



... to unite population cohorts across Africa, to harness the continent's diversity and research capabilities and to promote scientific breakthroughs ...



# A BLUEPRINT FOR AN AFRICAN POPULATION COHORTS CONSORTIUM



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# Executive Summary

The African continent is faced with a complex health crisis, marked by a confluence of infectious diseases and a surge in non-communicable diseases (NCDs) leading to chronic illnesses against a backdrop of inadequate health and social system performance. The African Population Cohorts Consortium (APCC) is an exciting new initiative bringing African scientists together to strengthen and promote excellence in cohort-based research on the continent. The overarching aim is to improve the health and wellbeing of populations across the African continent, deploying robust and innovative methods, and improve the health and social systems that serve them.

*... to unite population cohorts across Africa to harness the continent's diversity and research capabilities to promote scientific breakthroughs, build the African evidence base ...*



The vision and mission of the APCC is to unite population cohorts across Africa to harness the continent's diversity and research capabilities to promote scientific breakthroughs, build the African evidence base, and strengthen policy and practice towards attaining equitable universal health coverage. This strategic shift in health and research priorities will be achieved through a collaborative and multi-disciplinary effort underpinned by integrated data systems to leverage the more than eighty population cohorts in Africa for a whole population approach.

The journey to establish the APCC started in March 2020 with a meeting in Uganda and is now culminating in this detailed blueprint, providing a framework, approach, content and structure for the Consortium. It is the result of thorough consultation with a wide range of scientists and leaders of research institutions, thinktanks and universities, along with a variety of government organisations, policy makers, non-governmental and community-oriented organisations, and other stakeholders.

Population cohorts, many of which follow individuals from birth to death, and all of which seek to collect unbiased data irrespective of access or engagement with the formal healthcare system, are an excellent tool with which to gather data on health dynamics. Population cohort-based research seeks to answer vital context specific and policy related research questions at scale. The APCC brings African cohort leaders and researchers together so that they can network, share best practice, identify and use new technologies and achieve a step-change in sharing and harmonising data and analysis approaches to examine the complexity and regional heterogeneity of health outcomes and determinants. This approach would enhance health research and more effectively inform public health policy.

The APCC has identified three synergistic and strategic research programmes that are distinct in their primary focus yet share common goals and access to the common APCC research infrastructure:

- 1 Health and Wellbeing Across the Lifespan** aims to leverage longitudinal cohort data to gain insights into the multifactorial determinants of health and disease across different life stages and generations. This programme focuses on understanding the complex interactions between genetic, environmental, and socio-economic factors, including the impact of climate change, and complements the Climate and Health programme objectives. By identifying risk factors and biomarkers for diseases prevalent in African cohorts, this programme contributes to the development of targeted interventions and policies that can improve health outcomes and support the achievement of UHC.
- 2 The Climate and Health** programme emphasises the critical need to understand and mitigate the health impacts of climate change in Africa. It focuses on developing context-specific early warning systems, strengthening health system resilience against extreme weather events (EWEs), evaluating climate-sensitive physical and mental health outcomes, consequent economic and livelihood impact, and enhancing climate data collection. This programme's objectives are inherently linked to the broader goals of improving health and wellbeing across the lifespan and achieving universal health coverage by addressing the environmental determinants of health and ensuring health systems are prepared to respond to climate-related health challenges.



*... central to the work of the APCC will be fostering engagement, collaboration, and innovation with stakeholders within academic, research and regional network ...*

- 3 Leveraging Population Cohorts to Enhance Progress towards Universal Health Coverage** focuses on utilising population health cohorts to monitor and improve access to quality healthcare services, financial risk protection, and health system performance. This programme's emphasis on collecting granular, context-specific data at regular intervals aligns with the objectives of the other two programmes by providing a robust evidence-based policy and intervention development. The data collected through this programme will inform targeted strategies to address climate-sensitive health outcomes and support health and wellbeing across the lifespan, thereby contributing to the overarching goal of achieving UHC and making health care systems more responsive to the needs of the population.

Capitalising on the expertise of leaders in the field, the APCC will facilitate the development of harmonised cohort methodologies that enhance individual cohort outcomes and the effectiveness of multi-cohort research. This includes the development and use of a common cohort data model, the establishment of trusted research environments to promote data use, and the strengthening of guiding ethical principles to safeguard and involve cohort participants while enabling multi-cohort research.

Capacity building and training of cohort members of the APCC will be embedded within the development of cohort methodologies to enhance research and technical skillsets as well as organisational management skills.

Some collaborative studies within the APCC will include collection of biological samples and their processing and sharing, including associated data, across different institutions and with APCC. To facilitate this, an APCC biobanking network will be established.

Central to the work of the APCC will be fostering engagement, collaboration, and innovation with stakeholders within academic, research and regional networks.

### **Governance and organisation:**

The membership of the APCC comprises the population cohorts that align with the APCC Membership criteria. Each full member cohort of the APCC is eligible to nominate one delegate to the Members Council. The APCC hosts an in-person annual meeting that provides an opportunity for APCC members including associated scientists and stakeholders to connect, share ideas, build relationships, foster multi-cohort initiatives and present their research.

The APCC operates under the guidance of its Steering Committee selected by the Members Council. Day-to-day operations are the responsibility of the Secretariat situated in a well-respected Host Organisation. An Advisory Council of external experts provides guidance to the APCC executive.

Funding for the formative phase has been provided by the Wellcome Trust, Bill & Melinda Gates Foundation, and UKRI Medical Research Council. We intend to expand this funding base to support the establishment and implementation of the APCC.

## INTRODUCTION

# The APCC blueprint

The African Population Cohorts Consortium (APCC) is an exciting initiative bringing African scientists and researchers together to strengthen and promote cohort-based research on the Continent. The journey to establish the APCC started with a meeting in Uganda in March 2020 when the scientists and funders present agreed to establish a research population data platform to address the Continent's most pressing health and socioeconomic needs. In October 2022 the Collaboration for the Establishment of the African Population Cohorts Consortium (CE-APCC) commenced work, funded by the Wellcome Trust, Bill & Melinda Gates Foundation, and UKRI Medical Research Council. See Appendix 1 for detail on how the APCC Blueprint was developed.



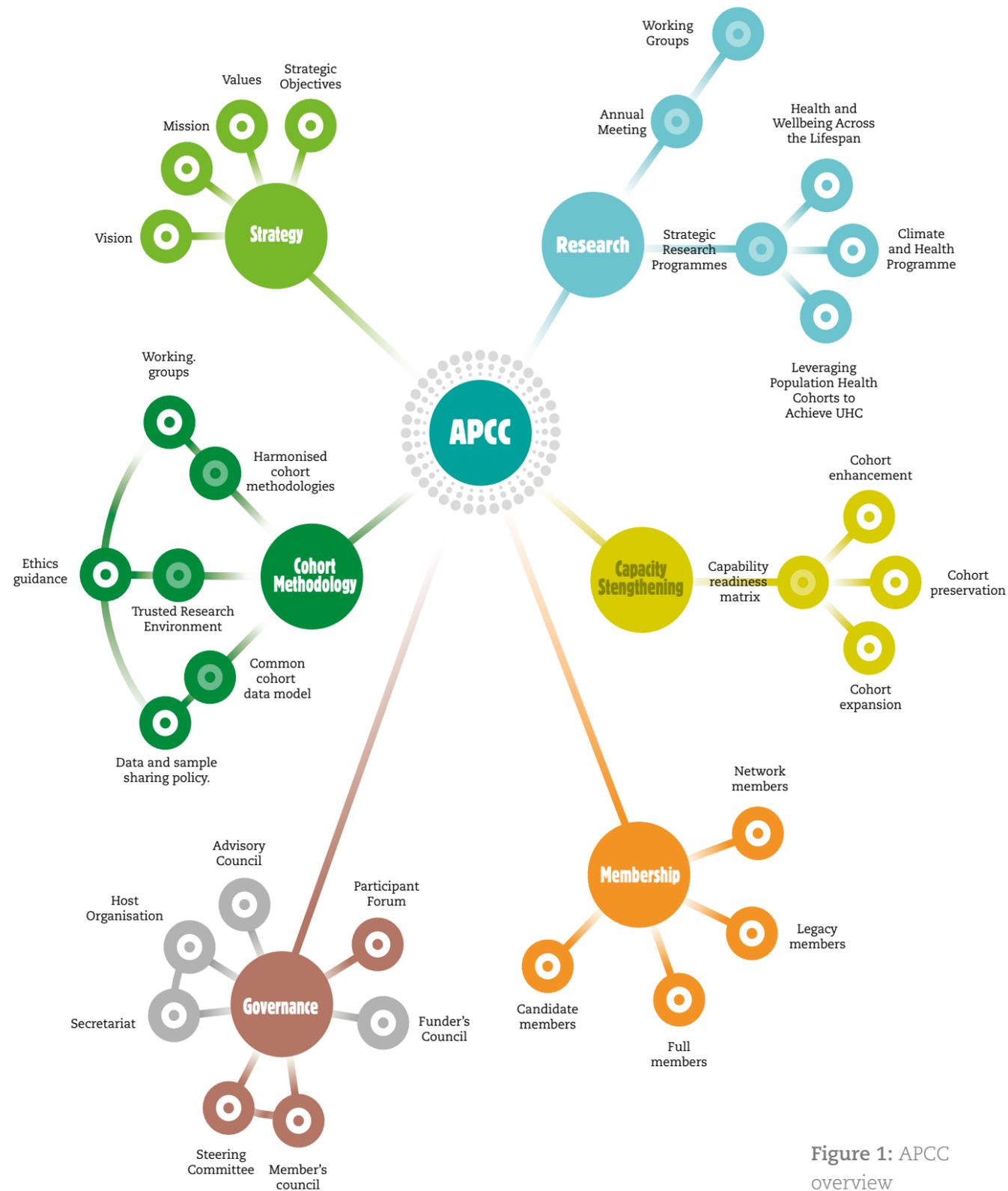


Figure 1: APCC overview

The CE-APCC did the scoping work and engaged extensively with various stakeholders, including the existing population cohorts in Africa, to develop the current APCC Blueprint.

The APCC unites population cohorts in Africa to leverage the Continent's diversity and scientific capacity in pursuit of a common Vision – the sustainable development of African populations towards good health and wellbeing. The APCC's Mission is to bring population cohorts in Africa together to harness research capabilities to facilitate scientific breakthroughs, build the African evidence base, and thereby strengthen policy and practice towards attaining equitable universal health coverage.

The APCC operates under the guidance of the Steering Committee selected by the Members Council. The membership of the APCC is made up of the population cohorts that comply with the APCC Membership criteria. Day-to-day operations are the responsibility of the Secretariat situated in a Host Organisation.

The interests of APCC funders are represented by a Funders Council, and an Advisory Council of external experts provides guidance to the APCC executive.

The primary functions of the APCC are:

- Promote population cohort-based research among cohort scientists and the broader scientific community to answer relevant context-specific and policy-related research questions at scale, bolstered by strategic research programmes.
- Develop and implement common methodologies, guidelines, and data models that will enhance individual cohort outcomes and the effectiveness of multi-cohort research. This step change in research and analysis will contribute well-curated, population-based data and metadata to the African and global scientific community in support of creative policy development, implementation, and evaluation.
- Strengthen the capacity of the population cohorts in Africa to contribute groundbreaking and high impact science within the continent. This also involves preserving vital cohort resources and expanding the reach of population cohorts to regions or population groups currently underrepresented in the APCC. By doing so, we aim to fully harness the continent's diversity.

The three strategic programme initiatives of the APCC are:

- 1 Health and Wellbeing Across the Lifespan
- 2 Climate and Health
- 3 Leveraging Population Cohorts to Enhance Progress towards Universal Health Coverage (UHC)

The APCC engages with stakeholders and cohort participants on a continuous and structured basis as reflected in its Value Propositions.

PART 1

# APCC Strategy



## Vision

The vision of the APCC is the sustainable development of African populations towards good health and wellbeing.

## Mission

The mission of the APCC is to enhance African population cohorts through a consortium to harness the continent's unique diversity and research capabilities, thereby facilitating scientific breakthroughs, building the African evidence base, and strengthening policy and practice towards attaining equitable universal health coverage.



*... uphold ethical research practices and fair and respectful collaboration in all our activities, balancing between individual cohort goals and the collective interests of the consortium ...*

## Values

- 1 Equity:** We foster inclusive participation and equitable collaboration among diverse stakeholders such as researchers, policymakers, and cohort members. We do so by utilising participatory approaches to ensure fair representation and access to resources and benefits in decision-making processes.
- 2 Transparency:** The APCC is committed to transparency in decision-making, resource allocation, and research to ensure data sharing, accountability, and adherence to policies and procedures.
- 3 Innovation:** We are inquisitive in our pursuit of scientific discovery and continuous improvements and innovation in research methods to align with or improve international best practices.
- 4 Integrity:** We uphold ethical research practices and fair and respectful collaboration in all our activities, balancing between individual cohort goals and the collective interests of the consortium.
- 5 Sustainability:** We aim to develop and implement sustainable research strategies through diversified funding, collaborative partnerships, and mindful resource utilisation. We prioritise sustainable socio-environmental impacts and the long-term viability of cohorts and the consortium.
- 6 Inclusivity:** We listen to all voices and intentionally pay attention to the least listened-to voices. We nurture, grow, and provide opportunities for young African scientific leaders of the future. We take care to reflect the full diversity of the African continent in our work.

## Strategic Objectives

These strategic objectives guide the APCC's efforts in harnessing the unique strengths of African populations and research capabilities towards achieving its vision of fostering sustainable development and promoting good health and wellbeing for all.

- 1 Facilitate Scientific Breakthroughs:** Support and conduct cutting-edge research to achieve significant scientific advancements that address critical health challenges. Specific formulation: *“By 2030 initiate at least 15 multi-cohort cutting-edge research projects directly addressing key health challenges faced by African populations and resulting in at least 150 peer review papers and five actionable health interventions.”*
- 2 Strengthen Research Infrastructure:** Develop and enhance cohort research capacities, partnerships, and infrastructures within African populations and across the global community. Specific formulation: *“Expand our cohort research capacity by developing 10 new partnerships and upgrading existing research infrastructure by the end of 2030, enhancing our collaborative capabilities and operational efficiency within African populations and globally.”*
- 3 Support Sustainable Development Goals (SDGs):** Align activities and initiatives with the United Nations SDGs to ensure a holistic approach to sustainable development. Specific formulation: *“Integrate the United Nations SDGs into all our project frameworks by the end of 2025, ensuring all our activities and initiatives contribute directly to at least one SDG, thereby promoting a holistic approach to sustainable development.”*
- 4 Cultivate Collaborative Networks:** Establish and nurture strategic partnerships with global and local entities, including academic institutions, governments, and non-government organisations, to enhance research impact and resource mobilisation. Specific formulation: *“Formulate and solidify 15 strategic partnerships with both global and local entities, including academic, government, and non-government organisations by 2030, aiming to amplify research impact and improve resource mobilisation.”*
- 5 Champion Inclusive Participation:** Involve a wide range of stakeholders, including cohort participants, in research and decision-making processes, ensuring fair representation and access to benefits, to foster inclusive and equitable collaboration. Specific formulation: *“Engage with a diverse group of stakeholders to ensure all our projects by 2025 incorporate inputs from across the spectrum, including underrepresented communities, to guarantee fair representation and equitable access to research benefits.”*

PART 2

# APCC Research

## Introduction

The robustness of health systems and their adaptability to new and existing health threats are central to the African continent's ability to ensure sustainable development toward good health and wellbeing for its population. Population cohorts, which follow individuals from birth to death and collect unbiased data irrespective of access or engagement with the formal healthcare system, are an essential tool with which to comprehend these health dynamics and offer significant benefits over standard research approaches to enhance health research and inform public health policy.



The African continent is currently facing a complex and multifaceted health crisis, this syndemic (1) is marked by the confluence of infectious diseases, a surge in non-communicable diseases (NCDs), and chronic illnesses (2), including common mental health disorders, all against a backdrop of inadequate health system infrastructure (3). This situation is further exacerbated by the persistently high incidence of HIV (4), stalled progress towards malaria eradication (5) globally with some countries reporting an increasing number of malaria cases and deaths, the emergence of other infectious diseases driven by climate change (6), and the effects of urbanisation and destruction of natural habitats (7) (8). The repeated outbreaks of diseases such as COVID-19, Ebola, and Yellow Fever have not only strained the already fragile health systems but have also highlighted the urgent need for a robust and responsive health infrastructure capable of addressing both existing and emerging health challenges (9).

The shifting epidemiological landscape in Africa is a clear indication that the continent's health and research priorities need to be realigned to better understand and tackle these evolving health challenges. This requires a comprehensive approach that not only focuses on the immediate health concerns but also considers the broader socio-economic and environmental factors contributing to these health outcomes. The availability and interrelation of social, health, and environmental data is crucial in this regard as it provides a holistic view of the factors influencing health and wellbeing across the continent.

To effectively respond to these challenges, policymakers must leverage data systems that adopt a whole population approach. Such systems should be capable of integrating diverse data sources, including social determinants of health, environmental changes, and health outcomes, to provide a comprehensive understanding of the health landscape. This integrated approach is essential for identifying vulnerable populations, understanding the root causes of health disparities, and developing targeted interventions addressing the multifaceted nature of health challenges in Africa.

The development and implementation of these data systems require a concerted effort from various stakeholders, including governments, international organisations, research institutions, and the private sector. Collaboration across these entities is vital for pooling resources, sharing knowledge, and fostering innovation in health data management and analysis. By working together, these stakeholders can build resilient health systems that are better equipped to manage current health issues and anticipate future challenges.

The African continent's ability to improve wellbeing and longevity amidst its unprecedented health challenges hinges on a strategic shift in health and research priorities. Understanding the shifting epidemiology and health system priorities through the lens of integrated data systems is paramount. Such systems, underpinned by a whole population approach, are critical for enabling policymakers to make informed decisions, implement effective interventions, and ultimately, improve the health of all Africans. This requires a collaborative and multi-sectoral effort to harness the power of data for health system strengthening and disease prevention, ensuring a healthier future for the continent.

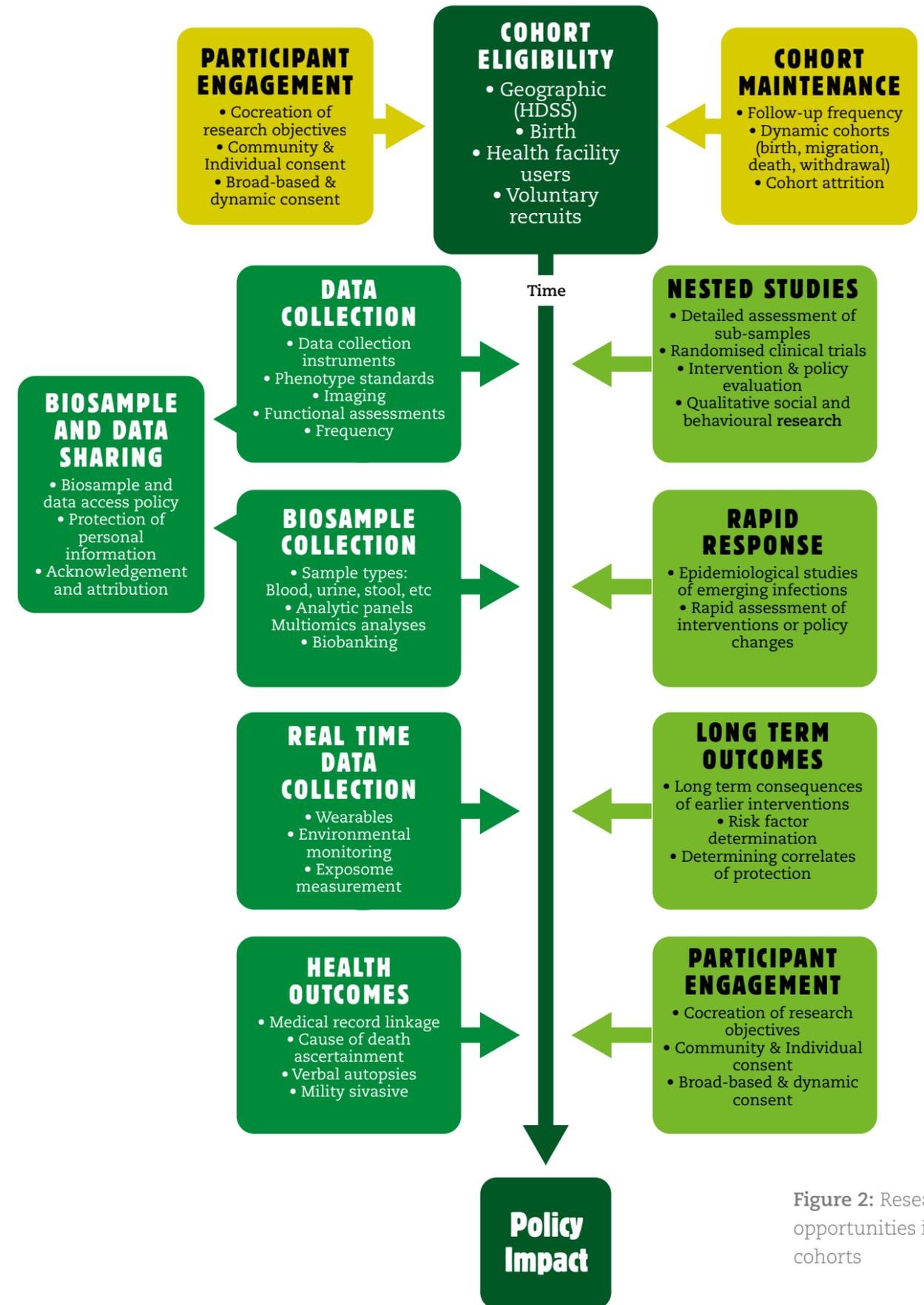


Figure 2: Research opportunities in cohorts

## Case Study • Developing an Ethical Framework for Health

Health and Demographic Surveillance Systems (HDSS) are interim sources of health-related data in Africa, Asia and Oceania, where many countries lack well-functioning vital registration systems and health information systems. HDSS occupy a grey area between research and practice, which makes it difficult to determine the relevance of traditional ethics guidance that often relies on a research-practice distinction. There is limited empirical evidence on ethical issues in HDSS, but the potential social value of longitudinal data from HDSS is thought to outweigh potential burdens.

