses on chronic kidney disease, which by one estimate affects 16% of Africans[2]. This work has validated the hypothesis that alteration of the *APOL1* gene, which is known to increase kidney disease among African-Americans, has the same effect in Africans. This research compared the genes of 4,000 people with kidney disease with those of 4,000 healthy controls.

Dwoama Adu, a nephrologist at the University of Ghana Medical School, says the next step is to fully understand the biochemical mechanisms through which APOL1 variants cause kidney disease. With that knowledge in hand, it might be possible to develop affordable drug treatments that thwart these biochemical processes. Adu estimates that at least another decade of research will be necessary to achieve this.

Funding from the NIH and the Wellcome Trust for H3Africa will total approximately US$180 million from 2011 to 2021, with all H3Africa projects scheduled to conclude by 2022. H3Africa's leaders are working hard to secure the future financial stability of the effort. Adu, who co-chairs H3Africa's sustainability committee, would like to see a shift from external sources of support to African ones. The top priority is support from African governments, he says, although African philanthropic support is also welcome. "The time has come. We've shown we have the infrastructure and capacity to get support locally," Adu says. ❐

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Published online: 13 January 2020
https://doi.org/10.1038/s41591-019-0704-z

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Tech giants, armed with wearables data, are entrenching in health research

Apple, Google and Samsung are partnering with academic researchers in new ways to leverage data from watches and smartphones.

Marcus A. Banks

We are long past the days when a wristwatch merely offered the time. For example, the latest Apple Watches can now conduct electrocardiograms, alerting wearers to potential arrhythmias. But smartwatches and smartphones track more than just physiological metrics. They also monitor health-related behaviors, such as the number of steps a person takes per day or how many hours of sleep they get each night.

In November 2019, Apple opened enrollment in three health studies designed in partnership with academic researchers, which will draw on data from US owners of its Watches and smartphones. Participants must opt into each study before their data are collected, and their participation requires downloading of a new Research app that Apple built for this purpose.

University of Michigan researchers will track the amount of time over two years that participants' average daily noise exposure (both in-ear and ambient) exceeds the World Health Organization's guideline of a maximum of 70 decibels, and they will seek to understand how this relates to hearing-loss risk. Meanwhile, investigators at Brigham and Women's Hospital will attempt to correlate such measures as people's walking speed and heart rate with their risk of developing atrial fibrillation or heart disease, in a five-year study that hopes to enroll at least 500,000 participants.

The largest and longest study—with a desired enrollment of one million women over ten years—is designed in conjunction with the Harvard T. H. Chan School of Public Health. For this study, researchers plan to use data about the frequency with which women have irregular menstrual cycles to inform screening guidelines for such conditions as polycystic ovary syndrome. Michelle Williams, Dean of the Chan School of Public Health, who leads Apple's women's health study, says the amount and variety of data obtained from smart devices is so vast that it can influence "individual behavior, clinical practice, even policy."

Apple was heavily involved in designing its health studies, according to cardiologist Calum MacRae of Brigham and Women's Hospital, who leads the heart-and-movement study. It is not the company's first foray into health research. In 2017, the company kicked off a project with Stanford Medicine, known as the Apple Heart Study, which sought to see how well its Watch could detect atrial fibrillation. More than 400,000 Apple Watch users across the USA participated in the study. Apple also launched the ResearchKit tool for health researchers to develop studies and connect with users of its devices, although some people voiced concerns about whether these tools ensured adequate patient-informed consent for participation.

Other tech companies have also sought to leverage their wearable products and smartphone devices for big data in the health space. Samsung partially funds a blood-pressure study called My BP Lab at the University of California San Francisco. Participants use their own Samsung device

Credit: d3sign/Getty

with built-in optical sensors—such as the Samsung Note 9 or the Galaxy Watch Active—to record their blood pressure three times a day for three weeks. After the first week, participants start to receive personalized insights about how and when their stress typically manifests physiologically. Wendy Berry Mendes, a psychiatrist leading the study, estimates that 100,000 people have participated since it launched in March 2018.

In the ongoing Breast Cancer Weight Loss Study, funded by the US National Cancer Institute, researchers at the Dana-Farber Cancer Institute are providing Fitbits to more than 3,100 women with stage II or stage III breast cancer. Participants use Fitbits to track their heart rate and weight-loss goals, as lower weight is associated with less risk of breast-cancer recurrence and mortality. Half receive individual coaching to support their weight-loss goals, along with health-promotion advice, while the other half receive only the advice. This study aims to understand if coaching leads to greater weight loss, and thereby less mortality from breast cancer, for the women who receive it compared with those who do not. Lead investigator Jennifer Ligibel, an oncologist at Dana-Farber, anticipates the final results will be available in three or four years.

Deloitte forecasts that the global market for wearable devices that can track behavioral and physiological influences on health will increase from US$4 billion in 2017 to $16 billion in 2022. Notably, in November, Google's parent company Alphabet acquired Fitbit for $2.1 billion, which many analysts saw as a move to become more firmly rooted in the healthcare space.

Reports based on large-scale health data are beginning to appear. Stanford data scientists analyzed 68 million days of walking activity recorded via the Argus smartphone app, for more than 700,000 people worldwide[1]. Researchers found that variations between people in their walking levels (some people may walk for miles every day, while others stay home) were more strongly associated with national obesity rates than was the mean number of steps walked by everyone in a country. One policy implication, researchers suggest, is that making it easier for people to walk may reduce national obesity levels.

Some people cannot afford a smart device, which means their experience will not be recorded in datasets no matter how large these become. This necessarily restricts the utility of findings based on these data to people who are demographically similar to the device owners, suggests epidemiologist Katherine Keyes at the Columbia University Mailman School of Public Health. "People get so excited about high velocity, high volume data," Keyes says, that they may lose sight of this limitation. ❐

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Published online: 13 January 2020
https://doi.org/10.1038/s41591-019-0701-2

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Sizing up big data

Just how big is big data? The numbers may surprise you.

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Big data—as opposed to small data—is too complex and varied to be contained in one spreadsheet or sometimes even in one computer. But while there might be slight differences in what precisely defines 'big data', the one thing everyone can agree on is that there is more of it these days. Here we take a bird's-eye view of how fast it is growing.

1. In 2013, an estimated 153 exabytes of health data were produced worldwide, which was projected to increase to 2,314 exabytes in 2020 (EMC Digital Universe with Research and Analysis by IDC, April 2014).
2. Researchers deposited 4.5 petabytes of data to the US National Cancer Institute's Genomic Data Commons from 2016 to 2017, its first year of existence (National Cancer Institute, June 2017).