The big picture

These long-term programmes seek to improve medical understanding of underserved populations from around the world. **By Anna McKie**

Longitudinal studies — which follow individuals to collect data about health, lifestyle and environment over a period of months, years or even decades — have helped researchers understand disease risk, inform prevention strategies and improve public health planning. They've often provided crucial evidence for tackling major health issues, ranging from smoking and heart disease, to cancer screening and dementia. But the majority of large-scale longitudinal research has historically taken place in Europe or North America, meaning many populations remain under-represented in the data that shape health science and policy.

As of June 2021, more than 80% of genomic data used in research have come from people of European descent, with the rest made up of East Asian (5.9%), African (1.1%), South Asian (0.8%) and Hispanic/Latino (0.1%). And a 2023 World Health Organization report noted that nearly 60% of African countries lack strong systems for collecting and using health data.

That matters, because findings from one population don't always apply neatly to another. Genetics, diet, environment, access to health care, and social and economic conditions all influence how diseases develop and how interventions perform.

A new generation of longitudinal studies is aiming to better reflect population diversity — not just by recruiting from underserved groups, but by embedding community involvement, local scientific leadership and context-specific questions into their design. These studies are not simply collecting data; they are also investing in infrastructure, governance and training. This series profiles three of those efforts.

Uniting Africa's many longitudinal studies

African Population Cohorts Consortium

In March 2020, just before borders closed and labs were shuttered by the COVID-19 pandemic, around 100 scientists gathered in Kampala to discuss forming a pan-African research consortium. Their idea: what if Africa's many longitudinal population studies — some of which have been running for decades — could be brought together?

Although Africa is home to more than 1.5 billion people and has some of the world's most pressing health challenges, those at the meeting felt the reach and impact of its population studies were less powerful than they could be.

That meeting marked the beginning of the African Population Cohorts Consortium (APCC), an initiative designed to connect and strengthen large-scale longitudinal studies across the continent. The 60-plus studies within the consortium, from 16 countries, have already contributed to important evidence-based health-care policies — from the first measles vaccine trials in Senegal to the roll out of malaria bed nets in The Gambia — but until now, they've remained largely siloed.

> **"Sometimes just walking researchers through how to anonymize data, how to phrase consent forms, can be incredibly powerful."**

"Many cohorts have contributed a great deal to science, but their potential is far from fully realized," says Kobus Herbst, interim steering committee co-chair and director of population health at the Africa Health Research Institute, based in Durban, South Africa.

The consortium was supported in its early stages by charitable funders the Wellcome Trust, based in London, and the Gates Foundation, based in Seattle, Washington, as well as the UK Medical Research Council. In 2024, Wellcome awarded £4 million (US$5.37 million) to establish a permanent secretariat, hosted by the Science for Africa (SFA) Foundation in Nairobi, and to launch the consortium's first initiatives.

"Wellcome has a long history of supporting health-data platforms such as longitudinal population studies," says Victoria Pelly, a senior research manager at Wellcome. "Although we fund some in lower- and middle-income countries, a lot of the large-scale studies are still based in high-income countries." Wellcome's support for the APCC was driven "by a recognition that there's a wealth of research capacity and context-specific data on the African continent that's underutilized", she adds.

The APCC's blueprint, which sets out its goals, governance structures and priorities, was developed by a team led by Herbst and Evelyn Gitau, chief scientific officer at the SFA Foundation, and has been endorsed by the teams and institutions running the studies.

Each cohort study has a seat on a members council, which elects the steering committee. A separate participant forum makes sure that communities involved in the cohorts have a role in shaping research priorities. Delegates from each cohort meet to share views on the research planned and how it's carried out.

Dorcas Kamuya, another co-chair of the interim steering committee, is keen to emphasize the importance of the participant forum as a way of directing the research. "We're creating a platform informed by values we hold dear — friendship, reciprocity, togetherness," she says. "It's essential we don't undermine them as we build systems."

The APCC has already actively engaged 67 existing studies, which together represent data from around 6 million participants. Most are Health and Demographic Surveillance System (HDSS) studies — long-running observations that track births, deaths and migrations in certain communities to monitor population health over time. Others include birth cohorts that follow children from infancy, genomic studies looking at genetic and environmental risk factors, and platforms that host clinical trials in everyday settings.

Many of these studies operate in under-resourced settings. According to the World Health Organization (WHO), 64% of countries in Africa lack the capacity to accurately count and register births and deaths. Health data availability and quality remain insufficient in many countries in the region, it says. "These cohorts provide ideal environments to engage with communities, involve them in the science, and build capacity of young data scientists and epidemiologists in Africa," says Herbst.

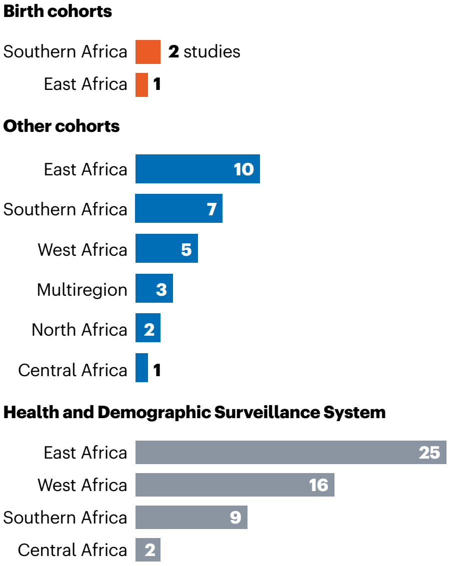
That's another goal of the APCC creators: to expand opportunities for African researchers. "One of the things I hope

MALAWI EPIDEMIOLOGY AND INTERVENTION RESEARCH UNIT

A medical researcher gathers information as part of a Health and Demographic Surveillance System in northern Malawi.

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.



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

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."

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