This case study<sup>1</sup> draws on empirical research conducted across seven HDSS sites in sub-Saharan Africa to outline ethical considerations for HDSS. HDSS ethics practices and application of traditional ethics guidance, which tend to focus on informed consent and data sharing for research which can potentially restrict the research benefits of HDSS. The most prominent anticipated benefit is the aspiration that HDSS can generate data for research, public health responses and policymaking. Participants also described employment and infrastructural development as potential benefits of HDSS. The research



## and Demographic Surveillance Systems

identified the risk of defining HDSS too narrowly and a disproportionate distribution of benefits and burdens among HDSS stakeholders. This case study also highlights the need for a HDSS-specific ethical framework that aligns with the real-world functioning and ethical considerations in HDSS.

A second study<sup>2</sup> looked at the value of HDSS data highlighted by the COVID-19 pandemic. We conducted a qualitative study across seven HDSS sites in sub-Saharan Africa to map out key ethical issues for HDSS and assess the relevance of current health research and public health ethics guidance in relation to HDSS. A key emerging issue was fairness in the overall balance of benefits and burdens to residents and front-line staff, particularly given the socio-economic contexts in which HDSS are generally conducted. Ethics oversight for HDSS in sub-Saharan Africa should prioritise considerations around fairness (considering structural inequities evident in HDSS settings), cost-effectiveness, ancillary care responsibilities, longitudinality and obligations of the global community to HDSS residents.

- 1 Hinga AN, Molyneux S, Marsh V. Towards an appropriate ethics framework for Health and Demographic Surveillance Systems (HDSS): Learning from issues faced in diverse HDSS in sub-Saharan Africa. *BMJ Glob Heal.* 2021;6(1):1–2.
- 2 Citation: Hinga AN, Molyneux S, Marsh V. Towards an appropriate ethics framework for Health and Demographic Surveillance Systems (HDSS): Learning from issues faced in diverse HDSS in sub-Saharan Africa. *BMJ Glob Heal.* 2021;6(1):1–2.

The core features of longitudinal population cohorts are to observe the entire population and to measure changes over time, document the sequence of events, and use repeated measurements to understand the impact of exposures, and/or interventions (Figure 2). This temporal dimension is crucial for unravelling causality in multifactorial health determinants. In Africa, where highly morbid infectious diseases coexist with a growing burden of non-communicable diseases, health systems also need to cope with the consequences of climate change. Longitudinal population cohorts can contribute to understanding the complex interplay of environmental, behavioural, and genetic factors determining health outcomes.

Population cohorts distributed across the African continent are uniquely positioned to bridge persisting gaps and facilitate in-depth analysis of intersectional data across multiple domains and over prolonged periods. Work like this helps to clarify and explain the dynamic interplay between fluctuating environmental conditions and diverse health outcomes. The advantages of long-term population cohorts are numerous:

- 1 Leveraging longitudinal datasets from these cohorts allows for the evaluation of climate-sensitive health determinants and outcomes, including the prevalence and incidence of infectious diseases, non-communicable diseases, mental health, and nutritional deficiencies attributable to evolving climatic patterns. Furthermore,

these longitudinally maintained cohorts enable the research community to develop robust evidence bases that are important for the formulation and implementation of adaptive, mitigative, and pre-emptive strategies aimed at ameliorating the adverse health effects of climate change. Although population cohorts are geographically restricted by their very nature, they can nevertheless provide important triangulation of sources and insight into nationally or regionally less detailed but representative data sources. As non-traditional data sources like remote sensing and mobile data become more crucial through the application of machine learning and big data techniques to fill information gaps about climate change's effects on human health and wellbeing, a consortium of population cohorts such as the APCC can play a vital role. Their individual and community level data collection offers essential ground truths that help validate these models. This validation boosts decision-makers' confidence in these data sources, thereby increasing the chances that the insights gained will influence policy decisions.

- 2 Population cohorts provide flexibility, permitting rapid response to emerging health threats. This feature was exemplified by the pivot to COVID-19 studies by several cohorts during the pandemic (10) (11). The COVID-19 pandemic also illustrated the usefulness of longitudinal cohorts to develop detailed infectious disease transmission models (12).

- 3 Longitudinal cohorts with linked biobanking permit deep phenotyping of participants as seen in projects such as the UK Biobank, Kadoorie Biobank in China, and All of Us in the United States. In the African context, this advantage allows the incorporation of additional biomeasures as newer technologies become available, thus enhancing the comprehensiveness and depth of the data. The longitudinal nature of cohorts permits linkage of this data with outcomes and disease trajectories.
- 4 Population cohorts offer several advantages when serving as sampling frames for clinical trials. Firstly, the deep phenotyping of the cohort enables the precise characterisation of the study population and stratification according to different factors, such as risk level or disease stage. This enhances the efficiency of participant recruitment resulting in more representative and generalisable trial results. Secondly, population cohorts are characterised by the long-term follow-up of participants, capturing data at multiple time points. This continuous data collection can be valuable for trials as it allows the observation of the temporal progression of disease and the long-term effects of interventions even after the trial's completion. Thirdly, the relationships established with the community and the trust built among the cohort members facilitate participant engagement and retention in clinical trials, reduce dropout rates, and enhance data integrity. Finally, a network of cohorts with harmonised capabilities offers an efficient base for the large number of participants required for phase IV clinical trials.
- 5 In addition to supporting experimental approaches, population cohorts also serve as excellent intervention research infrastructures for quasi-experimental approaches. These cohorts provide a comprehensive understanding of the multifactorial determinants of health outcomes within the community, thereby informing the development of contextually appropriate interventions. Moreover, the existing infrastructure of a cohort, including data management

systems, trained personnel, and established community and local health service relationships, provides an ideal platform to implement and evaluate community-based interventions, health policy changes (i.e. universal health coverage initiatives), external shocks, (such as pandemics), and regulatory changes (e.g. tobacco regulation or sugar taxes). Such infrastructure accelerates the intervention research process, reducing the cost and time associated with setting up new systems. The value of population cohorts is also enhanced by linkage to service records, such as electronic medical records (EMRs). Although establishing EMRs is more challenging in Africa due to low penetration, and their utility is impacted by limited access to care, investment in these records for cohort members could catalyse wider EMR adoption and better characterisation of burden of disease.

- 6 Finally, the enrolment of participants into a longitudinal cohort and ongoing community involvement and engagement foster improved participant engagement (13) (14) (15). This engagement translates into sustained trust, loyalty, and increased participation rates, thereby minimising loss to follow-up. In Africa, such active participant involvement has the potential to facilitate a citizen science approach (16) (17), augmenting the impact of the research on participant wellbeing, as well as fostering a research culture (18).

**Scientific networking is an essential part of the African Population Cohorts Consortium (APCC).** It allows researchers from different countries and institutions to share their knowledge and expertise, and to collaborate on research projects, taking advantage of synergies between different cohorts. This collaboration is essential for advancing scientific research in Africa, and for improving the health and wellbeing of African populations.

## Case Study • Ethiopian HDSS Sites

In Ethiopia, vital event registration systems that produce usable data on birth, death, migration, and marital status changes are not fully functioning. Traditional sources of health information collected from health facilities often serve as the basis for health services planning and allocation of resources. Yet, health facility-based data provide fragmented and biased information. Besides, not all population groups have geographic or economic access to health facilities. Thus, health facility-based data may not show the actual health problems of all rural and urban communities, and the data do not, therefore, reflect their health status. This void of valid health data or information for a large segment of the population makes it difficult for policymakers to formulate rational health policies to improve the health status of the population. Taking these facts into consideration, several HDSS sites have been established at different times.

Due to the increased number and expansion of higher education institutions, particularly graduate-level training in Ethiopia, the HDSS sites are serving as research platforms for staff, students, and international researchers to undertake quality research, in addition to generating evidence.

Currently, there are 15 functional HDSS sites structured under public universities in Ethiopia. The HDSS sites are being supported by their respective universities and the Ethiopian Public Health Institute. They primarily generate information about pregnancy observation and outcomes, mortality and causes of death, in and out migrations, and marital status changes. Some HDSS sites have also established morbidity and immunization surveillance.

**The APCC supports scientific networking through a variety of initiatives, including:**

- **Working groups:** The APCC will establish several working groups to focus on specific research areas guided by APCC member scientists. Working groups will evolve as research priorities change. These working groups will provide a forum for researchers to share their ideas and findings, and develop joint research projects, and submit grant applications. Each of the strategic programmes will have its own working group.
- **Annual meeting:** The APCC holds an annual meeting to bring together researchers from all over Africa as well as international colleagues with an interest in global health. This meeting allows researchers to present their work, learn about new research findings, and network with other researchers.

**In addition to these initiatives, the APCC also provides support for individual researchers and cohorts. This support includes:**

- **Access to diverse and representative populations:** The APCC provides researchers with access to a wide range of population cohorts from across Africa. This allows researchers to study diverse populations and ensures that findings are applicable or transferable to different African countries and communities.
- **Data sharing and collaboration:** APCC members can collaborate and share research data with other cohorts within the consortium. This fosters a collaborative research environment and enables the pooling of resources and expertise for more comprehensive and impactful research projects.
- **Capacity strengthening:** The APCC provides training and support to researchers associated with African population cohorts. This support helps researchers to build their skills and knowledge and helps cohorts to enhance their capabilities for the advancement of population research in Africa.

These initiatives and support mechanisms will contribute meaningfully to advancements in population health science within Africa, fostering a collaborative and innovative network of researchers and institutions.

## Strategic Research Programmes

The APCC will develop three synergistic strategic research programmes that reflect a comprehensive approach to addressing the complex interplay between health across the lifespan, climate change, and the pursuit of universal health coverage in Africa. These programmes, while distinct in their primary focus, share common goals and access to the common APCC infrastructure and collectively aim to improve health outcomes, enhance health system resilience, and ensure equitable access to effective healthcare services amidst the challenges posed by climate change and socio-economic disparities.

- 1 Health and Wellbeing Across the Lifespan** aims to leverage longitudinal cohort data to gain insights into the multifactorial determinants of health and disease across different life stages and generations. This programme focuses

on understanding the complex interactions between genetic, environmental, and socio-economic factors, including the impact of climate change, and complements the Climate and Health programme objectives. By identifying risk factors and biomarkers for diseases prevalent in African cohorts, this programme contributes to the development of targeted interventions and policies that can improve health outcomes and support the achievement of UHC.

- 2 The Climate and Health** programme emphasises the critical need to understand and mitigate the health impacts of climate change in Africa. It focuses on developing context-specific early warning systems, strengthening health system resilience against extreme weather events (EWEs), evaluating climate-sensitive physical and mental health outcomes, consequent economic and livelihood impact, and enhancing climate data collection. This programme's objectives are inherently linked to the broader goals of improving health and wellbeing across the lifespan and achieving universal health coverage by addressing the environmental determinants of health and ensuring that health systems are prepared to respond to climate-related health challenges.
- 3 Leveraging Population Cohorts to Enhance Progress towards Universal Health Coverage** focuses on utilising population health cohorts to monitor and improve access to quality healthcare services, financial risk protection, and health system performance. This programme's emphasis on collecting granular, context-specific data at regular intervals aligns with the objectives of the other two programmes by providing a robust evidence based policy and intervention development. The data collected through this programme will inform targeted strategies to address climate-sensitive health outcomes and support health and wellbeing across the lifespan, thereby contributing to the overarching goal of achieving UHC.

*... through their synergistic objectives and methodologies, these programmes have the potential to make extensive contributions to the Sustainable Development Goals ...*



The synergies between these programmes are evident in their shared emphasis on multi-disciplinary, data-driven approaches to addressing health challenges. This integrated approach supports the development of holistic, evidence-based policies and interventions that address the root causes of health disparities and enhance the resilience of communities and health systems to environmental and socio-economic challenges.

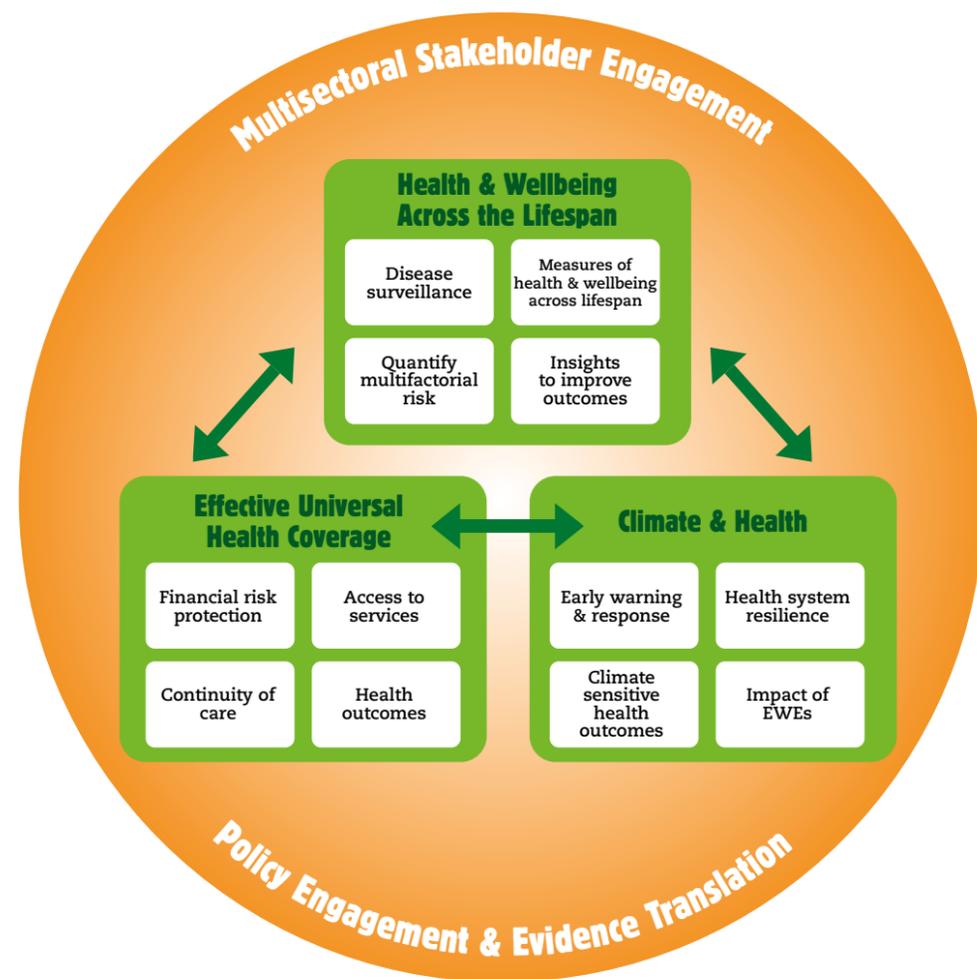
Furthermore, the collaborative nature of these programmes, as reflected in their engagement with a wide range of stakeholders, including researchers, policymakers, and communities, fosters a coordinated response to the complex challenges at the intersection of climate change, health, and healthcare access. By leveraging the strengths and insights of diverse partners, these programmes can drive meaningful

progress toward improved health outcomes, enhanced health system resilience, and equitable access to healthcare services in the face of climate change and other pressing challenges.

In conclusion, the Health and Wellbeing Across the Lifespan, the Climate and Health Programme, and Leveraging Population Cohorts to Enhance Progress towards UHC represent a comprehensive, integrated approach to improving health and healthcare in Africa. Through their synergistic objectives and methodologies, these programmes have the potential to make extensive contributions to the Sustainable Development Goals by ensuring healthy lives and promoting wellbeing for all at all ages, in the context of a changing climate and of evolving health needs.

The Stakeholder chapter of the APCC Blueprint describes how the APCC will manage multi-sectoral engagement to maximise evidence translation and stakeholder involvement.

**Figure 3:**  
Overview of the Strategic Research Programmes



## Health and Wellbeing Across the Lifespan

### African Context Today

Meeting the global SDGs in Africa, where poverty and inequalities are pervasive, is critical if the health-related goals are to be realised across communities and countries. Given the pace and intensity of health and social transitions underway, a deep understanding of interacting exposures, behaviours, life course trajectories, and intergenerational effects and the resulting outcomes is imperative. Such insights are often derived in high-income settings through linkages between routine health data systems, vital statistics, and related data that capture population dynamics. The African continent faces unique challenges, including accelerating multimorbidity, multimorbidity presenting at younger ages, the intersection of infectious and non-communicable diseases (NCDs), and intergenerational cycles of poverty and ill health. This complex health landscape is aggravated by widespread socio-economic inequities, population growth and ageing, and climate impacts, all against a backdrop of inadequate health coverage.

Responding to such challenges depends on a deep and context-sensitive understanding of health trajectories, outcomes, and their determinants across the lifespan. Strategically targeted approaches to the analysis of population-based cohort data are fundamental for effective societal responses. Without this, societies and the policy community will continue to ‘fly blind’ in their attempts to respond to the seemingly intractable challenges.

### Overall Aims and Objectives

Across diverse African settings to:

- 1 Capitalise on community-based, harmonised, and enriched longitudinal datasets to inform context-sensitive, effective responses to complex health challenges across the lifespan and between generations.
- 2 Link population-based data with health systems data to enhance the collection of chronic comorbidity health indicators, access, and disease control indicators, and multimorbidity.
- 3 Strengthen capabilities of the research, policy, and practice communities to interpret and apply population-based cohort data to near-intractable challenges posed by rapidly unfolding health and social transitions.
- 4 Integrating new data on critical contemporary challenges, including climate change, and pandemic preparedness into established and high-functioning cohort datasets.
- 5 Using standardised, thoroughly harmonised measures of health and wellbeing across the lifespan to:
  - quantify multifactorial risk factors associated with adverse health and wellbeing outcomes, focusing on the spectrum of multimorbidity;
  - identify biomarkers, molecular pathways, and polygenic risk factors for diseases prevalent in African cohorts; and
  - inform policy change through evidence generated from experimental and quasi-experimental studies including trials and policy evaluations.

## Background and Rationale

The African continent hosts approximately 80 population cohorts with over 5 million participants and some 50 million years of observation across 25 countries. These cohorts offer unique potential to understand health and wellbeing across the lifespan and the generations, through integrating diverse data types, including socio-demographic, behavioural, clinical, multiomic, and environmental data. However, their potential to address the continent's health and development challenges remains profoundly underutilised. APCC can change this by coordinating population cohorts and the data collected and facilitating the development of appropriate healthcare policies and practices.

Tackling multimorbidity presents unique challenges due to complex interactions between infectious diseases, NCDs, and common mental health conditions in the context of constrained health resources. This complexity hinders effective prevention, diagnosis, and management. Furthermore, the continent's health systems, often composed of multiple "vertical" programmes, struggle to provide accessible care for long-term conditions, both physical and mental.

## Methodology

- 1 Assessment of Existing Cohort Data and Sample Resources:** This programme will undertake a detailed evaluation of the longitudinal data, biosamples, and studies available within the APCC, focusing on their potential to contribute to an integrated understanding of health and wellbeing across the lifespan and generations.
- 2 Data Harmonisation and Standardisation:** By employing common cohort data models, the programme aims to harmonise historical data and standardise ongoing data collection efforts. This approach will enable the identification of long-term health trends and facilitate rapid responses to emerging health challenges.

- 3 Biobanking and Genomic Studies:** Catalogue biobank resources across cohorts and develop a cost-effective genotyping array tailored for African populations. This will include genome-wide genotyping and long-read whole genome sequencing for a subset of individuals to establish a reference genome dataset.
- 4 Intervention Studies:** Collate ongoing interventions and identify opportunities for new policy-relevant interventions. This will include expanding cohort data multi-sectorally, including linkage to administrative and health records.

## Expected Outcomes

- 1 Comprehensive Database:** The creation of a comprehensive, standardised database that includes population and health data that captures the multifaceted nature of health and wellbeing across the lifespan and generations, facilitating the analysis of disease burden trends within African cohorts.
- 2 Identify evolving disease and health profiles along the life course given epidemiological transitions across the region:** Provide insights into the multilevel, multifactorial risk factors associated with adverse health outcomes, focusing especially on patterns of multimorbidity. This will allow for identification of the highest priority modifiable risk factors for targeting, and the population of individuals who might most benefit from such prevention programmes.
- 3 Recommendation for and Evaluation of Community-based Interventions and Policy Changes:** The structure of the data will promote both recommendations for health policy priorities in the region and an evaluation framework to assess the impact of policy changes and community-based or population-level interventions, as informed by findings from experimental and quasi-experimental studies.
- 4 Strengthened Research Infrastructure:** Enhanced biobanking capabilities and a framework for the long-term management of biospecimens, facilitating future research.

## Case Study • AWI-Gen

**A**WI-Gen (Africa Wits-INDEPTH partnership for Genomics studies) was initiated in 2012 as part of the H3Africa Consortium, and is a strategic collaboration between the University of the Witwatersrand in Johannesburg (Wits) and the International Network for the Demographic Evaluation of Populations and Their Health (INDEPTH) to build capacity for genomic research in a cross-continental population cohort. Five of the six study centres are existing Health and Demographic Surveillance Systems (HDSS), and one is an urban Soweto cohort. All have vast experience in community engagement, and have existing infrastructure and data systems. AWI-Gen's main goal is to provide a research resource to investigate the prevalence of cardiometabolic diseases (CMD), associated risk factors and regional health burdens, and to explore gene-gene and gene-environment interactions that contribute to disease risk. Additional critical aims are to understand population structure from a genomics

perspective and to strengthen capacity for genomic research in Africa. At baseline the cohort included 12,500 older adults with ~60% recall roughly five years later. Community engagement was an important activity before going into the field, during the project, and at critical end-points to convey the findings of the study. Through AWI-Gen, 8 PhD students graduated, two are in progress, several Master's students and six postdoctoral fellows, as well as large teams at each study centre were involved. The scientific output includes over 60 AWI-Gen papers and more than 15 H3Africa papers with AWI-Gen input having been published in peer-reviewed journals. Under the H3Africa umbrella, guidelines for community engagement, consent models and data sharing were developed. AWI-Gen data and biospecimens are widely shared through collaborations managed by the AWI-Gen steering committee, and with the global community through the H3Africa Data and Biospecimen Access Committee.

