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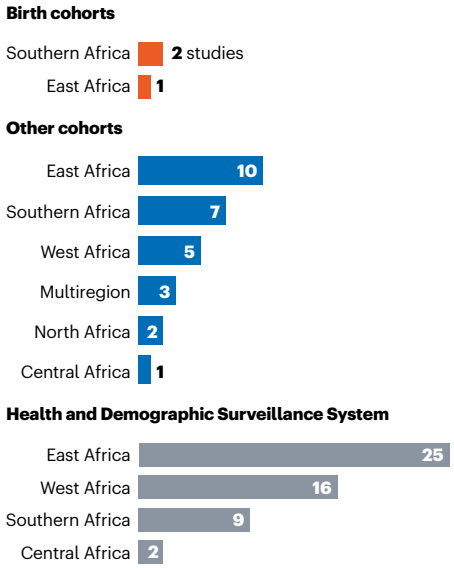
WIDER REACH

The studies brought together by the African Population Cohorts Consortium (APCC) extend across the African continent. The largest can be found in East Africa, where there are 12 studies based around population cohorts and 25 Health and Demographic Surveillance System studies (HDSS) that monitor health in particular communities.



KEY FACTS: APCC

- **Study name:** African Population Cohorts Consortium (APCC).
- **Number of participants:** Brings together 67 African studies, covering around 6 million people.
- **Population being studied:** Populations across the African continent, with a focus on diverse geographic, ethnic and socioeconomic groups, including rural and underserved communities.
- **Data collected:** Data vary by cohort but includes demographic, health, environmental, behavioural and — in some cases — biological and genomic data.
- **Launch year:** Formally initiated in 2020.
- **Duration:** Ongoing initiative building on existing cohort studies, many of which have been running for years or decades.
- **Funding:** Initial funding that culminated in the APCC Blueprint was around £1 million (US$1.35 million), with the bulk coming from the Wellcome Trust and additional contributions from the Gates Foundation and UK Medical Research Council. In 2024, Wellcome awarded £4 million to establish a permanent secretariat and launch the consortium's first initiatives.

to see is a large cohort of African scientists whose careers have been launched through this work," Herbst says. "People who've done their master's projects using cohort data, completed their PhDs within these studies, and gone on to postdocs and beyond."

As well as a way of bringing the science together, collaborating scientists say the APCC acts as a research community, where the cohort researchers and institutions can share results with others in the field, get inspiration on questions to pursue and identify follow-up collaborations and funding opportunities. Herbst adds that the APCC can also "amplify their voices to have policy impact on the continent", for example by pooling results or testing whether findings from one study apply in another region of Africa.

To guide those collaborations and to inform its own future funding calls, the APCC has set out three strategic research programmes: health across the life course, climate and health, and universal health coverage.

Tesfahun Melese, coordinator of the Dabat Research Centre in Gondar, Ethiopia, says being part of the APCC has opened up new opportunities for collaboration and capacity-building. The centre, based at the University of Gondar, runs three HDSS sites in the region, tracking data on indicators such as births, deaths and migration. "Being a member of the APCC, we can disseminate our research and data to the scientific community," he says. "We can collaborate with other HDSS sites, get support for data management and analysis, co-write papers, and apply for grants together. That makes a big difference."

Through connections made at an APCC event, Melese is setting up a partnership with another surveillance site in South Africa to do a study of youth employability, which is in the stages of securing funding from the Mastercard Foundation, a charitable Canadian funder supporting young people in Africa and Indigenous young people in Canada.

The APCC's platforms are set up to make data sharing fairer. Data remain at local institutions, but will be made accessible through systems that allow secure remote analysis. A researcher might design a question that each study site answers. But instead of sharing the full data, each site shares only summary results, protecting participants' privacy and ensuring that each study keeps control over its own data.

"The integration of biological data and metadata will generate a wealth of opportunities to support research questions around the aetiology of disease and its progression over time," says Pelly.

Kamuya, head of the health systems and research ethics department at the KEMRI–Wellcome Trust Research Programme in Kenya, has been working to ensure that consent, governance and data sharing align with the legal and cultural differences across African countries. "This kind of secure data set-up is new for a lot of institutions," says Kamuya. "Sometimes, just walking researchers through what's needed – how to anonymize data, how to phrase consent forms – can be incredibly powerful."

Melese cites this as an important element for his cohort study. "Almost all HDSS sites in Ethiopia face challenges with data management," he says. "Through APCC, we're having discussions to strengthen these systems."

A self-assessment tool is already being used to identify where support is needed, such as how to use the right language to get consent or how to prepare data for sharing. Some projects are highly experienced; others need more help or resources.