## Significance

This flagship programme, foundational to the APCC, will enable a far deeper understanding of the dynamic health landscape across diverse African settings, particularly the emerging challenge of multimorbidity. By leveraging the unique resource of population cohorts, the programme will provide critical insights into the risk factors, biomarkers, and pathways across molecular, individual, and population levels that are associated with prevalent diseases. Such insights will inform effective prevention strategies, guide integrated disease management, support healthier livelihoods, and tailor interventions to the African context, ultimately contributing to the accomplishment of the Sustainable Development Goals (SDGs) in health, wellbeing, and development.

## Working Group

- **Mia Crampin:** Malawi Epidemiology and Intervention Research Unit, Lilongwe, Malawi
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- **Stephen Tollman:** MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt), School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa
- **Mark Siedner:** Harvard Medical School, Boston, Massachusetts, USA
- **Emily Wong:** Africa Health Research Institute, Durban, South Africa
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- **Kobus Herbst:** Africa Health Research Institute, Durban, South Africa

## Climate and Health

### Background

The 10-year mean global temperature is now at 1.14 °C above pre-industrial levels, with the current warming trend occurring at a rate not seen in the past 10,000 years (19) (20). The past eight years have been the warmest on record globally, with 2023 surpassing previous records (21) (22).

Climate change or rising global surface temperature is the result of human activities that fuel rising greenhouse gas concentrations and accumulated heat (23). If the global health care system were a country, it would be the fifth largest contributor to greenhouse gas emissions, accounting for 5.2% of global net emissions (24) (25).

The most noticeable impacts of climate change include higher frequency and severity of extreme weather events (EWEs) such as droughts, storms, floods, wildfires, and heatwaves. EWEs impact health directly through deaths and injuries and other indirect mechanisms such as infectious diseases (for example, food-,

water-, and vector-borne diseases), and food and water insecurity, for example through forced displacement of populations (26) (27). EWEs can also impact human health indirectly, by disrupting people's ability to seek healthcare or diminishing the ability of local and national health services to deliver healthcare.

Some population groups (e.g., children, older adults, people with chronic illnesses or mobility challenges, poor or isolated people, indigenous peoples, and some occupational groups) may experience a disproportionate share of the health risks associated with EWEs because of their heightened physiological sensitivities, greater exposure, social marginalisation, discrimination, or low capacity to manage due to limited resources (26).

Additionally, it is imperative for the health care system to limit its own greenhouse gas emissions by adopting measures that are environmentally sustainable while at the same time protecting health, through the delivery of safe and high-quality care.

*... rising global surface temperature is the result of human activities that fuel rising greenhouse gas concentrations and accumulated heat ...*



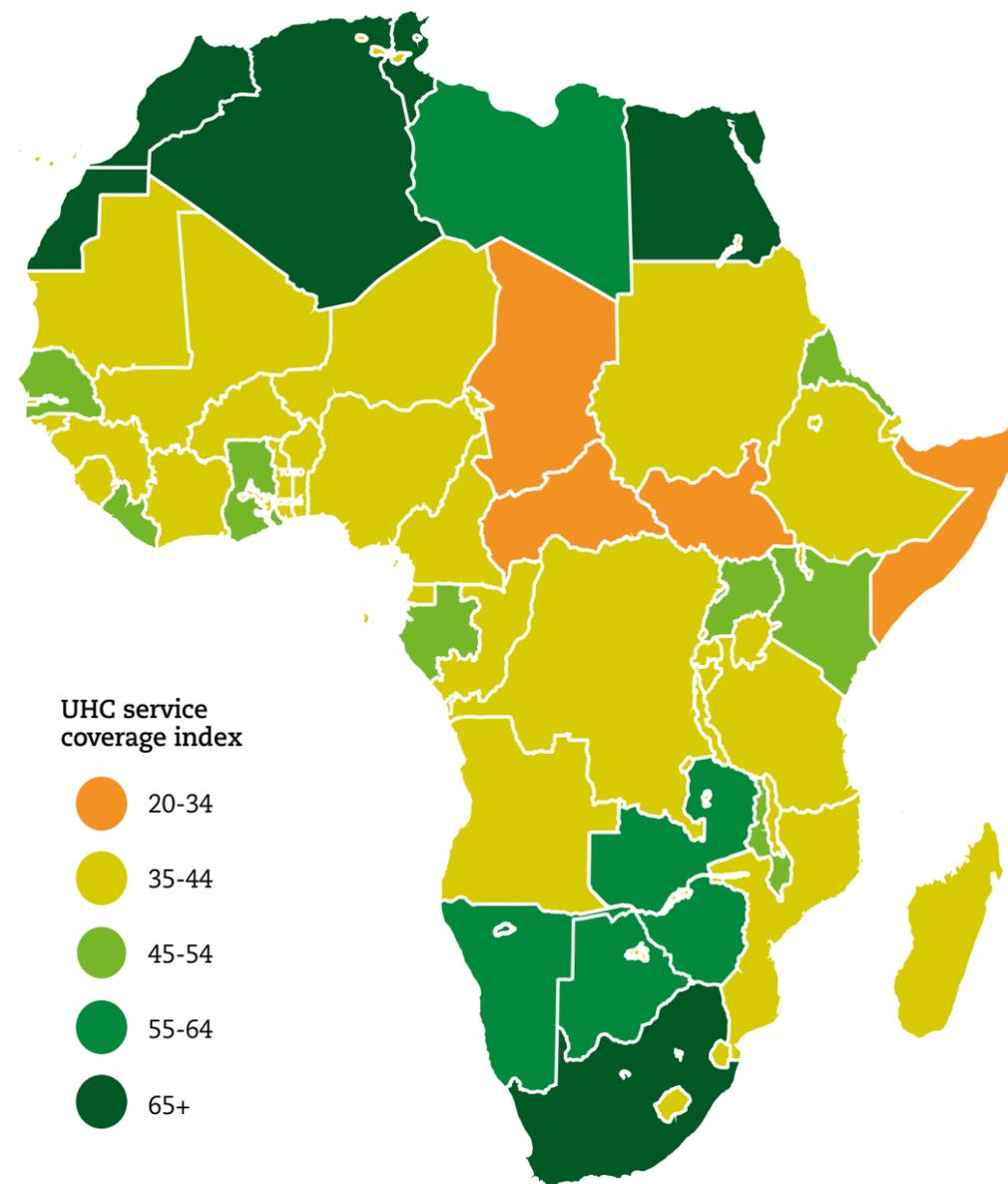
### The Case for Africa-Wide Research on Climate and Health

The APCC brings together cohorts from all regions of Africa, thereby capturing the climate diversity of the continent, critical for informing the expected impact of climate change on health for Africa and for contextualising adaptation and mitigation measures. The centre of the continent has a wet tropical climate with extremely heavy rainfall. The northern and southern regions are characterised by dry seasons, with areas experiencing longer dry spells and occasional droughts associated with famines in the Sahel. North of the Sahel lies the very dry Sahara desert. Finally, north and south of the desert regions are belts of Mediterranean climate, with hot dry summers and mild moist winters (28). Six island nations in Africa are at risk of sea level rise due to climate change coupled with coastal communities whose livelihoods are linked to being close to the coast.

Of particular concern is that the rate of temperature rise across Africa (approximately +0.3 °C per decade from 1991-2021) is faster than the global average (29). The lowest-income countries (many of which are in Africa) produce one-tenth of the world's greenhouse gas emissions but are the most heavily impacted by climate change. Compared to the 1980s, these countries have already experienced in the past ten years approximately eight times as many natural disasters (30).

Africa faces increased health challenges due to the disproportionate burden of other diseases, limited infrastructure and services, weak economies, large socioeconomic inequalities, and governance challenges which can also limit the capacity to adapt to EWEs and climate change.

**Figure 4:**  
UHC service coverage index in Africa. Source: World Health Organization, Global Health Observatory Data Repository (<https://www.who.int/data/gho>). Note: UHC service coverage index ranges between 0 and 100, where 0 is the worst service coverage



In 2022, the Emergency Event Database EM-DAT recorded 387 natural hazards and disasters worldwide, resulting in the loss of 30,704 lives and affecting 185 million individuals. Drought affected 88.9 million people in Africa. The human and economic impact of disasters was relatively higher in Africa, e.g., with 16.4% of the share of deaths compared to 3.8% in the previous two decades (31) (13).

As the impact of climate change is predicted to intensify in the coming years, there is a strong consensus that adaptation will be key to protecting populations in Africa from future climate impacts, and that early action is needed (32). However, African governments have all pointed to a lack of research on climate and weather-health relationships as a barrier to climate-informed decision making (33). Generating this evidence is critical to enabling African governments access to international adaptation finance which is required to tackle climate-related risks.

## Objectives

- 1 Design Context-Specific Early Warning and Response Systems:** Develop systems tailored to the unique climatic and socio-economic conditions of different African regions to protect health during EWEs using the capabilities of the cohorts in APCC.
- 2 Strengthen Health System Resilience:** Evaluate and implement interventions to enhance the capacity of health systems to withstand and respond to EWEs and climate-induced health challenges.
- 3 Evaluate Climate-Sensitive Health Outcomes:** Assess the impact of climate change on physical and mental health to inform public health strategies using the measurements developed by the Health and Wellbeing Across the Lifespan programme.
- 4 Assess Economic and Livelihood Impacts:** Understand the socio-economic consequences of EWEs to inform the development of comprehensive adaptation strategies.
- 5 Enhance Climate Data Collection:** Invest in localised climate data collection within the geographic boundaries of the APCC cohorts to improve the accuracy of health impact attribution and inform policy decisions.

## Methodology

The programme will employ a multi-disciplinary approach, integrating epidemiological, climate, and socio-economic research methods. Key activities will include:

- **Data Harmonisation and Integration:** Leverage existing cohort data and enhance it with detailed climate and health records.
- **Intervention Studies:** Conduct experimental and quasi-experimental studies to evaluate the effectiveness of health system interventions and early warning systems.
- **Policy Analysis and Development:** Engage with stakeholders to translate research findings into actionable policy recommendations.

## Expected Outcomes

- 1 Comprehensive Climate and Health Database:** A standardised dataset integrating health, climate, and socio-economic data to facilitate multi-dimensional analyses.
- 2 Evidence-Based Adaptation Strategies:** Tailored interventions to enhance health system resilience and protect vulnerable populations.
- 3 Policy and Practice Recommendations:** Guidelines and strategies for policymakers and practitioners to mitigate the health impacts of climate change.
- 4 Strengthened Research and Policy Networks:** Enhanced collaboration among researchers, policymakers, and communities to foster a coordinated response to climate-related health challenges.

## Significance

The Climate and Health programme represents a critical step towards understanding and mitigating the health impacts of climate change in Africa.



*... by leveraging the continent's rich cohort data and engaging with a broad range of stakeholders, the programme aims to develop evidence-based strategies that protect the health, promote resilience, and inform policy at both national and regional levels ...*

By leveraging the continent's rich cohort data and engaging with a broad range of stakeholders, the programme aims to develop evidence-based strategies that protect the health, promote resilience, and inform policy at both national and regional levels. Ultimately, the programme seeks to contribute to the Sustainable Development Goals by ensuring healthy lives and promoting wellbeing for all at all ages, in the face of climate change.

#### Working Group

- **Collins Iwuji:** Africa Health Research Institute, Durban, South Africa
- **Joanes Atela:** African Research and Impact Network (ARIN), Nairobi, Kenya

### Case Study • SAPRIN

The South African Population Research Infrastructure Network (SAPRIN) is a national research infrastructure. It forms part of the Department of Science and Innovation's (DSI) South African Research Infrastructure Roadmap. It is hosted within the South African Medical Research Council (SAMRC).

Comprising six Health and Demographic Surveillance Systems (HDSSs) across five provinces, SAPRIN includes three rural nodes in Agincourt, DIMAMO, and AHRI, and three urban nodes in GRT-INSPIRED, C-SHARP, and USINGA. The network will be expanded through the addition of a seventh node, shortly.

The nodes monitor over 415,000 individuals from 113,728 households. SAPRIN captures data on 644,548 unique individuals, representing over 5.7 million person-years of observations. SAPRIN operates with a standard shared surveillance protocol with communities of practise thus promoting high quality research operations.

The comprehensive data collected by SAPRIN facilitates the transferability of findings to similar contexts and the calibration of national data sets. This capability significantly enhances the understanding of health and demographic trends in South Africa, helping to inform decision-making and policy formulation. SAPRIN provides research capacity building through its links with approximately 10 tertiary

## Leveraging Population Cohorts to Enhance Progress towards Universal Health Coverage

### Background – Universal Health Coverage

Universal Health Coverage (UHC) has become a fundamental pillar in global efforts towards equitable health systems. In 2015 this commitment was solidified when all United Nations member countries, including the 47 countries in Africa, committed themselves to the UHC goal as part of the Sustainable Development Goals (SDG target 3.8) for 2030 (34).

UHC aims to ensure that every individual has access to the healthcare services they need, which are of good quality, without facing financial difficulties (35). The UHC goal encompasses three essential dimensions: population coverage, the availability of a comprehensive range of healthcare services, and the degree to which healthcare costs are covered for households (36).

### Background – Africa's Progress Towards UHC

Over the past two decades, African countries have made significant strides towards achieving UHC with efforts to broaden the scope of essential services, particularly targeting remote and underserved communities (37) (38) (39). However, disparities in

institutions affiliated with the nodes. Community engagement is an integral part of the SAPRIN model. Community participation is fostered through Community Advisory Boards (CAB). CAB representatives are also part of the Annual SAPRIN Conference.

SAPRIN is an example of national government's investment in population cohorts. The value of this investment is not only evidenced by its contribution to policy, but also through the considerable external research funding leveraged by the node at a level that is three to four times higher than the investment by DSI.



progress within and among countries persist, underscoring the complex challenges faced in achieving equitable healthcare access (39). World Health Organization data indicates an unweighted average UHC service coverage index in Africa of 48 (out of 100), with significant variability between countries (see Figure 4). Out-of-pocket health spending still constitutes a large share of current health expenditure in many African countries, exceeding 60% in Cameroon, Equatorial Guinea, Nigeria, and Togo using 2021 data (40).

Variability in progress is also evident across different health programmes, with notable advancements in infectious diseases and maternal, newborn, and child health (RMNCH) service coverage indicators. However, progress in non-communicable disease (NCD) coverage has been comparatively slower (39). While the overall coverage of essential services has increased in the past decade, 58% of the population still lacks healthcare access (41), with geographical and socio-economic factors driving disparities in access (42).



### *... disparity often leads to the exclusion of vulnerable and poor populations from essential health programmes, perpetuating inequalities in access ...*

African countries increasingly adopt various mechanisms to increase healthcare access and provide financial protection against health-related risks. This shift is highlighted by the rise of social health insurance schemes observed over the past decade (43) (44). However, despite these efforts, key commitments by African governments to increase domestic health financing have stalled. The 2022 WHO Africa report reveals that most countries finance less than 50% of their total health budget (44). Many countries are falling significantly short of the Abuja declaration target of allocating 15% of total government expenditure to health (45). Compounding these challenges is the low and inequitable population coverage within prepayment mechanisms such as national and social health insurance (43) (35). This disparity often leads to the exclusion of vulnerable and poor populations from essential health programmes, perpetuating inequalities in access (38).

The data point to a mixed picture when assessing the region's progress towards financial risk protection. Although there may be an issue with ordering impoverishment levels (46), the proportion of the population experiencing impoverishing health expenditures, set against the extreme poverty line of PPP \$1.90 per day, has gradually declined over time. However, the percentage of the regional population burdened by spending more than 10% of their household budget on health out-of-pocket has remained largely stagnant (39).

### **Monitoring Universal Health Coverage**

Measuring and monitoring progress toward UHC is essential for several reasons. It provides information on whether the country and global efforts to achieve UHC are on track, informing and motivating further investments to make meaningful progress (47). It also facilitates the identification of critical gaps in countries' UHC efforts. These include gaps in equity and pro-poorness of both financing and service coverage.

Monitoring UHC entails measuring progress on two key dimensions, namely service coverage and financial risk protection. Two indicators (SDG indicator 3.8.1 – coverage with essential services, and 3.8.2 financial protection when using services) are used to monitor SDG 3 and are typically used as the standard approach to monitoring UHC. Tracer health interventions that represent the range of needed healthcare services are typically selected and used to calculate both indicator-specific and composite indicators of service coverage (48), although this is challenging, especially in terms of comprehensiveness (49) (50). While country approaches may vary, the WHO and the World Bank UHC global monitoring initiative typically selects health intervention indicators related to RMNCH, infectious diseases, NCDs, and service capacity and access (34). While there are two sub-indicators for measuring and monitoring progress on financial risk protection (i.e., the incidence of catastrophic health expenditures and the impoverishing effect of out-of-pocket healthcare costs), the SDG framework only focuses on catastrophic health expenditures. Households are considered to have incurred catastrophic expenditures if their total out-of-pocket healthcare spending in a year exceeds a threshold level of a measure of household expenditures. Popular thresholds include 40% of household annual non-food expenditure (often referred to as capacity to pay), and the 10% and 25% of total household expenditures used by the WHO and World Bank UHC Global monitoring initiative (34).

### **Leveraging Population Cohorts to Enhance Progress Towards UHC**

Population cohorts provide a unique opportunity to monitor progress towards UHC in ways that complement existing UHC monitoring initiatives. While existing efforts to measure and monitor progress towards UHC are valuable, several gaps exist. First, they rely on nationally representative survey data on service coverage and household expenditures that are typically periodically conducted, with long time intervals (often five or more years) between survey waves in low- and middle-income countries (LMICs). This means the data have a low temporal resolution, requiring modelling between surveys with questionable validity. While these data might be useful in tracking progress globally, year-on-year data gaps make it challenging to inform policy action at the country level. Second, the global monitoring efforts measure indicators that tell us about progress towards UHC (the WHAT) but do not provide information that might explain the observed progress (the WHY). This is typically because of challenges with data availability. Measuring and monitoring intermediate indicators that explain the observed levels of the ultimate indicators is essential as it provides targets for intervention and policy levers that policymakers can act on to accelerate progress towards UHC.

Population cohorts provide a valuable platform to monitor countries' progress towards UHC while filling the gaps and complementing global monitoring efforts for the following reasons:

- 1 They can be used to collect granular data at regular intervals, and hence provide data with finer temporal resolution to inform country efforts to enhance progress towards UHC.
- 2 They can be used to collect data on intermediate indicators that explain progress on service coverage and financial risk protection.
- 3 They can be leveraged to conduct studies to answer specific context-specific indicators.
- 4 They provide regular data that can be used to create feedback loops for policymakers to improve policymaking and implementation. In this sense, population cohorts are not just platforms for monitoring progress and deploying studies but are also interventions by themselves.

We propose the use of population health cohorts to enhance UHC in the following ways:

**Monitoring Financial Risk Protection** Population cohorts should be used to monitor progress on financial risk protection by collecting **conventional indicators** of financial risk protection. Standardised questions on out-of-pocket payments made by individuals when seeking healthcare, and when making household expenditures, can be incorporated in population cohort datasets to monitor financial risk protection using the two commonly used indicators, namely, incidence of catastrophic health expenditure at the 10% and 20% household expenditure threshold, and impoverishment.

Cohorts can also be used to measure and monitor **intermediate indicators** that explain the observed levels of financial risk protection. For example, by linking data on the health facility type visited by cohort individuals, and whether out-of-pocket payments were made, an assessment of the extent to which financial risk protection policies, such as free healthcare policies, are adhered to, can be achieved. Another aspect of financial risk protection that population cohorts can monitor is the incidence and misdistribution of informal healthcare payments. These are payments made by individuals to healthcare providers that are outside the scope of official tariffs and are essentially a form of corruption in the health system that presents a financial barrier to access. Informal payments made by users are not explicitly collected in regular surveys.

**Monitoring Coverage with Essential Health Interventions** Population cohorts could also be used to collect data on indicators of coverage with selected essential health services. To complement global monitoring efforts, the selection of service coverage indicators should primarily be guided by local context and priorities and include indicators that are representative of the range of needed healthcare services. Cohorts can also include the standardised service coverage indicators to facilitate cross-country comparisons.

Cohorts could also be used to collect data on intermediate indicators that explain observed service coverage levels. These could include indicators of

**availability of services**, such as whether sought services were actually available in health facilities and whether individuals had to seek services elsewhere. Cohorts can be used to monitor the **geographical accessibility of services**. Geo-mapping health facilities and households in the cohort can help create dynamic maps of spatial distances individuals travel to access healthcare facilities. Further, standardised questions on **patient perception and satisfaction** can be used to monitor user acceptability of health services as an aspect of access and quality. Thus, population cohorts can also empower citizens by providing them with a platform to express their views and preferences over health services.

**Monitoring Inequalities in Coverage and Financing** Beyond measuring levels or population means of outcomes of interest, population cohorts can provide insights into service access, coverage, and financing inequalities. This can be achieved by incorporating questions on both standardised and context-specific social stratifiers such as gender, socio-economic status, geographical location, ethnicity, and race.

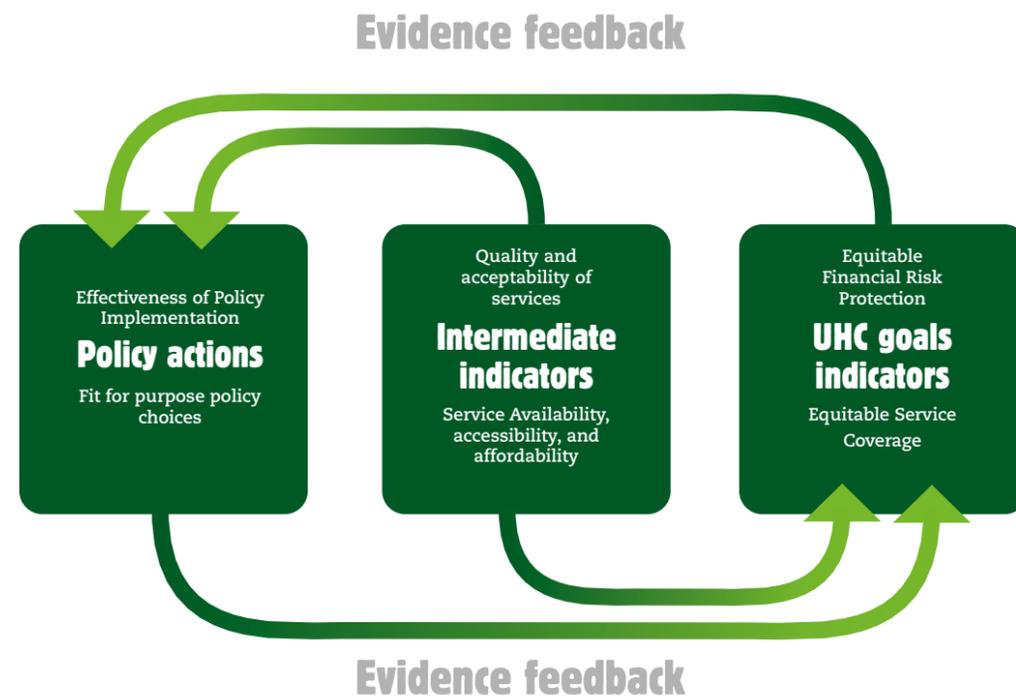
**Monitoring the Effectiveness of Policy Implementation** While most LMICs are reforming their health systems to accelerate progress towards UHC, there is limited routine data to provide insights regarding the effectiveness of policy implementation. Population cohorts can be leveraged to provide data to track progress on policy implementation. Developing data needed to facilitate this will need to be context-specific and guided by local level priorities. For instance, in contexts where countries have introduced health financing mechanisms that require population enrolment, such as social health insurance schemes, population cohorts can be leveraged to provide regular population-level data on the scale of population enrolment, and complement routine administrative data collected by social health insurance authorities. Further, given that several African countries are prioritising investments in community health systems as a service delivery model, population cohort data could be used to monitor the scale and coverage of community health services.

**Population Cohorts as Health System Interventions** Lastly, population cohorts can be used as health system interventions that aim to improve the performance and quality of health systems. This can be achieved by leveraging the data collected by cohorts to provide positive feedback loops to health system decision-makers to incentivise reform. Cohorts should be at the core of health system performance improvement frameworks that collect standardised performance data at the population level, conduct analytics and visualisation of performance, provide feedback to health system decision-makers, prioritise action targets, and formulate and implement actions to improve health system performance. To achieve this, population cohorts need support and buy-in from local health system stakeholders and decision makers, and be embedded in local health systems.

## Conclusion

This section underscores the significance of monitoring UHC in Africa and proposes that population health cohorts are a powerful tool to enhance such monitoring efforts. While African countries have made strides towards UHC, significant challenges remain, including disparities in access, slow progress in service coverage,

**Figure 5:** Framework for monitoring and intervening to enhance UHC in Africa using population health cohorts



and inadequate domestic health financing. Existing monitoring mechanisms face limitations in data resolution and explanatory power. Population cohorts offer a solution by providing granular, context-specific data at regular intervals, enabling the monitoring of progress on essential health interventions and financial risk protection. Moreover, they facilitate the examination of intermediate indicators that explain UHC performance and act as intervention targets and policy levers for improvement. Population cohorts can also be leveraged to provide insights into inequalities and the effectiveness of policy implementation. Additionally, population cohorts can serve as interventions themselves by forming part of evidence feedback loops that inform policy decisions and drive health system improvements. Figure 5 summarises the proposed framework for monitoring and intervening to enhance UHC using population health cohorts in Africa.

### Working Group

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### Working Groups

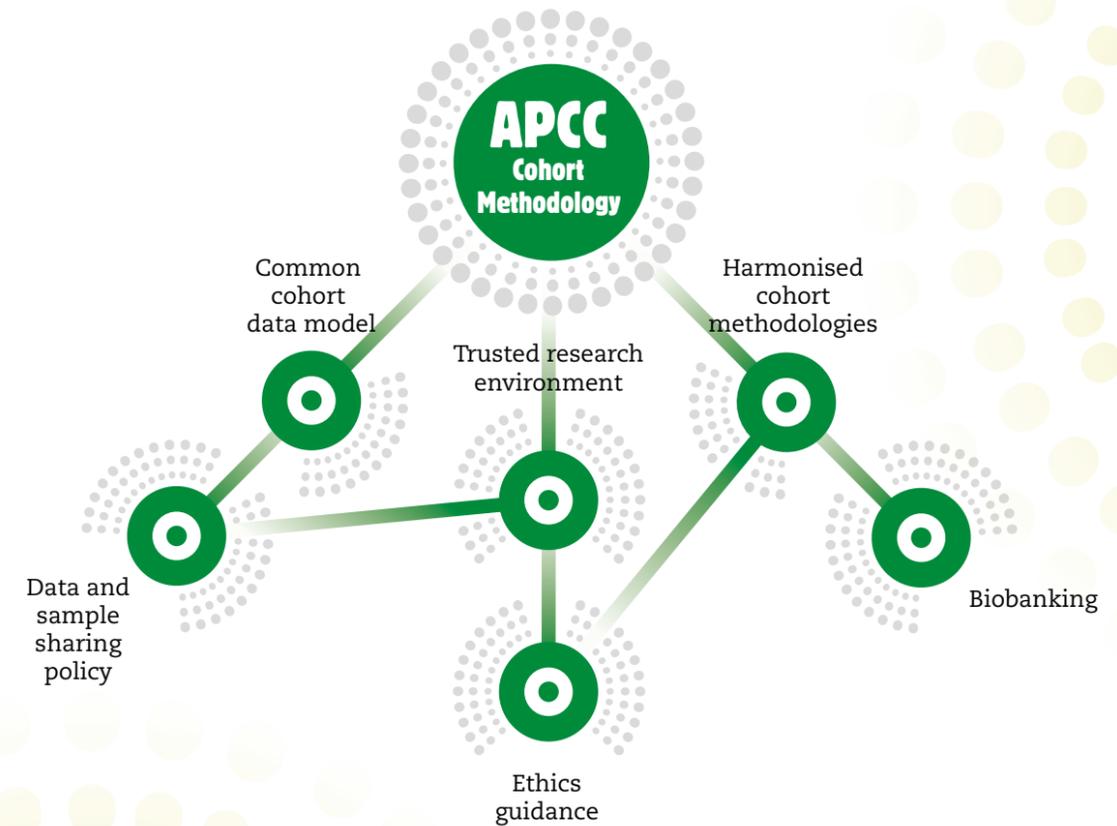
Working groups are a means for scientists from the APCC Membership to collaborate on a specific research topic. The Secretariat will provide organisational support to a working group once its establishment has been approved by the Steering Committee. Working group membership is voluntary and based on the interest of the member cohort and associated researchers in the topic. A working group will select a convenor from amongst its members, who may also be the principal investigator of research studies emanating from the working group. Working groups are dynamic and will exist as long as the topic is actively pursued and could split into separate groups or join with other groups. Additional working groups can be created as opportunities emerge. The APCC Annual Meeting will be a prime venue where such working groups are initiated.

Secretariat support for working groups will depend on the extent to which the group aligns with the Mission and Strategic objectives of the APCC. There will be a working group for each of the Strategic Programmes of the APCC, but also working groups for important scientific objectives that are not included as Strategic Programmes, such as omics, and mental health.

PART 3

# APCC Cohort Methodology

Cohort methodology is aimed at developing and promoting the implementation of harmonised cohort methodologies that enhance individual cohort outcomes and the effectiveness of multi-cohort research. This includes the development and adoption of a common cohort data model, the establishment of a trusted research environments to promote data sharing, and the development of guiding ethical principles to safeguard and involve cohort participants and to facilitate multi-cohort research. A data and sample sharing policy will govern access to the APCC shared data and the trusted research environment. APCC will promote the sharing and curation of bio-samples through a biobanking initiative.



There are several key benefits to adopting new data methods, including the use of a common data model. These include:

- Improving data quality by opening the data to scrutiny.
- Developing new analysis which can be done in partnership with other population cohorts.
- Building better, standardised vocabularies for African population health data.
- Joint training and mentoring of data scientists.
- Allowing interoperability and reuse of valuable resources.
- Creating FAIR data and metadata which becomes a common resource.

## Harmonised Cohort Methodologies

Standard harmonised methodologies will be developed for the following cohort themes:

- 1 Data collection:** This will allow for standards for generating cohort data, including data collected through structured interviews, audio-computer-assisted self-interviews (ACASI), and wearables (e.g., smartwatches).
- 2 Data documentation:** Metadata are increasingly important in finding and accessing data across the internet (often by machine actionable programmes). Recommendations and training in the documentation of data and metadata will be provided, along with a repository for metadata.
- 3 Imputation of common missing data:** In African cohorts, variables such as dates of birth or events are often missing or imprecise. Recommendations for capturing date imprecision and data imputations will be defined.
- 4 Analysis packages for population cohort data harmonised through the OMOP CDM:** Harmonisation of data allows for federated analysis using standard analysis packages, which can be run using R or other agreed software. Using methods developed by the INSPIRE network we will offer standard analysis packages to APCC population cohorts.
- 5 Record linkage in cohorts:** In the absence of biometric identifiers, standards will be developed for linking cohorts to routine observational health data.
- 6 Publication and authorship guidelines.**



*... research questions can be formulated and answered using data across multiple locations while keeping the data secure ...*

An objective of APCC is to develop safe data environments for population cohorts which means that research questions can be formulated and answered using data across multiple locations while keeping the data secure. This will require training and

implementation in new data science methods which will be coordinated by APCC.

## Common Cohort Data Model

APCC will develop a common data model for longitudinal population cohorts in Africa. Borrowing from the [OHDSI – Observational Health Data Sciences and Informatics](#) (OMOP) Common Data Model (CDM), Observational Medical Outcomes Partnership (OMOP), APCC will work with the OHDSI African chapter to create a customised CDM that caters for the longitudinal data from population cohorts, building on the work led by the INSPIRE network under the APHRC.

The OMOP Common Data Model (CDM) was initially developed to standardise hospital electronic health records, organising the structure and content of observational data to facilitate efficient and reliable analyses. This standardisation primarily focused on data generated within U.S. hospitals, leading to vocabularies tailored to this specific context. For the APCC Cohort CDM (CCDM), the APCC plans to collaborate with the OHDSI Africa chapter to develop new or adjusted vocabularies that better capture data relevant to African populations. The CCDM aims to enable cross-cohort analyses by leveraging the accumulated knowledge from various cohorts, including different waves of data collection, to elucidate the relationship between exposures and health outcomes across diverse populations. Additionally, the CCDM will play a crucial role in harmonising data from emerging APCC workgroups, addressing complex issues such as multimorbidity, the impact of climate change on health, emerging infectious diseases, and mental health.

## Leveraging Artificial Intelligence and Machine Learning for the APCC

The APCC will enhance the traditional methods of analysing population cohort data by using AI and ML techniques to support (51) (52) (53) (54):

- 1 Data integration:** AI tools can assist with merging structured and unstructured data sources such as electronic health records, wearable device data, community-generated datasets, and other text data, thus providing a complex view of cohort participants' health trajectories. This calls for complex AI tools such as natural language processors, large language models, and other software that can ingest multiple data sources.
- 2 AI-driven pattern recognition and predictive modelling in longitudinal population data:** The power of AI-driven data scraping and data wrangling methods have the potential to enhance traditional data management techniques to identify new patterns in cohort data. Specifically, AI tools can be used to identify new data trends and unveil new correlations and variable dependencies, risk factors or unrecognised patterns, and clusters in the datasets, that can then be used to predict health trajectories.
- 3 Risk stratification to guide strategic programmatic health interventions:** AI-driven and machine learning tools such as classification methods will support data in the three APCC strategic programmes. Specifically, AI tools can

be used to identify and categorise cohort participants based on their likelihood of acquiring multi-morbidity, experiencing EWEs, or even identifying persons in greatest need of UHC in different African countries. Using the pooled data generated under the APCC, the AI-driven analyses will inform the design of targeted interventions to improve African population health.

## Data and Sample Sharing Policy

APCC is committed to maximising the use of the data and samples in a responsible, ethical, and legally compliant manner, recognising the complexities of working across different African jurisdictions. Each of the cohorts may share the data and biospecimens generated according to their local cohort processes in compliance with in-country permissions, including consent from participants, and in adherence with in-country data protection laws (legal compliance). The joint APCC resources will be managed through mutually agreed processes.

The APCC will appoint a Data and Biospecimen Access Committee (DBAC) that, amongst its functions, will ensure that data shared to the APCC meets certain minimum conditions for sharing and is legally and ethically compliant. The DBAC will develop guidelines and mutual agreements to guide the APCC on processes that include access and use of data and biospecimens, as well as publications and authorship.

### Approach

- Sharing and use of data and biospecimens must remain ethical, purposeful and consistent with the missions of the APCC, this will be monitored and enforced by an APCC Data and Biospecimen Access Committee.
- APCC will largely play a stewardship role, facilitating scientific collaboration that makes use of the data and biospecimen hosted by individual APCC members (individual cohorts will remain custodians of their own data sets and biospecimens).
- The APCC will clarify who has decision-making powers on the responsible use of the data and samples, and will be bound by the responsibility to guard the confidentiality of study participants and strengthen the process of de-identification of any data and biospecimens that APCC might be responsible for.

### Principles

- Protect the rights and privacy of the study participants.
- Follow the rules and regulations stipulated by the ethics committees.
- Ensure that data and biospecimens are legally compliant with local/in-country laws.
- Promote the ethical sharing of biological materials and data in a responsible manner.
- Maximise the availability of biological materials and data for research purposes.
- Strengthen de-identification of data and biospecimens.
- Enhance capacities and promote the deposition of research data in public data repositories (individual level data, aggregate data, and summary statistics).

- Put in place mechanisms to minimise any potential for research to stigmatise individuals and communities, including considering different research designs where the risk exists.
- Ensure that shared data meets the FAIR (Findability, Accessibility, Interoperability, Reusability) principles (55), to allow for wider use of data to advance scientific knowledge.
- APCC leadership has the responsibility of ensuring the ethical integrity and scientific merit of proposals from researchers seeking to use APCC resources.
- APCC will share its resources responsibly to both internal and external users:
  - **Internal users** are members of the APCC and include cohort leads and their co-investigators, project leads, researchers, students, and staff members. The APCC will maintain and frequently update a list of researchers associated with cohorts.
  - **External users** are the broader scientific community who are not directly associated with an APCC member cohort.

## Trusted Research Environment

The APCC trusted research environment (TRE) will use best practice from existing safe data environments (Trusted Research Environments (TRE) Green Paper (56) using the principles of the Five Safes (57) to protect data integrity (58). The proposed TRE will support the following capabilities:

- 1 Data Security and Privacy:** Implementation of strong data protection measures to ensure that sensitive information is kept secure and private. This includes encryption, secure access controls, and auditing capabilities to track who accesses the data and what they do with it.
- 2 Controlled Access:** Access to the data within a TRE is strictly controlled and monitored. Researchers will go through an approval process before they can access the data, and their activities within the environment will be logged and reviewed.
- 3 Data Anonymisation and Pseudonymisation:** To further protect privacy, data within a TRE will be anonymised or pseudonymised, removing or replacing personal identifiers with artificial identifiers or none at all, making it difficult to trace data back to individuals. Specific consideration will be given to the complexities associated with pseudonymisation of longitudinal data.
- 4 Secure Analysis Tools:** The TRE will provide researchers with tools and software for analysing the data within a secure environment. This ensures that sensitive data does not need to be moved outside of the secure environment, reducing the risk of data breaches. Learning from initiatives such as G4GH we will develop means for federated access to data held directly by cohorts themselves.
- 5 Legal and Ethical Compliance:** The TRE will be designed to comply with relevant laws and regulations in African countries, ensuring that data is handled legally and ethically. Close collaboration with the DSI-A Africa Law project will facilitate this process.
- 6 Collaboration Support:** The APCC TRE will support collaboration among researchers, allowing them to work together securely on shared datasets.

## OpenSAFELY Collaboration

The OpenSAFELY Collaborative has developed a range of open source TRE tools that have successfully addressed major challenges around privacy, transparency, reproducibility of analyses, shared data management, federated analysis across multiple data centres, and an efficient user experience. These tools have been successfully deployed in relation to the full NHS primary care electronic health records of the whole population of England (split across two data centres), with strong support from privacy advocates and professional bodies who have historically objected to all prior means for accessing this structured data. The tools are now being used on 155 projects from 22 different organisations. The team also has extensive experience of running TREs: they have run the NHS England Open SAFELY TRE on GP data for four years, and the OpenSAFELY head of platform development previously developed and ran the UK Office of National Statistics Secure Research Service. OpenSAFELY offers a pathway for fulfilment of the APCC aim to create a community of practice around secure and trusted access to cohort data.

Specifically with the OpenSAFELY team, we have the following aims/objectives:

- 1 To develop a technical specification/design for the development and deployment of OpenSAFELY-based TREs in individual cohort data centres or shared data centres within countries as part of the wider APCC community with the APCC and individual cohorts' delivery teams. The OpenSAFELY team will conduct a detailed scoping exercise to decide to develop a new TRE or leverage commercial TREs that build on proprietary and customisable platforms that are packaged as SaaS. The overall aim will be to transfer knowledge on TRE set up in Africa through the APCC.
- 2 To co-develop and implement a harmonised data model for population cohorts with advisory input from the OPENSafely and INSPIRE teams with active involvement and support from cohort data managers.
- 3 Lead on designing and then collaboratively delivering (with suitable capacity building and technology transfer) a set of tools and a service for joined-up federated analytics of cohort data across multiple data centres. This will make the best use of prior art including OpenSAFELY components and other prior open-source tools for federated analytics, including those developed and deployed in APCC sites already. This will all be done in close collaboration with APCC and individual cohort delivery teams.
- 4 Capacity building and technology transfer. The INDEPTH iSHARE experience and the common data model, ETL and Centre-in-a-Box are examples of prior continental initiatives towards data harmonisation and sharing in secure environments. This has also been used as a starting point for INSPIRE. Exposure and training in other types of data models beyond OMOP, that adequately map population cohort data and allow modification of vocabularies and ontologies for African data, will be encouraged. Leveraging experience in modifying different ontologies and vocabularies, OpenSAFELY will leverage existing initiatives such as the OHDSI community.

## Ethics Guidance

**Ethics approval** must be obtained for each cohort, study, and sub-study according to the guidelines and rules for the institution and country. Copies of the ethics approval documents (including applications, responses from IRBs, certificates, information sheets and informed consent templates and questionnaires) should be available on request and approval numbers must be included in the publications.

These documents need to be stored in a central APCC archive in order to evaluate and monitor compliance with APCC policies and guidelines. Where data is collected without an approved protocol (for example, routinely collected health care information), APCC will work with individual data suppliers to ensure that the appropriate permissions are obtained before the data is shared. These permissions will be contingent within the countries. In countries whose research regulatory systems are still developing and where there is no review process for data sharing, APCC will work with in-country researchers (PIs) and may recommend applying the APCC guidelines in the absence of any in-country guidelines.

*... the primacy of informed consent is central to any research conducted under the auspices of APCC ...*



**Consent information and options:** In addition to appropriate ethical approvals, the primacy of informed consent is central to any research conducted under the auspices of APCC. Specific guidelines and consent templates will be developed by the Ethics working group for use in studies supported by the APCC, or where cohorts want to update their current consent wording to facilitate multi-cohort research. Data and biospecimens shared with APCC members must be accompanied by approved consent forms. The information in the consent forms must include statements that explain data and biospecimen sharing. The consent forms must explicitly seek permission from participants to share their data and biospecimens. Several options for sharing are available; different countries ascribe to different forms of consent. APCC will work with country permissions rather than impose its own, while also building in-country capacities. Where participants refuse data and/or sample sharing, that data cannot be shared with APCC and will be under the custodianship of the primary research/host institution. Where consent for sharing is provided, this can be in form of **broad consent** where data and biospecimens can be shared with others and for an indefinite time. Other forms of consent include **dynamic consent** where participants request to be re-contacted and re-consented for any subsequent sharing. **Specific consent** is given for sharing data for a very specific question/research area, with specific institutions/individuals, or for specific time frame. APCC will be guided by in-country regulations and permissions. It will also aim to support – as far as possible – countries whose ethics guidance are still developing.

### Data Anonymisation or Pseudonymisation

- All data will be de-identified and linked to a study ID.
- Identifiers will only be kept by the cohorts that collected the data and biospecimens and who could provide linking back to participants, should this become necessary.
- Standardised guidelines will be developed to guide cohort data managers in methods for data masking, generalisation of cohort data, data swapping, and aggregation to promote the privacy of cohort data.
- Where data anonymisation or pseudonymisation is not possible, we will implement decentralised TREs based on the OpenSAFELY model.

### Benefit Sharing

The types and forms of benefit that can arise from research conduct varies. A critical aspect of research is to generate new knowledge. The transformation of that knowledge to sharable benefits is a long and complex process. Recognising this, however, means that as far as possible, research should consider the different forms and types of benefits that can arise in research, and how those are equitably shared. Some of the benefits from research is to inform and transform health care practices. Policy engagement and translation of research into policy decisions and actions will be a critical aspect in research conduct. APCC offers a platform in which large scale studies can be conducted efficiently and generalisability of findings can be assessed. Benefit sharing with the cohort communities should be discussed and the results and outcomes of the individual studies should be communicated through appropriate contextually relevant channels. In all the dissemination of findings, the protection of privacy and confidentiality of individual participants and of participating communities – as far as possible – should be upheld.

Engaging communities is a key aspect of all APCC activities. Benefit sharing will seek opinions from diverse stakeholders including the community members and cohort populations. In some instances, increased capacity of local research teams to undertake community engagement will be necessary, in which case APCC will consider how such initiatives can best be supported, while also encouraging individual researchers to seek funding support as much as possible.

For each approved request for access, APCC will check if the requestor may derive any form of commercial gains from the use of the data or biospecimens or develop a new product or intervention. If so, APCC, in consultation with ethics committees and Intellectual Property (IP) offices, shall assess the potential benefits and risks of this activity to participants or their communities. The APCC will then decide on whether the agreement should be modified to include specific benefit-sharing arrangements.