By 2050, one in four people globally will live in Africa. The APCC wants African science to be at the front of understanding and improving health, says Herbst. "Most research is done in Europe or the US, so it might not reflect the interests of Ethiopia or Africa," says Melese. "Having the APCC can help focus on studies that are useful for African populations. It shows Africa can generate knowledge and discoveries."

"This is where we need to look for the talent and energy to tackle some of the world's most intractable health challenges," Herbst says. "The talent and capability we're building through the APCC will make a global contribution in the years ahead."

SOURCE: RAMSEY, M., CRAMPIN, A. C., BAWAH, A. A., GITAU, E. & HERBST, K. *ANNU. REV. BIOMED. DATA SCI.* 7, 277–294 (2024).

Fixing the imbalance in cancer rates between Black and white women

VOICES of Black Women

When epidemiologist Lauren McCullough began working in cancer research in the United States, she was struck by a glaring omission in population-level studies. "When thinking about large-scale cancer studies, one of the groups that have been left behind have been Black women," she says. "That's despite the fact that Black women are more likely to get an aggressive disease and, with very few exceptions, are more likely to die of their cancer."

Now, McCullough, visiting scientific director at the American Cancer Society (ACS), is leading a research effort to help change that. The VOICES of Black Women study aims to enrol 100,000 Black women aged 25–55 with no prior history of cancer. The longitudinal study, which launched in 2024, will follow participants for at least 30 years, capturing a range of data on health, lifestyle and lived experience to reach a depth and scale not seen before for this

population, say those involved.

For McCullough and Alpa Patel, co-investigator on the study and senior vice-president of population science at the ACS, researchers on the team had to be more than just experts. They wanted people who "really had the passion for the topic and were committed to ensuring the study was going to be designed and executed in a way that we all felt really proud of", McCullough says.

The VOICES team hope the data will begin to clarify what is behind disparities in cancer risk for Black women in the United States. They are around 40% more likely to die from breast cancer than white women, for example, despite having lower incidence rates. According to the ACS, Black women have a 12% higher overall cancer death rate than white women.

Initially spanning the 20 US states with the largest populations of Black women, the study now recruits nationwide, working in partnership with a network of hospitals, community organizations and health centres.

The VOICES team wants to look beyond the biological data typical of a standard longitudinal study – such as genetics, diet or medical history – to capture some of the potential social drivers of health. "Something that was really missing when I emerged from my training was understanding how the social aspects impact cancer," McCullough says. "How do social elements above the skin impact the biology below the skin?" To that end, the study asks participants about factors such as their experiences of racism, access to quality health care and what social support they receive.

This information is collected through a 60-minute baseline survey and shorter follow-ups, in which participants are asked about day-to-day discrimination and economic stressors. "A lot of the existing data are at the area level, like residential racial segregation, but that doesn't really capture the specific insults an individual might experience," McCullough says. By capturing individual experiences, the team hopes to uncover how these cumulative exposures interact with biological processes to influence cancer risk.

This is important, McCullough says, because "the data among Black women doesn't match our ideas about how socioeconomics should lead to better health outcomes. In fact, some of the greatest health disparities are among Black women with higher levels of socioeconomic status." Recent studies have shown that racism-related stress contributes to persistent health gaps between Black and white women by disrupting cortisol patterns, as demonstrated in a 2024 study[1] published in *Scientific Reports*, and by activating cellular stress-response pathways linked to aggressive breast cancer, according to research from the Duke Cancer Institute in Durham, North Carolina[2]. The VOICES study also includes biological sampling. Participants can voluntarily provide blood samples and undergo height, weight, waist and blood-pressure measurements. These will help researchers investigate the role of ancestry, hormones, inflammation, infections and genetic mutations in cancer development.

"My goal is to leave behind a resource that will improve health for this demographic, and help emerging scientists to study it in a robust way."