### Intellectual Property Rights and Patents

- The APCC is in support of initiatives aimed at developing products and interventions that may improve health outcomes in Africa and the world.
- Intellectual property will be dealt with through relevant laws related to the

applicable protocol and underlying third-party agreements.

- Specific IPR policies and guidelines for APCC will be developed, with the involvement of legal experts, ensuring that they provide grounds for resolving that might arise in the attribution and management of IPRs.
- Should IP arise from the joint project, attribution will be managed according to the processes of the relevant parties considering the contributions from all those involved in accordance with the legal frameworks in each country.
- Each Party will be mindful of the needs of the other about disclosure of information that may attract IP. Should either party consider that a joint publication would disclose Joint Project IP, the other Party should be notified at least thirty days prior to publication, that Party may request a delay in publication of up to ninety days to secure protection of the Joint Project IP.
- Any IP, patents or royalties arising from APCC data should be equitably divided among the originator of the data and the innovator. IP and patents will only be pursued if they will not impede further research.
- All investigators and external users have the responsibility to honour the policies of their respective institutions in the acquired IPs.

*... the principle would be to publish its research findings widely and without unnecessary delay ...*



### Publication and Authorship Guidelines

APCC aims to promote the wide and international use of data and therefore needs to provide guidance on publications emanating from the use of its resources. The principle would be to publish its research findings widely and without unnecessary delays to optimise appropriate translation that will contribute towards scientific knowledge in Africa and worldwide. Implementing and interpreting this guideline is the primary responsibility of the senior leadership of all publications.

**Objectives** The following objectives will be considered to promote and facilitate publication:

- 1 Timely dissemination of findings
- 2 Fair and appropriate authorship and attribution of credits
- 3 Equity in opportunities to earn authorship in publications
- 4 Transparency of planned publications to avoid overlap and encourage collaboration
- 5 Encouragement of APCC-led publications without sacrificing the principles governing authorship practices
- 6 Publication in open access format
- 7 Assurance of appropriate communication of publications
- 8 Attribution and acknowledgements to study participants and the funding organisations

**Authorship** Authorship of publications is important for the integrity of the work presented (authors take responsibility for the content and presentations of the data and outcomes) and for the authors' own career development. Authorship is an important development tool to promote knowledge generation and to build investigator careers within the APCC, and the principle of inclusiveness is encouraged.



*... authorship is an important development tool to promote knowledge generation and to build investigator careers within the APCC ...*

Briefly, the key requirement for being an author (IJME criteria) is intellectual contribution as shown by all three of the points below:

- Substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- Drafting the article or revising it critically for intellectual input on content; and,
- Final approval of the version to be published.
  - **Lead author:** Takes responsibility for all phases of the manuscript. This person will articulate the study question, coordinate inputs from other members of the writing team, conduct (or at least direct closely) all analyses, and draft the manuscript. A manuscript should have one or (at most) two 'lead authors' (i.e. lead and senior author).
  - **Senior author:** If the lead author is not a senior author, the senior author takes responsibility for ensuring that the lead author knows about and applies the APCC guidelines.
  - **Core named authors:** Take responsibility for interacting closely with the lead author(s) at all stages of the project, providing regular and constructive feedback and inputs.
  - **Other named authors:** Commit to periodic inputs at key stages. This will likely include inputs to define the precise study question and agree on an approach to analysis; agreement as to the tables and figures to be presented; review of the full draft of the manuscript; and approval of the final version.
  - **Group authorship:** Specific APCC projects may elect to use group authorship where the research involves a collaborative effort among a significant number of contributors, each potentially bringing specialised knowledge or resources to the project.
  - **Acknowledgements:** Individual contributors who played a significant role in the research but did not meet the criteria for authorship might be acknowledged separately.

- **Datasets:** Contribution to the curation and sharing of datasets must be acknowledged. Datasets will have digital object identifiers (DOIs) and citation requirements, acknowledging study investigators and data managers responsible for the dataset. Publications based on the dataset must cite the dataset using the provided citation and quote the DOI of the dataset to acknowledge the origin of the dataset and contributing to the traceability of the use of the dataset.

### Biobanking

Some of the studies undertaken in collaborative research within APCC will inevitably include biospecimen collection which will involve processing and sharing across different institutions and with APCC. Population cohorts across multiple African countries and regions will provide an invaluable resource in terms of specimens and associated data for a better understanding of the health and wellbeing of populations. To facilitate this, we will establish an **APCC biobanking network**. Africa CDC is now a focal point for coordinated efforts across Africa by providing support and funding for regional biobanks. This is opening up an important synergistic opportunity for the APCC. This initiative will draw on work underway by regional biobanks to implement metadata standards and working towards biobank accreditation.

### APCC Biobanking Network

This will involve:

- Developing a set of minimum essential data elements.
- Building the APCC biobanking network along the lines of the International Society for Biological and Environmental Repositories (ISBER) framework, and leverage existing initiatives by the Africa CDC and H3Africa Biorepository working group.
- Promote best practices across the network and the implementation of international biobanking guidelines and ISO accreditation of biobanks by collaborating with:
  - ISBER (<https://www.isber.org/>) International Society for Biological and Environmental Repositories.
  - ESBB (<https://esbb.org/>) European, Middle Eastern & African Society for Biopreservation and Biobanking.
- Promote the adoption of ISO 20387:2018 'General requirement for biobanking' (<https://www.iso.org/standard/67888.html>) that will:
  - improve access to qualified biological resources and data;
  - ensure an appropriate quality of sample to fit an intended use;
  - harmonise and standardise procedures to enable exchange of biological material and related data among Biobanks and researchers;
  - increase stakeholder confidence and assurance; and,
  - foster the reproducibility of biomedical research thus reducing costs.

- Promote increased awareness and the necessity of high-quality bio-samples for omics studies, addressing the fact that there are few biobanks in Africa implementing international standards.

### Specific Needs for APCC Biobanks

- Standardised SOPs.
- Material transfer agreements (MTAs).
- Harmonised consent language for biospecimen collection and release, and data standards and biorepository data management practices.
- Biobanking governance guidelines.
- Compliance with policies and regulations or laws governing the access, transfer, and release of biospecimens.
- Help with adaptation of policies and procedures to local/in-country context for APCC member cohorts.



*... addressing appropriate and ethically approved consent models and decision-making processes that will permit the reuse of the data through access and/or sharing ...*

## Omics Data Management

### Objectives:

- To develop a strategy for omics data storage and distribution (central, distributed, mixed), including data sharing and access processes and decision making (governance)
- Quality assurance to ensure alignment with international data sources and databases
- Harmonisation (depends on capabilities and needs – clusters/region)
- Being mindful of the FAIR principles in the context of the omics
  - **Findable:** Having an APCC catalogue of data resources
  - **Accessible:** That the necessary skills and resources are in place to provide access the data is an accepted format – preferably being used in situ and not transferred to other locations
  - **Interoperable:** Ensuring that the way data is stored and retrieved can be analysed in a way that it can be compared to other data sources (e.g. alignment to which human genome reference build)
  - **Reusable:** Addressing appropriate and ethically approved consent models and decision-making processes that will permit the reuse of the data through access and/or sharing

### International Organisations:

- GA4GH (Global Alliance for Genomics & Health) (<https://www.ga4gh.org/>), PHA4GE (<https://pha4ge.org>)
- H3Africa (<https://h3africa.org/>)

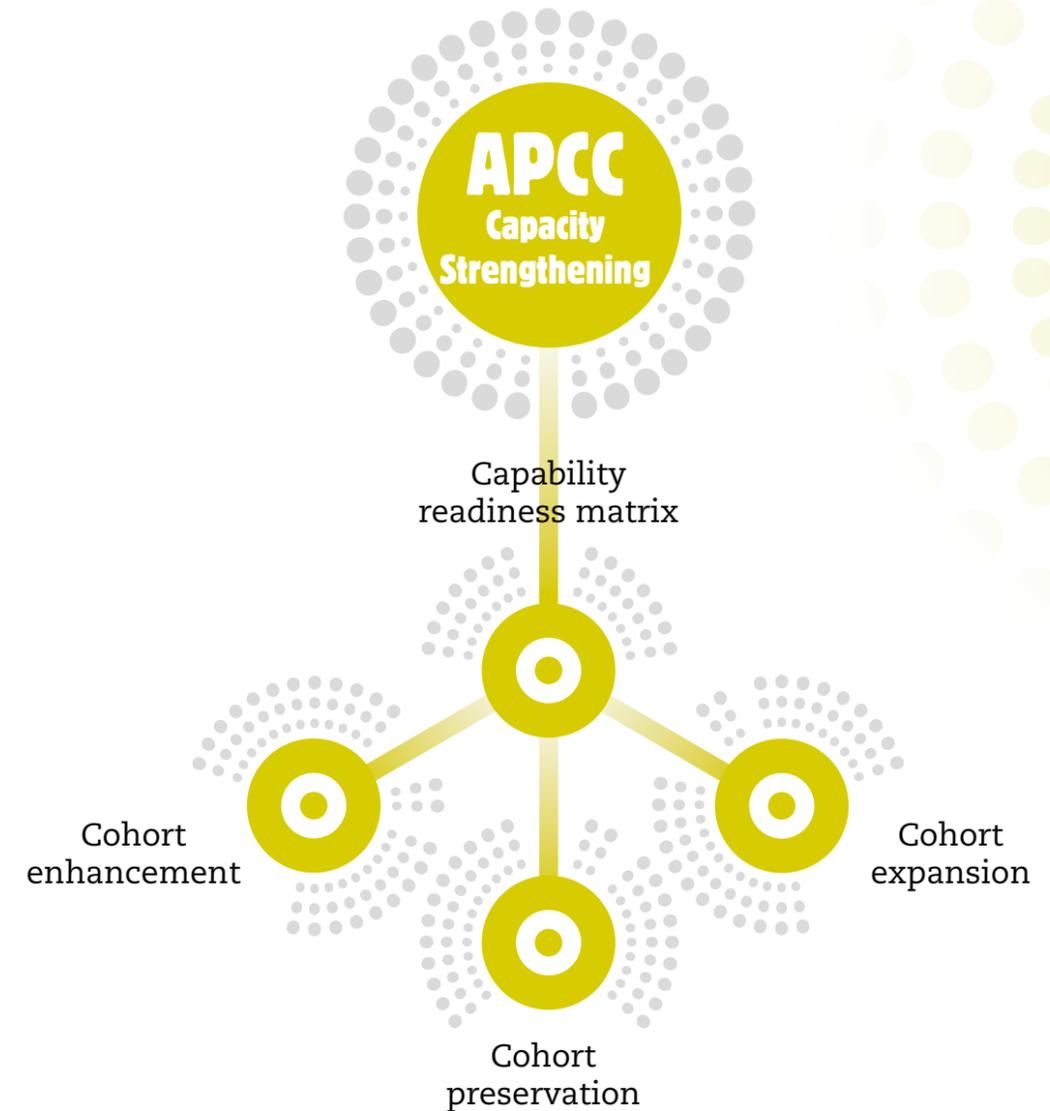
### Activities:

- Assess data and capabilities of cohorts, retrospective and prospective
- Establish a sub-group to develop guidelines for data QC, storage, and access
- Information sharing and discussion for a to debate the pros and cons of distributed (federated) data models and centralised storage, or a mixture of these (being mindful of national legislative and ethical practices)

**PART 4**

# APCC Capacity Strengthening

Capacity strengthening in the APCC aims to enable population cohorts in Africa to contribute to the APCC Mission to achieve its Vision. Capacity strengthening is based on a Capability Readiness Matrix that is maintained by the Secretariat and reviewed annually by the Steering Committee. The Matrix has an entry for each cohort in the APCC Membership across several dimensions that represent key capabilities of a cohort to contribute to the APCC's Mission.



## Capability Readiness Matrix

The Capability Readiness Matrix is a structured approach to document the capabilities present in the APCC member cohorts and assess the level of implementation or readiness of these capabilities. The Matrix will serve to:

- Identify capabilities where cohorts need strengthening
- Assess the extent to which a cohort meets certain capabilities that are required for a specific multi-cohort research project or access to funding
- Facilitate researchers finding cohorts with specific capabilities that they can collaborate with.

The initial Capability Readiness Matrix is intended to be simple and facilitate participation and engagement. Over time, the APCC may develop more complex capability readiness measures. The Matrix will be published on the APCC website as a searchable database.

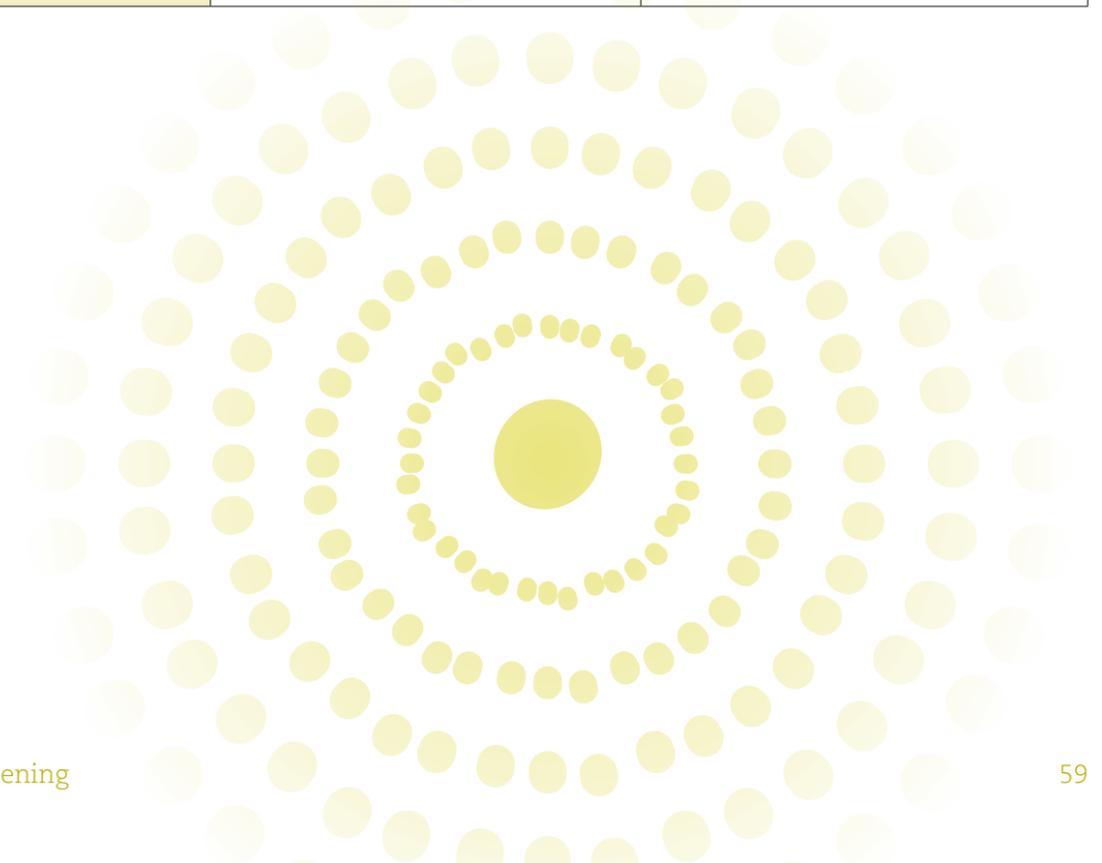
### Readiness Levels

The readiness for each capability is assessed as follows:

Readiness	Description	Level
Not implemented	The cohort has not implemented standard practice yet	0
Partial implementation	The capability is at a basic but acceptable level	2
Implemented	The capability is implemented at an advanced level	4
Advanced implementation	The cohort leads other cohorts in this capability	8

## Dimensions

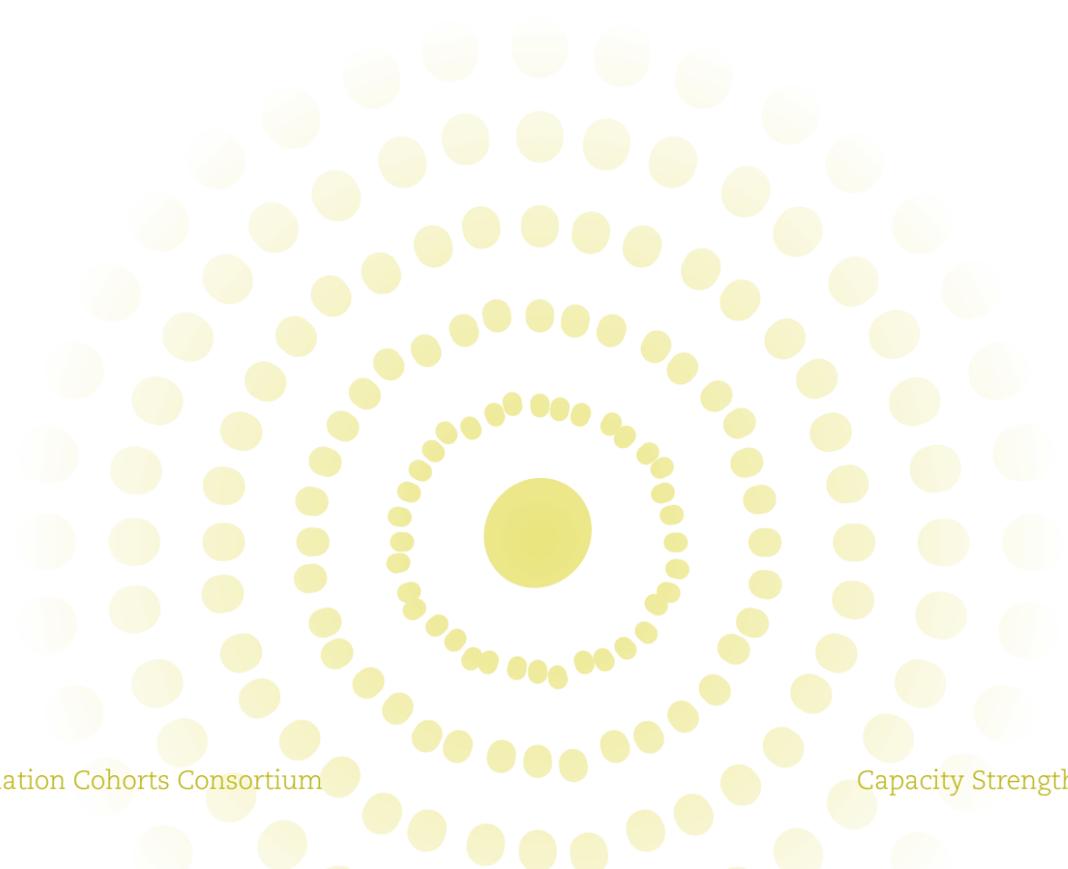
Dimension	Category	Elements
<b>Dimension 1 Cohort Operations</b>	1.1 Longitudinal follow-up 1.2 Operational management 1.3 Quality assurance 1.4 Data collection 1.5 Data processing 1.6 Sample collection 1.7 Sustainable funding	22 elements
<b>Dimension 2 Ethics &amp; Governance</b>	2.1 Ethics approvals 2.2 Consent 2.3 Organisational policies 2.4 Governance structures 2.5 Finance	13 elements
<b>Dimension 3 Community &amp; Participation</b>	3.1 Participant engagement 3.2 Community engagement 3.3 National stakeholders 3.4 Regional & international stakeholders	6 elements
<b>Dimension 4. Data &amp; Biosample Access</b>	4.1 FAIR principles 4.2 Biorepository	8 elements
<b>Dimension 5 Knowledge Production &amp; Impact</b>	5.1 Research strategy 5.2 Research capacity building 5.3 Research dissemination 5.4 Policy briefs 5.5 Peer reviewed outputs 5.6 Scientific collaborations	12 elements



## Dimension 1 Cohort Operations

Category	Element	Not implemented	Partially Implemented	Implemented	Advanced implementation	Documentation
1.1 Longitudinal follow-up	Regular follow-up	Last follow-up more than one year ago	Annual follow-up	Regular follow-ups scheduled and completed > = annually	Continuous follow-up through real time reporting of events	Data monitoring reports
	Loss to follow-up	Unable to determine or more than 10% loss per annum	Less than 10% loss to follow-up per annum	Less than 5% loss to follow-up per annum	Less than 1% loss to follow-up per annum	Data monitoring reports and annual report to ethics national bodies
	Contact rate	Unable to determine or less than 60% contact rate per annum	More than 60% contact rate per annum	More than 80% contact rate per annum	More than 95% contact rate per annum	
1.2 Operational management	Surveillance Schedule	No explicit surveillance schedule	Some form of systematic process covering schedule for each surveillance round	Weekly programme of exactly which subset of the cohort should be contacted	Data collection performance management programme linked to weekly schedule	
	Standard operating procedures	No SOPs	Basic SOPs covering some but not all aspects of cohort management	Up to date SOPs covering all aspects of cohort management	SOPs and operational manuals in place and up to date	SOPs, operations manuals
1.3 Quality assurance	Operational audit	No quality control or assurance programmes	Some quality control or assurance, but not systematic or comprehensive	Comprehensive quality assurance programmes based on internationally accepted standards	Received internationally recognised accreditation of processes with external assessment	Policy, SOP, report, certification
1.4 Data collection	Tools: method	Paper and pen	Electronic collection or Paper + double entry	Using recognised software with QC checks	Real-time monitoring of data collection through web-based tools	
	Tools: instrument validation	None or only some available	Available in English (with translations)	Pretested and validated questionnaires	Documented pretested and validated questionnaires available with training guides	
	Tools: data validation/checks	None	Ad hoc checks by data manager. No feedback to field team	Ad hoc checks on the data with feedback to field team to resolve	Daily automated, data validity & integrity checks with immediate feedback to data collection teams	
	Geocoding	None	GPS mapping of dwellings done in the past but not updated within the last year	GPS mapping kept up to date, with newly constructed or destroyed dwellings updated on a regular basis	Health care and other facilities of interest mapped as well	
	Meteorological measurement	None	Surface weather station in proximity of cohort location	One or more automated weather stations within the geographic boundaries of the cohort, measuring at least temperature, humidity, wind speed and direction, precipitation and solar radiation	A climate reference station within the geographic boundaries of the cohort	
1.4 Data collection	Frontline staff skills	No documented training	Documented pre-survey training, but no training continuity	Formalised training events and periodic refresher training with skills assessment and development	Formalised training events and periodic refresher training with skills assessment and development linked to ongoing performance appraisal	
1.5 Data processing	Programming	Ad hoc or legacy software with no maintenance plan or source code	Incomplete set of programmes for data processing	Complete and maintained data collection software environment	Capacity to develop or part of an open source development community	