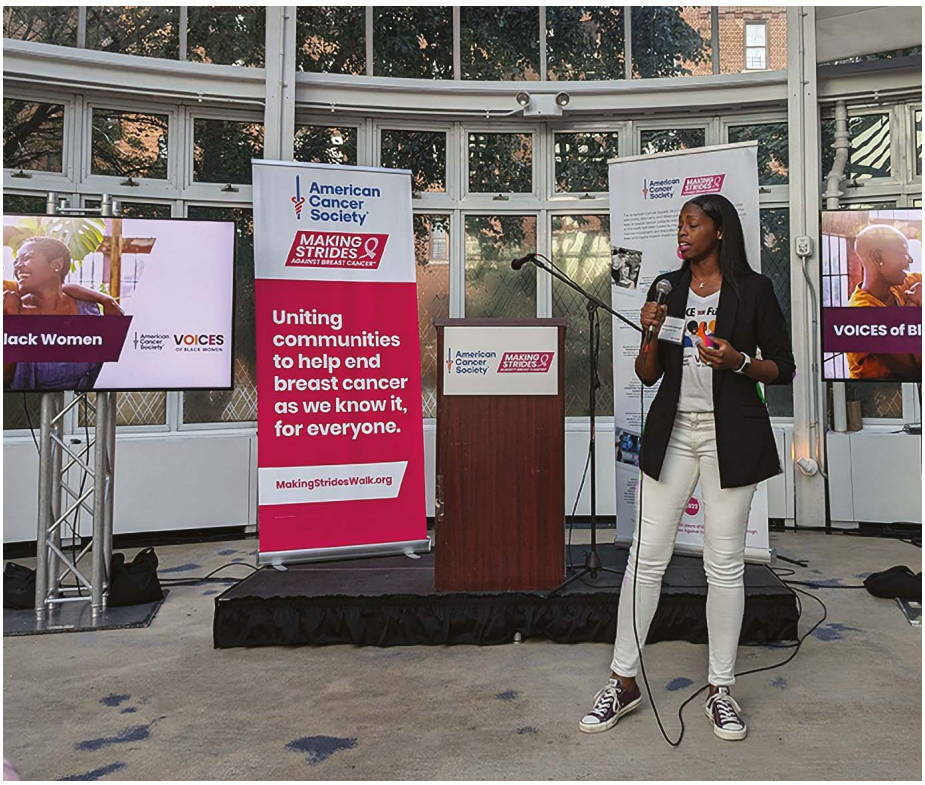
"In five years or so, I think we will better understand the various exposures that might differentially impact Black women," says McCullough. For example, it could lead to better regulation of products frequently used by Black women, such as chemical hair relaxers, which were linked to an increased risk of uterine cancer by a 2023 study[3].

Enrolled participants, who so far number almost 4,000, will receive regular follow-ups – two 30-minute surveys per year – with the hope this will build trust. McCullough says early feedback suggests participants feel their experiences are well represented.

"It takes a different level of comfort and trust to join a study. So, I am always grateful for every single person that joins," she says.

The study's design deliberately incorporates cultural and social understanding, recognizing that Black women have been subject to historical injustices in medical research. Despite racial disparities in breast cancer mortality, Black women remain under-represented in clinical trials, a 2022 review[4] found. As the ACS notes, Black women's bodies have been exploited to advance science without equitable benefit. In the 1840s, for example, James Marion Sims developed a revolutionary gynaecological procedure by practising on enslaved Black women. In 1951, Henrietta Lacks's tumour cells were taken without consent, and used to create the HeLa cell line, which revolutionized biomedical research. Her family was unaware and uncompensated for decades. VOICES sets out to confront that legacy directly. "Our team is focused on ensuring that we've built a study that is unbiased and inclusive of all aspects of health, through a multidisciplinary lens," says McCullough.

Monica Peek, a clinical researcher at the University of Chicago, who studies health-care disparities, says studies such as VOICES are important because social drivers account for



COURTESY OF LAUREN MCCULLOUGH

Epidemiologist Lauren McCullough is leading the VOICES of Black Women study.

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the majority of health outcomes. "It is critical that we continue to deepen our understanding of the mechanisms by which these factors influence health, particularly for populations that have disproportionate burdens of disease," she says. "There is growing evidence that chronic exposure to the toxic effects of discrimination and poverty can affect the biological systems that fight disease."

Such research is taking place in an increasingly fraught political landscape. Since returning to office this year, President Donald Trump has taken a series of actions to roll back diversity, equity and inclusion (DEI) efforts across the federal government. These have included an executive order targeting DEI programmes, threats to withdraw medical research funding from institutions with diversity policies, and calls to revoke accreditation for universities promoting such initiatives. Several DEI-related research programmes funded by the National Institutes of Health (NIH) have already lost grants or seen reductions.

The VOICES study is solely supported by the ACS, a non-profit organization that receives almost all of its income from private donations and fundraising. This independence might become increasingly important support for studies that tackle racial disparities in medicine, such as VOICES. "There is so much work to be done — and that's why the continuation of funding of research on racial equity is important to the health of many Americans," says Peek.

McCullough is focused on the long view. "Eventually, we will be able to look at associations with factors that are related to cancer, for example obesity or precancerous conditions, which can inform screening and public policy," she says. "Long-term, my goal is that we actually are able to give insight to why Black women are getting more aggressive cancers and create new prevention messages."

Although McCullough might not be at the helm for the next 30 years, she's always planning for the future. "I don't anticipate that I'll be around to really see the full maturity of the study, but I know the study will be in good hands," she says. "My goal is just to leave behind a resource that not only will improve health for this demographic", but also help emerging scientists to "study this population in a robust way".