Category	Element	Not implemented	Partially Implemented	Implemented	Advanced implementation	Documentation
	Archival data storage	On researcher/PI computer	Institutional server	Institutional server with off-site backup or cloud storage	Institutional or cloud server with business continuity fail-over	
	Data extraction, transformation, loading and analysis (ETLA)	Not available	Mainstream data analysis tools available	Standardisation on a limited set of tools with institutional user training and usage guidelines	Automated routine analysis for regular indicators needed in the study	
<b>1.6 Sample collection</b>	Biosample collection frequency	No biosample collection	Ad hoc collection (when needed by others)	Frequency of sample collection established	Frequency established and complied with for > 5 years	
	Sample collection completeness	Not applicable	Ad hoc collection on part of cohort	40-60% of cohort target group sampled	> 60% of cohort target group sampled	
	Sample storage	Not applicable	Some samples stored and labelled, no systematic storage	Samples stored and labelled and mostly available in computer database	Complete LIMS system for samples with knowledge of missing samples and use of samples for different analyses	
	Relevance and sufficiency	No assessment of relevance	Relevance and sufficiency of the samples reviewed more than five years ago	Regular review of relevance and sufficiency of samples collected	Sample relevancy and sufficiency reviewed with annual reports to oversight board	
<b>1.7 Sustainable funding</b>	Available funding	No current funding for cohort operations	Funding for the next year of cohort operations	Funding for three years or more for cohort operations	Funding for at least 5 years of cohort operations and/or a sustainability business plan based on user fees for nested studies	
	Sustainability	Ad hoc project-based funding	Cohort-specific project funding	Institutional core funding for cohort maintenance	Long-term funding as a national or regional research infra-structure	



## Dimension 2 Ethics and Governance Dimension

Category	Element	Not implemented	Partially implemented	Implemented	Advanced implementation	Documentation
2.1 Ethical approvals	National ethics	Ethics approval and/or renewal documents not available	Ethical approval document available	Ethical approval and latest renewal certification available	Ethics approval from a national body that permits data sharing and biobanking[1]	Ethics certificates
	International ethics[2]	No international ethics approval, but required	Ethical approval document available	Ethics approval from international collaborating institutions or not required	National framework for multi-country ethics approvals exist	Ethics certificates
2.2 Consent	Individual consent	Verbal consent only	Written consent for data collection only	Written consent for data collection, linkage and sharing obtained at each contact	Multi-level consent, including biosample collection and broad consent for sample re-use. Consent to be contacted for recruitment into studies nested within the cohort	Consent forms
	Community/household consent	No household level permission	Verbal consent by household representative for household level data collection and permission for household member contact	Written consent by household representative for household level data collection and permission for household member contact	Written consent for non-individualised data (e.g. assets etc.) to be shared and permission for household members to be contacted for recruitment into studies nested within the cohort	Consent forms
2.3 Organisational policies	Harassment and bullying	Not available	Available	Regular training and verification	Anonymous tip-off hotline managed by external party	Policy document, evidence of training and enforcement
	Anti-corruption and fraud	Not available	Available	Regular training and verification	Anonymous tip-off hotline managed by external party	Policy document, evidence of training and enforcement
	Women in science	Not available	Available	At least equal representation at executive level		Policy document
	Executive and management committees	None	Exists	Meets regularly and has formal terms of reference		Terms of reference
	Independent oversight[3]	None	Exists	Meets regularly, has terms of reference	Complies with generally accepted good governance standards e.g. King IV	Terms of reference
	Independent Scientific Advisory Board[4]	None	Exists	Meets regularly, has terms of reference	Reports available annually and evidence of responses	Terms of reference
	Community Advisory Committee/Board	None	Exists	Meets regularly, has terms of reference	ToR includes ability to exercise meaningful control over nature of studies conducted in the community	Terms of reference
2.5 Finances	Documentation	None	Infrequent reports	Audited financial statements available	Audited financial statements published annually in the public domain	Financial statements
	Audit	None	External auditors	External and internal auditors	Annual external audited statements that pass without major comment, audit and risk committee in place and reporting to governing body	

1 Some countries may not require explicit ethical approval for data sharing and/or biobanking.

2 May only be required if there are investigator/s from another country on the study.

3 "Board of Directors", "Board of Trustees", "Governing Council" or "Steering Committee" in some contexts. These bodies are

tasked with overseeing the organisation's management and operations, ensuring that executive actions align with the broader goals and policies set by the board. They also have a fiduciary duty to protect the interests of stakeholders.

4 Provides objective, expert advice on strategic direction, research priorities, and policies.

### Dimension 3 Community and Participants

Category	Element	Not implemented	Partially implemented	Implemented	Advanced implementation	Documentation
3.1. Participant engagement	Cohort participant engagement	No contact	Through committees and groups	Processes for participants to engage with institution	Processes for participants to engage with institution, including vulnerable groups	
3.2. Community engagement	Cohort community	No contact	Meeting ad hoc in response to requests	Regular meetings and reports	Community bodies integrated into the cohort activities. Outreach into community structures (schools, health facilities). Community recognises and values cohort's contributions. Co-design of research	
	District and local authorities	No contact	Meeting ad hoc in response to requests	Regular meetings and reports	Involved in planning and implementation	
3.3. National stakeholders	National government stakeholders	No contact	Meeting ad hoc in response to requests	Regular meetings and reports	Involved in planning and implementation	
	National non-government stakeholders (NGO, industry etc.)	No contact	Meeting ad hoc in response to requests	Regular meetings and reports	Involved in planning and implementation	
3.4. Regional and international stakeholders	Presence	None in past five years	Stakeholders who implement their projects within the cohort	Several stakeholders with diverse interests in the cohort workings	Equal partner in collaboration. Joint strategic decision making	

## Dimension 4 Data and Biosamples Dimension

Category	Area	Not implemented	Partially implemented		Implemented	Advanced implementation	Documentation required
<b>4.1 FAIR principles</b>	Findable	Not findable	Data documentation available, but data not in an accessible repository		Datasets have a globally unique & persistent identifier. Standard metadata for all shared datasets (e.g. DDI). (Meta)data are registered or indexed in a searchable resource	Metadata remains accessible even if data is no longer available	
	Accessible	No publicly available information on how to access data	Information on how to access data available publicly (e.g. institutional website)		Datasets are accessible in a data repository, with a clear data use agreement	(Meta)data are retrievable by their unique identifier using a standardised communications protocol which allows for an authentication and authorisation procedure. Metadata accessible, even when the data are no longer available	
	Interoperable	Non-standard data formats are used or data only available in proprietary data formats	Data available in commonly used or standard data and file formats		(Meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation and (Meta)data use vocabularies that follow FAIR principles	Relationships within (meta)data, and between local and third-party data, have explicit and 'useful' semantic meaning, e.g. complies with commonly used approaches such as OMOP	
	Reusable	Permissible data usage not specified	(Meta)data released with clear and accessible data usage licence		(Meta)data meet domain-relevant community standards	(Meta)data are associated with detailed provenance	
<b>4.2 Biorepository</b>	Location	None	Samples stored in other country		Nationally hosted biorepository with appropriate technical support to international standards	Institutionally hosted biorepository with appropriate technical support to international standards	
	Documentation	No sample transfer agreements	Ad hoc agreement for sample transfer		Samples transferred to collaborators but no results obtained from the samples	Samples transferred and results obtained and logged in LIMS	
	Contribution to resource	Not applicable	Exported sample results not accessible		Results generated often held by institution and made available to other researchers	Formal requirement to ensures results become accessible part of resources	
	Governance	No formal governance	Internal decision no agreed criteria		Formal governance with agreed criteria	Formal governance with agreed criteria, internal and external independent representation. Documentation of decisions.	

## Dimension 5 Knowledge Production and Impact Dimension

Category	Element	Not implemented	Partially implemented		Implemented	Advanced implementation	Documentation required
<b>5.1 Research strategy</b>	Research	None	Strategic direction predominantly determined by external actors		General statement on research strategy and some generation of proposals within institution	Strategy and research proposals generated predominantly internally and updated and implemented	
<b>5.2 Research capacity building</b>	Post-docs	None	One post-doc in the last three years		Regular post-doc applications and more than one successful in past 3 years	Post-docs actively engage in new strategic research and contribute to future vision	
	Post-graduate students	No post-graduate students making use of cohort data or samples	Small number (< 10) post-graduate students making use of cohort data or samples, no formal agreement with or programme involving local universities		Research capacity building programme involving local and/or international educational institutions covering spectrum from master's to post-docs	Funded research capacity building programme aimed at making optimal use of cohort resources for training	
	Research community	No active research community	Seminars organised when others visit and some discussion of findings		Ad hoc journal club and science presentations	Active journal club regularly discussing new papers and science presentations and discussions	
<b>5.3 Research dissemination</b>	Scope of dissemination	No local or wider dissemination, or confined to social media	Occasional local and national dissemination events		Regular programme of local and national dissemination with agreed channels	Active programme of evaluated community level and national dissemination sessions early in process, in combination with international dissemination and social media where appropriate	
	Presentations	None	Presentations in local and national conferences		Several staff presented at international conferences over last 3 years	Results presented at national and international conferences with follow up to network and involve staff in collaboration	
	Attendance	None	Local conferences attended infrequently		Encouragement for all staff to attend face-to-face and virtual conferences	Active participation in conferences by all staff. Strategic decision on which conferences would be good for the cohort	
<b>5.4 Policy briefs</b>	Policy briefs	None	Policy briefs produced occasionally on an ad hoc basis		Policy briefs regularly produce at national level	Standard procedures for national and international policy briefs	
<b>5.5 Peer-reviewed output</b>	Strategic programme	No review or strategy for increasing outputs (quality or quantity)	Ad hoc review of outputs		Annual review of outputs from the cohort. Available in report	Evidence of comparison of outputs with other cohorts and recommendations to undertake new outputs based on report	
	Contributions	No institutional contribution to peer-review papers	Most papers with senior authors from outside / collaborating institutions		Cohort personnel taking key role in papers	Cohort personnel taking the lead in collaborative papers and international comparisons	
<b>5.6 Scientific collaboration</b>	Collaborative projects	None	At least one study in cohort with outside collaborators		Participate in at least one multi-country cohort study	Leads at least one multicohort study	
	Networks	Not a member of a network	Member of network but not active		Active in at least one network	Lead a working group in a network, or is represented at steering committee level of a network	

## Cohort Enhancement

Cohort enhancement is aimed at levelling up the capabilities (represented in the Capability Readiness Matrix) of cohorts to achieve their own objectives as well as increasing their ability to contribute to multi-cohort science in support of the APCC's Mission.

The starting point of the cohort enhancement programme is the Capability Readiness Matrix; by analysing the matrix areas requiring capacity strengthening will be easily identifiable.

Based on the core information about the cohort and workshops with cohorts during the APCC formative phase, the following cohort enhancement programmes are anticipated:

### Cohort Enhancement Programmes

- 1 Data preparedness:** The aim is to enhance the ability of cohorts to comply with FAIR data principles and more reliable data collection and processing.
- 2 Cohort Ethics:** The aim is to enhance compliance with ethical principles, and statutory requirements, and develop a consistent approach to participant consent to facilitate cross-cohort research, data sharing and biosample access.
- 3 Good Cohort Management:** The development of a discipline of good cohort management practice and a curriculum to train operational managers of cohorts. In addition to training workshops, this will also involve exchange programmes of staff to cohorts with leading capabilities, and sharing of resources, such as SOPs, training material, data collection tools, and other research materials.

These cohort enhancement programmes will be built into the strategic research programmes to ensure that cohort enhancement is closely linked to specific research objectives.

## Cohort preservation

Cohort preservation addresses at-risk cohorts or biosample collections and is aimed at supporting the sustainability of cohorts with leading capabilities but a break in core funding, or cohort biobanks with valuable specimen collections that they can no longer sustain.

### Criteria for Consideration of Core Support

- 1** Full membership status
- 2** Dependence on time-limited research grants
- 3** No access to national funds
- 4** Representation of priority geographic area
- 5** Nationally unique
- 6** Representation of priority LMIC status – eg LIC or VLIC
- 7** Researching topic areas defined as “high priority” by APCC
- 8** Recognised centre of excellence

## Specific Objective

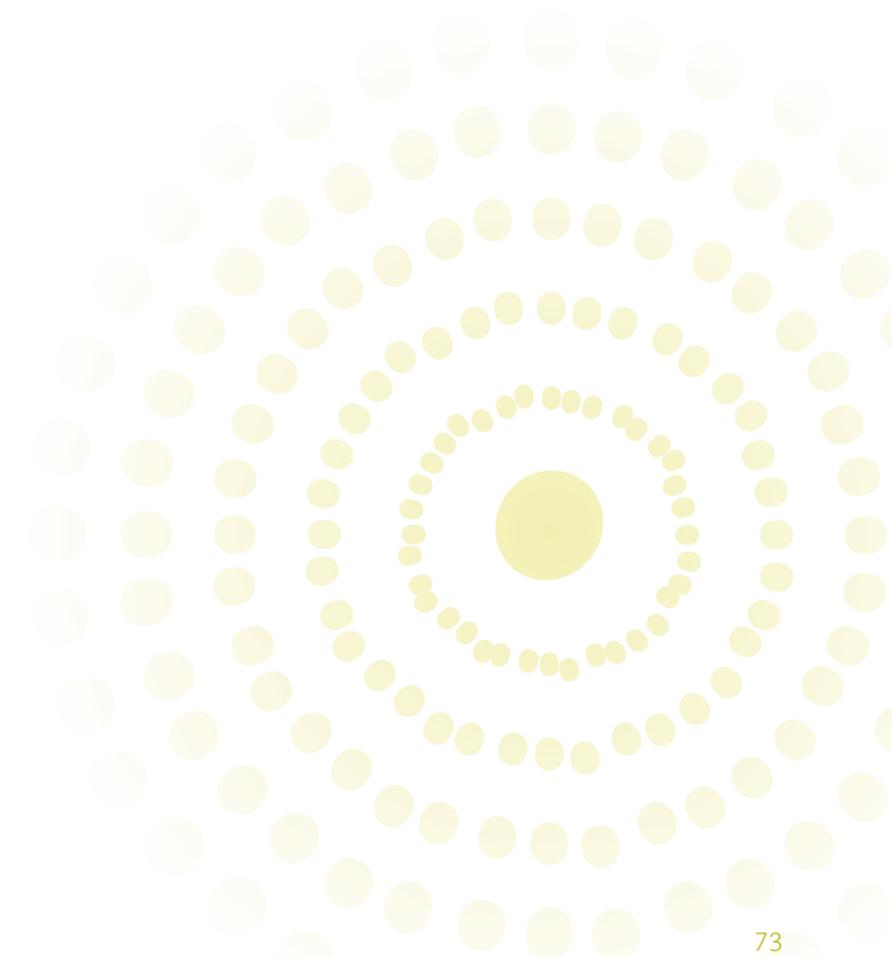
During the two years of the APCC launch, a call for applications to provide core funding to three population cohorts with leading capabilities, but in imminent danger to cease cohort surveillance due to lack of funds, will be made.

## Cohort Expansion

Cohort expansion is aimed at **establishing new cohorts** in regions or populations groups that are under represented in APCC to the detriment of the APCC's Mission. Specifically, the information collected by the APCC has identified regions and countries in Africa without population cohorts. This can be to the detriment of APCC's ability to represent the full diversity of people and ecology in Africa.

## Specific Objective

During the first two years of the APCC will identify initiatives in at least three African countries without large population cohorts which can be supported to establish a population cohort and provide seed funding for feasibility studies for their establishment.

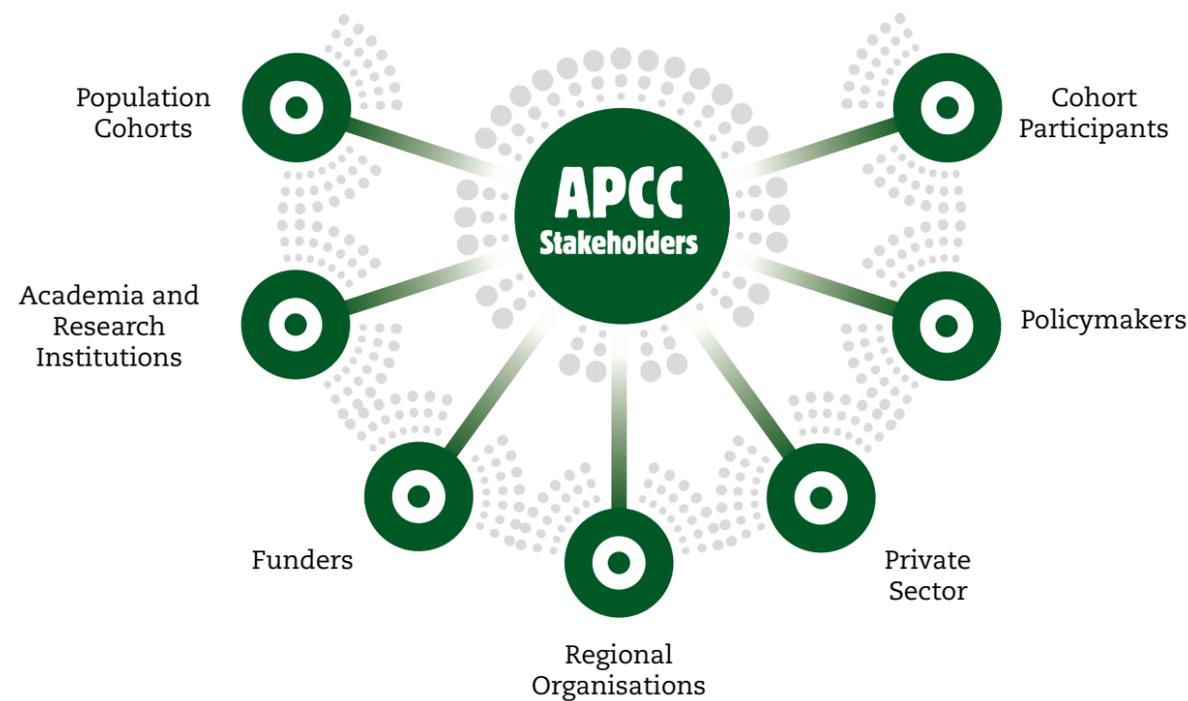


PART 5

# APCC Stakeholders

## Introduction

One of the key objectives of the APCC is to foster collaboration and knowledge exchange among researchers, institutions, and policymakers across Africa and beyond. The consortium will promote interdisciplinary research, capacity building, and evidence-based decision-making to improve population health outcomes by sharing population health data, expertise, and resources. The APCC realises that a key activity to achieving collaboration, ownership and co-creation is engaging relevant stakeholders, thus the importance of this programme.



## Stakeholder Categories

- **Population Cohorts:** As actual and potential members of the APCC, they are the primary stakeholders of the APCC.
- **Cohort Participants:** Cohort participants and community organisations are stakeholders in their own right, and involving them will foster a sense of ownership and investment in the research process and outcomes among participants and facilitate the co-creation of knowledge.
- **Academia and Research Institutions:** Academic institutions are crucial in population cohort research, providing expertise and knowledge, through sourcing for funding support, designing and implementing research projects, as well as the analysis and dissemination of findings.
- **Policymakers and Influencers:** This group comprises individuals and organisations that shape research policies and guidelines and includes government agencies and ministries, civil society, advocacy groups, and non-government organisations, among others. They contribute to the development of research questions and provide insights into the policy landscape, ensuring that the research aligns with the broader goals of the initiative. They are involved in policy-formation and advocacy activities, including in knowledge transfer, translation and implementation of evidence to policies and practices.

- **Funders:** Funding organisations and institutions are vital stakeholders in population cohort research. They provide the necessary financial and allied resources to support research activities, capacity strengthening, and training, ensuring the sustainability and success of the initiatives.
- **Regional Organisations:** These entities, including regional entities such as Africa CDC and regional economic communities (e.g. ECOWAS, SADEC, EAC, etc.), and African offices of international organisations (e.g. WHO Afro, Africa CDC, etc.). They play a significant role in supporting initiatives to identify regional research priorities, in shaping the research agenda, and in providing support for population cohort research in Africa.
- **Private Sector:** The health tech industry (including pharmaceutical, technology companies and start-ups) contributes to the research landscape by providing innovative tools and solutions for data and sample collection, analysis, and management, and is often interested in obtaining access to cohort resources.

In the subsequent section three of the crucial stakeholder groups (academia and research institutions, policymakers and influencers, and cohort participants) will be expanded upon to show how the APCC will leverage engagement with them to achieve its vision.

## Case Study • Clinical Trials Community (CTC)

The Clinical Trials Community (CTC) online platform, funded by the Bill & Melinda Gates Foundation, makes the process of identifying African clinical trials sites effortless by providing easy access to African clinical trialists, site feasibility data and regulatory and ethics information all on one platform. CTC promotes clinic trial sites by providing a platform where they are easily searchable and findable by key stakeholders. The goal is to increase the level of Clinical Trial investments in Africa by increasing the visibility of African clinical trialists and research centres as well as making transparent and accessible individual country regulatory and ethics procedures to inform decision making by sponsors. We provide a platform for constant engagement among key stakeholders to increase efficiency and promote collaboration. [<https://ctc.africa>]. The Clinical Trials Community Africa Network (CTCAN) project, having the Science for Africa Foundation (SFA) as the scientific coordinator, lays the foundation for the creation of a coordinated and sustainable umbrella network of clinical trial sites and laboratories capable of undertaking high quality clinical research in Sub Sahara Africa. The objective is to make this “network of networks” easily accessible to African and international sponsors with all deliverables and objectives linking back to the CTC platform. CTCAN’s clinical trial preparedness framework provides the necessary tools to assess site and laboratory

capabilities and any potential quality and operational gaps clinical researcher centres may have, along with the instruments to mitigate and overcome these gaps. In addition to the European & Developing Countries Clinical Trials Partnership (EDCTP) call-specific objectives, CTCAN optimally leverages and strengthens other features of the CTC platform that are critically important for effective and efficient trial execution in Africa: demography of diseases-of-interest and patient populations paired with ready-to-use operational information on local and national regulations impacting clinical trial start-up and conduct [<https://ctcan.africa>] and illustrates the benefits of private sector partnerships in research.



## Academia and Research Institutions

The activities of the APCC will not take place in isolation. There are many ongoing initiatives that the APCC should take into account to avoid duplication of effort and to obtain maximum synergistic benefit in pursuing its Vision and Mission. Some of these initiatives include:

### Network of African Genomics Centres of Excellence (GenCoE)

The **Network of African Genomics Centres of Excellence (GenCoE)** was co-created by African investigators with support from international leaders to advance translational genomics on the continent. The leadership team are currently developing a funding approach to support genomics implementation and capacity building across Africa through the development of centres of excellence comprising academic and public health institutions. The centres will focus on translational genomic medicine, pathogen surveillance response, and genomics workforce development. Discussions have taken place with the Africa CDC as a possible host for the coordinating centre for GenCoE. The timelines for the rollout are currently being developed and will be dependent on successful fundraising.

There is an opportunity for the APCC and its cohorts to partner with GenCoE, whose sites may be collocated with APCC sites or within the same geographical regions. The APCC aims to gather a wealth of phenotypic data spanning across time, which offers longitudinal insights. GenCoE and APCC can partner to develop data collection/standards and geographic scope. GenCoE can facilitate the generation of genome sequence data for APCC members for which genomics can offer a diagnosis or further insight into possible disease risk. The combination of genomic and phenotypic data not only presents a powerful tool for discovery research but also holds immense promise for translational research, especially when targeted towards specific disease-related inquiries. GenCoE can work with the APCC to develop nested cohorts for specific diseases, with GenCoE providing the link between academia, public health and industry. APCC cohort participants can feed into the GenCoE pipeline for research, health intervention and clinical trials. APCC and GenCoE will have common requirements for data infrastructure and skills, so capacity building in these areas can be coordinated and shared.

### INSPIRE

The **Implementation Network for Sharing Population Information with Research Entities (INSPIRE)** is an initiative under the African Population Health Research Centre (APHRC) which brings together African investigators and international leaders to advance data science on the continent. The leadership team has used project funding to develop a coordinated framework for cutting edge data science, including collection, management and analytics for federated databases. INSPIRE has created data hubs where institutions will be able to develop, implement and build capacity, leading to centres of excellence across Africa within academic and public health institutions. The centres will focus on population health, linkages with clinical and genomic data, pandemic surveillance and workforce training and development. Discussions have taken place with the Africa CDC for an Africa wide

### APCC & GenCoE Coordination Areas

- Electronic Health Records
- Nested Project Cohorts

### APCC, PGI & GenCoE Coordination Areas

- Clinical Trials

### PGI & GenCoE Coordination Areas

- Bioinformatics Needs
- Data Analysis & Response

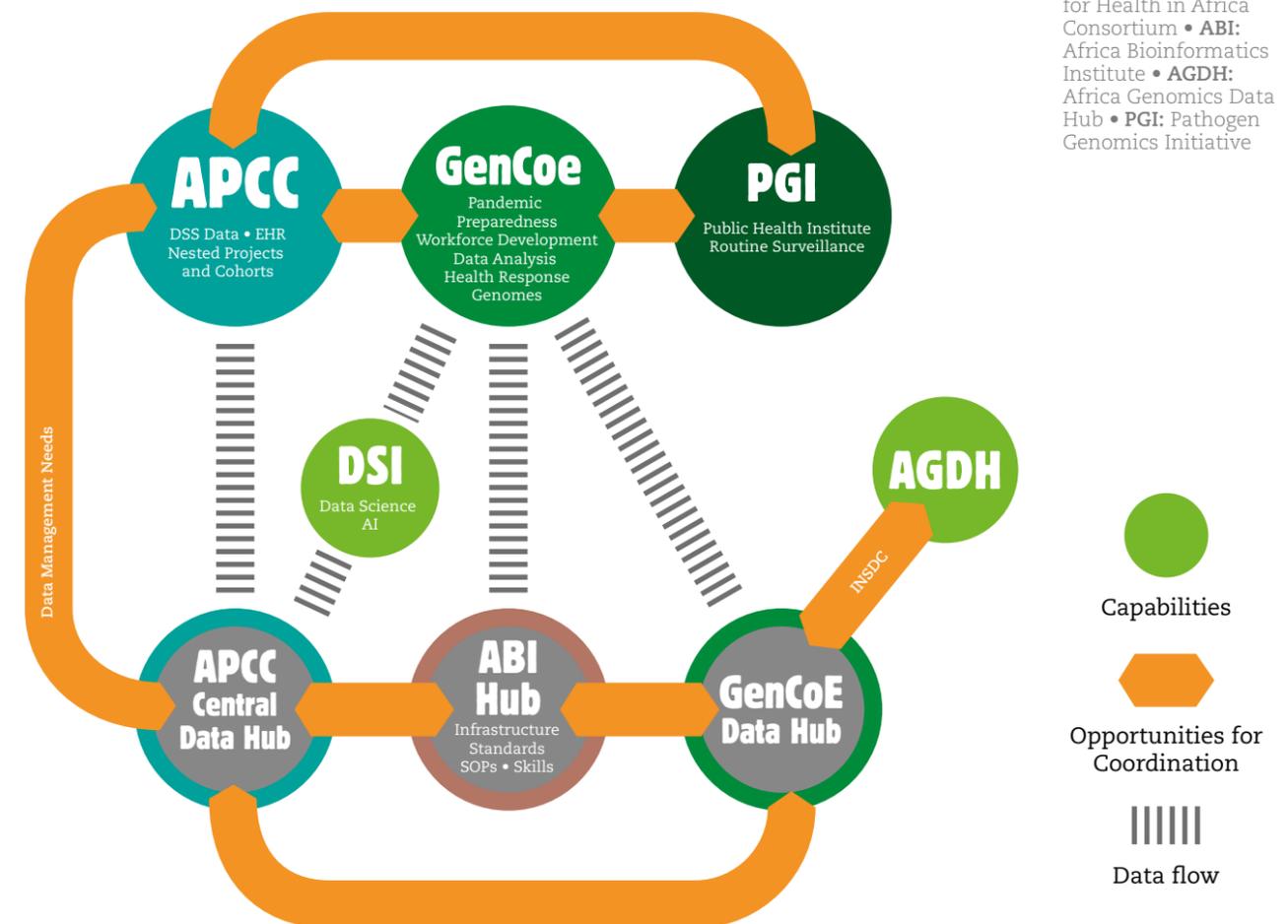


Figure 6: APCC in relation to GenCoE

Acronyms:  
 APCC: Africa Population Cohort Consortium •  
 GenCoE: Genomic Centres of Excellence for Health in Africa Consortium •  
 DSI: Data Science in Africa Consortium •  
 ABI: Africa Bioinformatics Institute •  
 AGDH: Africa Genomics Data Hub •  
 PGI: Pathogen Genomics Initiative

approach to data science and for the roll out of successful initiatives. The timelines for rollout will be dependent on successful fundraising.

There is an opportunity for the APCC and its cohorts to partner with INSPIRE whose hubs may be collocated with APCC sites or within the same geographical regions. The APCC aims to build common data models, coordinate the development of standardised vocabularies for population health, and create trusted research environments for specific questions that can be answered using existing and new data. APCC cohort participants can feed into the INSPIRE common data models for research, health intervention and clinical trials. APCC and INSPIRE will have common requirements for infrastructure and skills, so capacity building in these areas can be coordinated and shared. INSPIRE will provide a link between academia, research projects, public health and industry to build data science capacity for population health in Africa.

### **African Research Universities Alliance (ARUA)**

ARUA is a network of 24 universities from 12 different African countries with different historical backgrounds, but with a common vision. The network is generally about expanding and enhancing significantly the quality of research being conducted in Africa by African researchers. ARUA is intended to develop local research excellence through collaboration to find solutions to the development problems of Africa. It is set to become a pan-African network for bringing research and academic excellence to the fore throughout the region by developing strong and viable research universities.

ARUA provides a forum for the APCC to interact with the academic heads of research of the ARUA member universities to jointly explore and develop the APCC research vision and objectives. Through this channel the APCC team will be linked to scientists at their member universities working on longitudinal populations studies or seeking to answer key research questions by accessing the platform of population cohorts represented by the APCC. ARUA is also very interested in the capacity-building opportunities offered by the APCC for post-graduate students and emerging researchers in accessing the wealth of data and research materials represented by such a consortium.



**... the APCC team will be linked to scientists at their member universities working on longitudinal populations studies ...**

### **Data Science for Health Discovery and Innovation in Africa (DS-I Africa)**

DS-I Africa is a NIH Common Fund initiative aiming at leveraging data science technologies to transform biomedical and behavioural research and develop solutions that will lead to improved health for individuals and populations. To accomplish this, the DS-I Africa initiative aims to contribute to the development of the necessary expertise among African scientists, and to establish networks of African investigators. The vision of DS-I Africa is to create and support a robust pan-continental network of data scientists and technologies that will be equipped to apply advanced data science skills to transform health.

Their goal is to advance data science and related innovations in Africa to create an ecosystem that can begin to provide local solutions to countries' most immediate public health problems through advances in research. Specifically they aim to:

- Create a pan continental network with broad academic, public, private and industry partnerships.
- Enhance data science capacity through training toward developing a new generation of interdisciplinary African data scientists.
- Develop new data collection and analytic systems, applications, and tools with attention to usages that are population-relevant, affordable, acceptable, and scalable.
- Facilitate advances in policy surrounding ethical issues related to data use.

- Facilitate access to data resource for the global scientific community.
- Establish recognised regional and continental data science centres of excellence.
- Enable new interdisciplinary collaborations and new scientific knowledge.
- Demonstrate the feasibility of advanced data science to improve health in Africa.

There are many synergies between the APCC and DS-I Africa, and cohorts can and already are participating in many of these activities. The APCC methodology development and data standardisation and access efforts will be able to implement many of the advances facilitated by DS-I Africa.

### **Developing Excellence in Leadership, Training, and Science in Africa (DELTAS AFRICA)**

DELTAS Africa is a long-term, multimillion dollar programme launched in 2015 to support collaborative consortia led by Africa-based scientists to amplify Africa-led development of world-class research and scientific leaders on the continent, while strengthening African institutions. DELTAS Africa generates data and evidence driven by world class science leaders working in conducive and enabling environments to inform policy and Africa's development agenda.

DELTAS Africa seeks to produce researchers who drive locally relevant and high-quality health research impacting on science, policy and practice in Africa and contributing to improved health and sustainable development on the continent and globally. The Science for Africa Foundation (SFA Foundation) is implementing the DELTAS Africa programme and manages the second phase, DELTAS Africa II, 2023-2027 with support from Wellcome and the UK Foreign Commonwealth and Development Office (FCDO). This second phase kicked off in 2023 with 14 consortia from nine African countries, namely Côte d'Ivoire, Ethiopia, Ghana, Kenya, Mali, Senegal, South Africa, Tunisia and Zimbabwe, with partnerships across Africa and globally. The focus is to improve Africa's research ecosystem through the production of quality science and a critical mass of world class science leaders. This initiative seeks to address and link country-level challenges via science innovation, translation, and entrepreneurship, in order to strengthen science ecosystems and infrastructure to deliver targeted R&D outcomes for Africa.

The DELTAS Africa's governance model influenced the APCC Blueprint, and many of its participating scientists are responsible for cohort-based research.

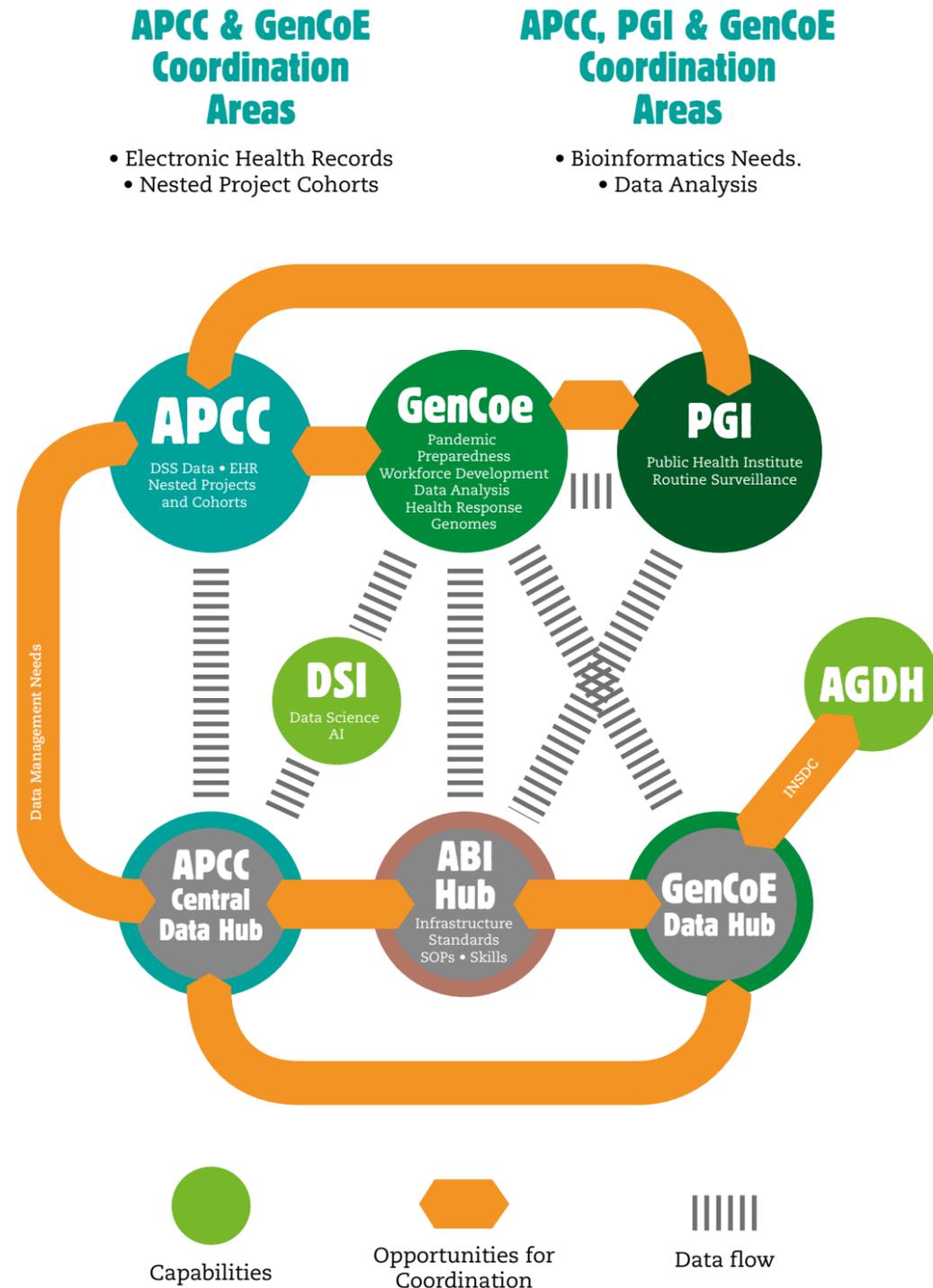
### **Africa Bioinformatics Institute (ABI)**

Building on the successes of H3ABioNet, the African Bioinformatics Institute (ABI) will create a well-coordinated federated network of computational biologists and data scientists across Africa. The ABI will directly empower and support multiple African life science and biomedical initiatives that are poised to produce large amounts of valuable data, and thus require access to infrastructure, expertise and training to manage, interpret and distribute those data. The ABI will be a geographically distributed institute implementing high quality bioinformatics research, training and services, with group leaders from multiple institutions and a centralised leadership and administration. Its governance will ensure both equitable representation of its stakeholders and accountability to its funders. An

initial meeting of all stakeholders will seek a consensus on the modalities of its implementation. The ABI will ensure long-term adherence of the African research and public health community to the principles of data quality, governance and sharing established by the H3Africa and DS-I Africa programmes. It will provide a home for collaboration, sharing of data and computational infrastructure and expertise, and development of research projects for African computational biologists.

**Figure 7:**  
African  
Bioinformatics  
Institute,  
genomics  
connections

**Acronyms:**  
**APCC:** Africa  
Population Cohort  
Consortium •  
**GenCOE:** Genomic  
Centres of Excellence  
 • **DSI:** Data Science  
for Health in Africa  
Consortium • **ABI:**  
Africa Bioinformatics  
Institute • **AGDH:**  
Africa Genomics Data  
Hub • **PGI:** Pathogen  
Genomics Initiative



The ABI aims to:

- 1 Serve the African life science community by offering easily accessible world-class competencies, expertise and support in bioinformatics.
- 2 Create, maintain, and disseminate a portfolio of reliable, sustainable, and top-quality core bioinformatics services and resources.
- 3 Federate world-class bioinformatics researchers and deliver training in bioinformatics.
- 4 Provide a high-quality bioinformatics infrastructure for several existing and upcoming continental initiatives, including but not limited to:
  - Pandemic preparedness, including pathogen surveillance, contributing to global health security and enhancing global preparedness for infectious disease outbreaks;
  - A network of genomic centres of excellence (GenCoE) and population cohorts in Africa (APCC), promoting collaboration, knowledge exchange, and sharing of genomic data and insights to strengthen genomic medicine and global health efforts; and,
  - Initiatives to explore and utilise the vast biodiversity in Africa through genomics.
- 5 Become the preeminent institution for managing, overseeing and analysing life science and health data across Africa.
- 6 Foster an open-source culture, promoting collaboration and knowledge sharing among bioinformatics researchers and institutions in Africa, driving innovation and progress in the field, and facilitating the development and dissemination of innovative computational tools, algorithms, and methodologies.

Initiatives such as the APCC and others generating big or complex data across multiple sites, will share a need for computational expertise and require access to infrastructure (hardware, software, databases, data management systems, interoperability standards), individuals with proven expertise in computational genomics, and training programmes at all levels for their staff and collaborators. The creation of the ABI is driven to a large extent by the need to ensure that there is a stable, sustainable core group in Africa with the infrastructure, expertise, and training experience to serve the requirements of the current explosion in data-driven projects and potential future large-scale omics initiatives. Its primary role will be to work together with the staff and leadership of projects such as APCC to ensure their success.

The ABI will be established as an independent legal entity (non-profit organisation) with a governance similar to that of the Swiss Institute of Bioinformatics, which has successfully served the needs of a very diverse community for over 25 years. The core concept behind the ABI is that it will federate scientists across Africa who are active in computational biology. These group leaders will be collectively responsible for carrying out the missions and projects of the ABI while, for most of them, keeping academic affiliations in their home countries. The ABI will be headed by an Executive Director, supported by an Associate Director of Training and an Associate Director of Services, and aided by a five-member Board of Directors including representatives of ABI scientists

and institutional partners. A Foundation Council representing all partners and stakeholders will have the ultimate authority, and an independent Scientific Advisory Board will advise on scientific issues. A Council of Group Leaders will channel the voices of the ABI scientists.

## **Policymakers and Influencers**

### **Africa Centre for Disease Control and Prevention, Africa CDC**

Point person: Dr Elvis Temfack (Senior Research Officer, Division of Public Health Institutes and Research).

The Africa Centre for Disease Control and Prevention is based in Addis Ababa, Ethiopia. Through its programmes, it aims to strengthen the capacity and capability of Africa's public health institutions as well as partnerships to detect and respond quickly and effectively to disease threats and outbreaks, based on data-driven interventions and programmes. It also supports the establishment and strengthening of National Public Health Institutes to coordinate surveillance systems in a multi-sectoral approach and ensure that surveillance data informs national policy and public health actions.

As a research and technical institution, it facilitates and strengthens the Regional Collaborating Centres to promote inter-country and regional collaboration on surveillance, shared data use, and engagement with laboratory networks.

The APCC can leverage on Africa CDC's wide regional outreach through its coordination centres in public health as well as its research work across the continent for early warning, risk assessment, disease predictions, and response. Africa CDC should be informed regarding the ongoing longitudinal studies across Africa to gauge how best its research work can enhance the APCC programme including engagement with cohort leads on the longitudinal health research studies.

### **East Africa Community (EAC)**

Point person: Dr Eric Nzeyimana (Principal of Health).

The East African Community (EAC) is a regional intergovernmental organisation of eight Partner States comprising the Republic of Burundi, Democratic Republic of Congo, Republic of Kenya, Republic of Rwanda, Federal Republic of Somalia, Republic of South Sudan, Republic of Uganda and United Republic of Tanzania, with its headquarters in Arusha, Tanzania.

The EAC provides room for increased collaboration in disease surveillance and epidemic control. This is because the frequent population movement across the five shared borders of the eight countries poses a greater risk of spreading diseases from one country to another. The response to such a potential regional epidemiological emergency is complex and involves national, regional and international agencies requiring an efficient and quick flow of information across the borders. In order to promote the achievement of the health-related objectives as set out in Article 118 of the Treaty for the establishment of the EAC, there are five standing Technical

Working Groups. These are:

- 1 Medicines and Food Safety;
- 2 Control and Prevention of Sexually Transmitted Infections (STIs), HIV and AIDS;
- 3 Control and Prevention of Communicable and Non-Communicable Diseases;
- 4 Health Research, Policy and Health Systems Development; and,
- 5 Reproductive, Child, Adolescent Health and Nutrition.

As part of the stakeholder engagement work, APCC acknowledges the importance of EAC as a regional governmental institution in leading and managing systems geared towards delivering health as a human right. As evidenced by the COVID-19 pandemic, the EAC provides a platform for communicating and coordinating national and cross-border agreements in strengthening health systems and delivering care. With the objective of engagement with key stakeholders at local and national, regional, and continental/global levels, APCC intends to capitalise on the existing network of experts and influencers in advocating for a well-coordinated continent-wide hub of knowledge.