Singapore's rich diversity is ideal for Asian health study

Health for Life in Singapore

When John Chambers first shared his genetic studies on Asian populations in London two decades ago, they were scientifically accepted but the international response was muted. "They weren't always taken seriously," Chambers, a cardiovascular epidemiologist recalls, "partly because they focused on a small migrant group in London. And that's not where most Asians live."

One of those early studies, published in 2014[5], analysed the full genetic sequence of more than 300 South Asians and revealed millions of previously undocumented genetic variants. It helped show why South Asians are more vulnerable to conditions such as diabetes and heart disease. However, it had become clear to Chambers, who was based at Imperial College London at the time, that the research needed to be rooted in Asia, to fully capture the region's cultural, behavioural and genetic diversity.

In 2015 he got a call from James Best, then the dean of the Lee Kong Chian School of Medicine at Nanyang Technological University (NTU) in Singapore, which was at the beginning of a collaboration with Imperial and Singapore's National Healthcare Group to create a state-of-the-art cohort study. Best wanted Chambers involved as one of the six principal investigators.

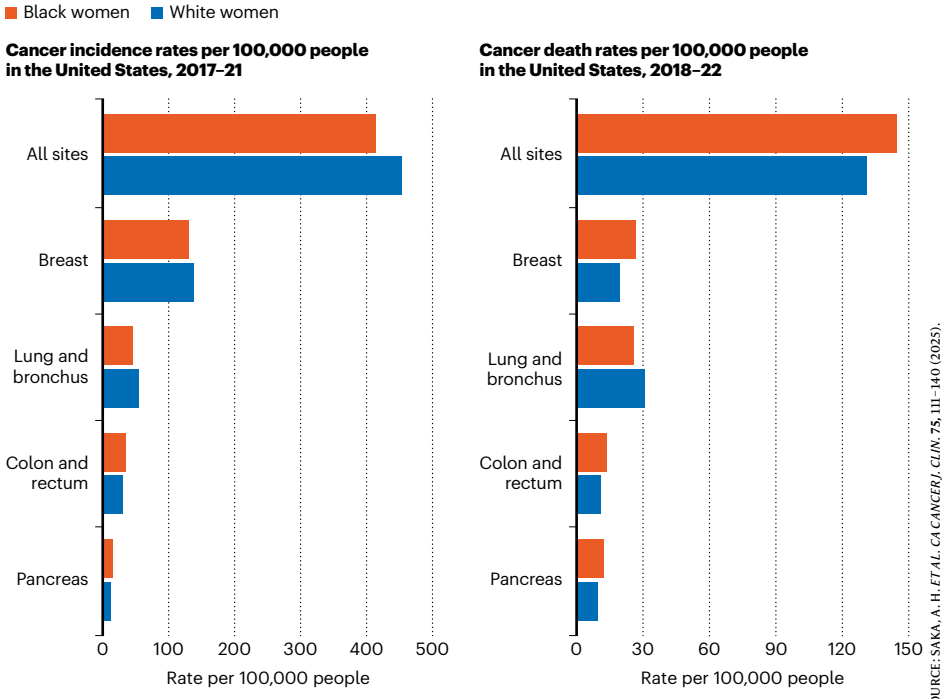
It marked the start of an ambitious longitudinal population cohort study called Health for Life in Singapore (HELIOS). Since it began in 2018, HELIOS has recruited 10,004 people across Singapore's three main ethnic groups

KEY FACTS: VOICES

- **Study name:** VOICES of Black Women.
- **Lead institution:** American Cancer Society (ACS).
- **Principal investigators:** Lauren McCullough, visiting scientific director at the ACS, and Alpa Patel, senior vice-president of population science at the ACS.
- **Participant goal:** 100,000 Black women aged 25–55, cancer-free at enrolment.
- **Current participant numbers:** 4,850
- **Data collected:** Online surveys (60 minutes at baseline, two 30-minute follow-ups per year) covering health behaviours, discrimination, social support, economic stress and personal care product use; optional blood samples; anthropometric and biometric data (such as height, weight, blood pressure).
- **Launch year:** Pilot 2023, official launch 2024.
- **Duration:** At least 30 years.
- **Funding:** Solely funded by the American Cancer Society.

VARYING IMPACT

Cancer mortality rates in the United States are higher for Black women despite the incidence rate for the same group being lower than for white women. The disparity is particularly stark for breast cancer, a disease that Black women are around 40% more likely to die from compared with white women.



Note: Exclusive of Hispanic ethnicity. Rates are per 100,000 and age adjusted to the 2000 US standard population.

SOURCE: SAKA, A. H. *ET AL. CA CANCER J. CLIN.* **75**, 111–140 (2025).