### **East Africa Health Research Commission (EAHRC)**

Point person: Dr Fabian Mashauri (Deputy Executive Secretary/Principal Health Officer at the East African Health Commission (EAHRC)).

The EAHRC was established by the Heads of State of the EAC Partner States, as stipulated by the provisions of Article 118 of the Treaty of the establishment of the East African Community. It is the principal advisory institution to the EAC on Health Research and Development (R&D) regarding knowledge generation, technological development, policy formulation, and practice.

The EAHRC is implementing a five-year Strategic Plan that is aimed at promoting and coordinating the conduct and application of health research for the improvement of public health in East Africa. It also has established research programmes, networks, partnerships and centres of excellence in health research which the APCC can take advantage of for health research knowledge sharing and management. The East African Health Research Commission coordinates and maps out a regional agenda on health research as well as the translation of its results into policy and practice within the Partner States which is crucial to the objectives of the APCC i.e. knowledge brokering for population health research and policy formation.

### **WHO-AFRO**

Point Person: Dr Ngongoni Chipso (Health Innovation Ecosystems Management Specialist - World Health Organization).

The WHO Regional Office for Africa (WHO-AFRO) is one of WHO's six regional offices around the world. It serves the WHO African Region which comprises 47 Member States with the Regional Office in Brazzaville, Republic of Congo. As the lead health authority within the United Nations (UN) system, they work with the Member States in the African Region and development partners to improve the health and wellbeing of people. Their work involves translation of global health

initiatives into regional plans that respond to the specific needs and challenges of countries in the Region. The Office also supports countries to achieve better health outcomes through technical and policy advice, development of norms and standards, generation and sharing of knowledge and convening health partners. Together with countries, they attain health objectives by supporting national health policies and strategies.

APCC acknowledges the current role of the WHO-AFRO in tackling the five most neglected tropical diseases in Africa through its flagship programme, Elimination of Neglected Tropical Diseases (ESPEN). In implementing this programme, it has leveraged on its public and private partnerships across various countries in Africa to provide evidence based guidelines on effective tropical disease interventions and enhanced data sharing mechanisms. We hope to capitalise on the WHO-AFRO's ESPEN programme network of experts and influencers in advocating for a well-coordinated continent-wide hub of knowledge, as well as on their links with key stakeholders on all levels from local to global. We will also engage with them regarding becoming a funding partner of the APCC.

## Partners in Population and Development (PPD)

Point person: Patrick Mugirwa (Programme Manager, PPD ARO).

Partners in Population and Development (PPD) is an intergovernmental initiative created specifically for the purpose of expanding and improving South-to-South collaboration in the fields of reproductive health, population, and development. It stresses the need to establish mechanisms to promote development through the sharing of experiences in reproductive health (RH) and family planning (FP) within and among countries, and to promote effective partnerships among governments, non-government organisations (NGOs), research institutions and the private sector.

Notably, the PPD are the point institution for the Network of African Parliamentary Committees on Health (NEAPACOH) hence the APCC can leverage on its evidence-based health research resources across African countries as well as strong linkages with policy makers across Africa.

In order to gain and retain their interest, PPD has to be well informed regarding the work being conducted by the population cohorts in the APCC and the overall aims and objectives of the consortium, as PPD has strong government linkages which can be crucial to the policy and governance aspects of the APCC programme.

## Cohort Participants

Population cohorts present a unique and valuable opportunity for researchers to engage with participants and the broader community in a continuous and meaningful way. Engagement with participants and their communities includes initial conceptualisation of research priorities and research questions, contextually sensitive research designs and research implementation plans, and dissemination of research findings to those that have participated in the research.

Involving participants and the community on an ongoing basis with research offers several benefits. Firstly, it fosters a sense of ownership and investment in the

research process and outcomes among participants. This can enhance the quality and relevance of the research conducted and the data collected, as participants are more likely to provide accurate and comprehensive information when they feel their contribution is valued and impactful.

Secondly, continuous engagement helps to build and maintain respectful relationships and trust between researchers and the community. This is particularly important in longitudinal studies, where sustained participation over time is crucial. By keeping participants informed and involved, researchers can mitigate potential concerns or misunderstandings that might otherwise lead to withdrawal or disengagement from the study.

Thirdly, involving participants and the community in the research process can facilitate the co-creation of knowledge. This approach recognises the expertise and insights that participants bring to the table, allowing for a more nuanced and contextually relevant understanding of the research topic. It can also lead to the identification of new research questions and directions that are of direct relevance and interest to the community.

Finally, ongoing engagement with research participants and the community can enhance the impact and applicability of research findings. By involving stakeholders in the interpretation and dissemination of results, researchers can ensure that their work is accessible and meaningful to those it aims to benefit. This can also facilitate the translation of research findings into practical applications and policy recommendations, thereby maximising the societal impact of the research.

## Value Propositions

An important basis for stakeholder engagement is to have a clear understanding of the value propositions that the APCC offers its different stakeholder groups.

### For the APCC Membership

- **Access to large, diverse and representative populations:** Being a member of the APCC provides access to a wide range of population cohorts from across Africa. This allows researchers to study diverse populations, undertake large-scale studies significantly more efficiently, and ensures that findings are applicable or transferable to different African countries and communities.
- **Data sharing and collaboration:** APCC members can collaborate and share research data with other cohorts within the consortium. This fosters a collaborative research environment and enables the pooling of resources and expertise for more comprehensive and impactful research projects.
- **Capacity building and training:** The APCC offers capacity building and training programmes to its member cohorts. These programmes include workshops, seminars, and mentoring opportunities that aim to enhance research skills and strengthen research capacity within member cohorts.
- **Policy influence and advocacy:** A member cohort can multiply its ability to influence local policy decisions and advocate for evidence-based interventions by accessing similar findings or expertise from other member cohorts.
- **Long-term sustainability and data management:** The APCC provides guidance

and support in data management and governance to member cohorts. This ensures that data is securely managed and ethical standards are upheld, contributing to the longevity and credibility of member cohorts' research.

- **Enhanced research opportunities:** Being a member of the APCC opens up additional research opportunities for member cohorts. This includes access to funding opportunities, collaborative research projects, and the chance to expand professional networks through engagement with other researchers and institutions within the consortium.
- **Knowledge sharing and dissemination:** Member cohorts have the opportunity to share and disseminate their research findings through conferences, publications, and other knowledge exchange platforms facilitated by the APCC. This allows for the exchange of knowledge, learning from each other's experiences, and contributing to the overall knowledge base in Africa.
- **Collaboration with international partners:** The APCC collaborates with international partners, providing member cohorts with opportunities to work with renowned international institutions. This fosters global research collaborations and allows for the sharing of resources, expertise, and best practices.

#### **For Researchers:**

- Access to diverse and representative populations for their research
- Collaboration opportunities with other researchers and institutions
- Capacity building and training programmes to enhance research skills
- Networking opportunities with other professionals in their field
- Access to funding opportunities for research projects
- A focus on prioritising the health and wellbeing of African populations

#### **For Research Organisations:**

- A platform for data sharing and collaboration with other organisations and opportunities for more collaborative research
- Enhanced research capabilities through access to diverse populations and collaborative opportunities
- Increased visibility and recognition in the research community
- Potential for policy influence and advocacy efforts
- Access to funding opportunities through collaborations and partnerships

#### **For Cohort Participants:**

- Opportunity to contribute to population-based research that can improve healthcare outcomes
- Opportunity for their views to inform research ecosystem in the continent including on priority research areas
- Access to improved healthcare practices and interventions based on research findings

- Potential for increased awareness and understanding of their own health and risk factors
- Opportunity to be part of a long-term cohort study that can provide ongoing support and follow-up

#### **For Funders:**

- Impactful investment opportunities in population-based research in Africa
- Potential for significant advancements in understanding health outcomes and risk factors in African populations
- Contribution to evidence-based policy decisions and targeted interventions
- Networking and collaboration opportunities with other funders and stakeholders
- Potential for long-term sustainability and lasting impact through support of the consortium

#### **For Policy Makers:**

- Access to evidence-based research to inform policy decisions and interventions
- Collaboration opportunities with researchers and institutions to develop effective policies
- Improved healthcare delivery and outcomes through evidence-based interventions
- Potential for addressing social inequalities and promoting economic development through targeted policies
- Influencing global health research agenda through collaboration with international partners

#### **For Governments:**

- Improved healthcare systems and services based on evidence and data
- Increased capacity for research and data management through the consortium's support and training programmes
- Potential for economic development through evidence-based policies and interventions
- Networking and collaboration opportunities with other governments and stakeholders
- Improved health outcomes and reduced healthcare costs through targeted interventions

#### **For Other Stakeholders (including Industry):**

- Access to comprehensive and holistic data on health outcomes and risk factors in African populations
- Collaboration opportunities with researchers, organisations, and institutions
- Potential for policy influence and advocacy efforts
- Contribution to evidence-based interventions and programmes
- Increased awareness and understanding of health issues and potential solutions.

## Stakeholder Engagement Plan

### Introduction

The APCC scoping process has generated great interest and enthusiasm among the health science research community in Africa. Most stakeholders consulted at various levels, including international initiatives such as WHO and regional ones such as the Africa CDC, are keen to be involved in the APCC blueprint implementation process. They would like to draw from the insights of the process and also feed into the process. This will therefore require dedicated engagement sessions that can capture the changing needs, opportunities and priorities of stakeholders at different times over the period that the formal establishment of the APCC is being implemented. Policy Labs and Community of Practice platforms have been suggested for this purpose. At the same time, there are several groups that might not be involved in a direct link with the APCC. These include primary beneficiaries of population health research and policy programmes such as vulnerable communities, indigenous persons, and persons with disability. Opportunities and spaces must be created through which their voices can be amplified and considered in the context of APCC research and actions.

Our consultation with stakeholders reveals that population health demands are changing rapidly given uncertainties such as pandemics (e.g. COVID-19) and climate change. The engagement process needs to capture these changing priorities and support proactive programming and action under the APCC. Policy makers at national and regional level are also highly influenced by context, including shifts in socio-political systems and health systems. Keeping track of changing priorities and evidence requires dedicated engagement and consultation with policy makers through the proposed policy labs to ensure that APCC research is responsive to those needs.

Stakeholder engagement activities may include:

- 1 Key Informant Interviews:** Key informants will be purposively selected from the stakeholder matrix to provide diverse, anonymised perspectives and allow for information triangulation. Efforts will be made to include influential individuals in key positions whose responsibilities require tracking a broad range of health policy and evidence issues, including those with a specific focus on population health and cohort research.
- 2 Targeted Surveys:** Questionnaires can be used to elicit generalisable opinions and experiences on a specific issue for a specific aspect of population health and cohort research.
- 3 Bilateral engagements:** These can be used to engage stakeholders and introduce intentions of engagement initially, and later on to catch up on the progress of specific tasks. Such meetings are less structured with pre-planning, but still require objectives to guide the conversation and keep it focused on specific outputs.
- 4 Thematic Workshops:** This activity provides the opportunity for two-way communication with the key figures in population health and cohort research as we work towards a common goal. Efforts will be made to include influential individuals in key positions for a more high-level discussion.

- 5 Establishing Communities of Practice:** Communities of practice are crucial in ensuring the APCC is inclusive of cohort participants and categories of stakeholders in diverse contexts. These communities of practice will catalyse lesson and skills sharing among stakeholders in-country, across contexts/countries and with other platforms. Community of practice platforms can promote resilience in population health systems in the face of ongoing shocks such as climate change events, disasters, and pandemics.
- 6 Policy Labs:** Policy labs involving key stakeholders and policy makers can strengthen relationships and facilitate knowledge uptake from the population cohort research outputs of APCC members.
- 7 Participatory Community Labs:** These labs reflect the key concerns regarding inclusivity and community input and hence are a key component of stakeholder engagement. Community groups will have the opportunity to provide input and feedback on the core objectives of the APCC. This will also be an opportunity for the voices of vulnerable members of the community such as women, youth, persons with disabilities, elderly, widows, etc. to be profiled.

Products that may be developed as part of these activities could include:

- 1 Policy Briefs:** Policy briefs are sometimes viewed as advocacy documents. The term 'policy brief', refers to an "evidence-based policy brief" or an "evidence brief for policy", which brings together global research evidence (from systematic reviews) and local evidence to inform deliberations about local health policies and programmes. A policy brief describes a policy problem, summarises the best available evidence to clarify the size and nature of the problem, describes the likely impacts of key options for addressing the problem, and notes potential barriers to implementing the options and proposes strategies for addressing these barriers.
- 2 Research Summaries/Fact Sheets:** This is a professional piece of writing that describes one's research to some prospective audience. The main priority of a research summary is to provide the reader with a brief overview of the whole consortium agenda. A quality summary involves identifying the important information and condensing the science for the specific reader or audience.
- 3 Briefing notes:** These are usually written for an audience requiring concise background information on an issue or situation. Briefing notes are used to prepare for meetings, conferences or similar events, as well as high-level strategic discussions. They can also be used in more administrative settings, for example, to communicate a complex procedure for someone required to use it. Typically, a briefing note outlines an issue or situation, analyses the matters involved, and offers solutions. The briefing note must provide just enough background for the audience to understand the context and should ideally cover only the main topics to be addressed.
- 4 Newsletters:** Organisations use newsletters to share relevant and valuable information with their network of stakeholders and subscribers. Newsletters give direct access to the audience, allowing for the creative communication of content and the driving of traffic to a website or platform for more information.

## Activities

**Aim:** To engage and collaborate with targeted key policy influencers, regional economic communities, Africa offices of international health organisations, community health actors and other stakeholders in population health research for a needs driven APCC.

### Short Term Objectives:

- 1** To concretise engagement pathways with key stakeholders to support the APCC i.e. signing MoUs with key population health actors (e.g. EAC, WHO-AFRO, Africa CDC).
- 2** To identify and map out the needs of critical population health stakeholders to be met through the APCC and leverage on these to identify opportunities for intervention and collaboration.
- 3** To convene and engage community groups (via population cohorts already based in the representative regions i.e. eastern, southern, northern, central, western regions) through participatory community labs to identify their population health needs, aspirations, challenges and opportunities as part of the APCC programme.

**... our consultation with stakeholders reveals that population health demands are changing rapidly given uncertainties such as pandemics (e.g. COVID-19) and climate change ...**

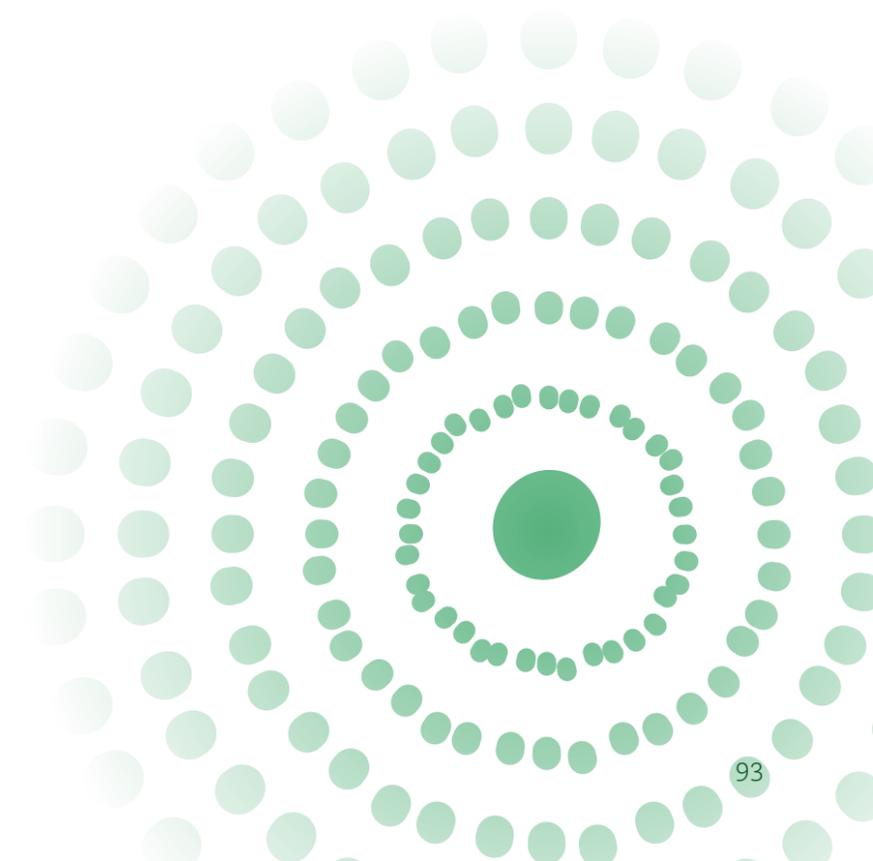
### Short Term Activities

- 1** Develop terms of reference for the Participant Forum with input from participant representatives from APCC member cohorts from all regions in Africa, culminating in the convening of the Participant Forum at the first APCC Annual meeting.
- 2** Convene three policy labs in representative regions i.e. eastern, southern, northern, central, western Africa.
- 3** Convene three inclusive and diverse community labs with participant representatives from APCC member cohorts and community groups from all regions in Africa for participatory workshops on the APCC Programme. Community groups engaged should be diverse and inclusive, including women, persons with disabilities, widows, and people with other vulnerabilities depending on the context.
- 4** Conduct key informant interviews with pre-identified priority stakeholders (high influence, high interest).

**Long Term Objective:** To build an inclusive and diverse community of practice around population health studies with the aim of increasing production and uptake of needs driven evidence to enhance public health.

### Long Term Activities:

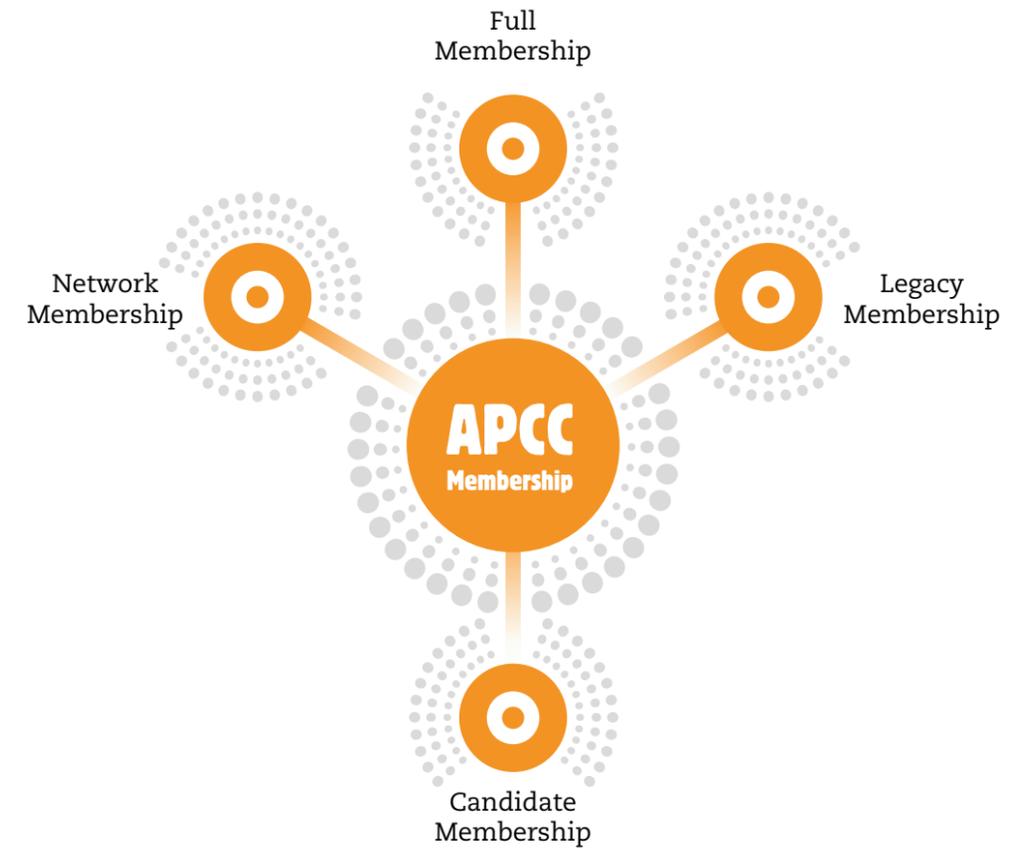
- 1** Develop and share three policy briefs for uptake by policy makers and key stakeholders in the population health research domain sourced from the APCC Strategic Programmes.
- 2** Convene a high-level in person workshop to concretise a co-created Community of Practice (COP) on population health studies that responds to the needs of vulnerabilities in Africa.
- 3** Develop a digital platform/network from the COP to identify best practices in population health studies for Africa.



PART 6

# APCC Membership

The unit of membership of APCC is a cohort. The membership of the APCC, therefore, is made up of the population cohorts that comply with the APCC Membership criteria. Membership applications are considered and approved by the Steering committee. Where more than one cohort is managed by the same institution, each of the cohorts will be considered as a separate member. Cohorts nested in a member cohort, or a network of cohorts, where the network member cohorts are members in their own right, cannot be full members of the APCC.



## Membership criteria

All cohorts in Africa which wish to become members will be considered once they:

- 1 Meet the definition of a population cohort (defined below);
- 2 Have submitted basic core information about the cohort to the Secretariat and have allowed this information to be publicly shared;
- 3 Have shared documentation (cohort protocol and ethics approval); and,
- 4 Have completed a baseline Capability Readiness Matrix with supporting documentation where required.

Each application will be reviewed by the Steering committee for approval and categorisation into a specific membership type.

Membership will be confirmed once the cohort has signed up to the APCC Charter. The APCC Charter will be finalised by the Interim Steering Committee based on the APCC Blueprint and in consultation with the potential member cohorts of the consortium, and will be formally adopted at the first Annual Meeting of the APCC.

A registry of members will be kept. The registry, core information and Capability Readiness Matrices of members will be publicly available but will be devoid of any personally identifiable information. Member cohorts will be required to update information annually to retain membership.

The unit of membership is the cohort. An institution that operates multiple discrete cohorts (must be geographically distinct and not include the same participants, therefore not “nested” cohorts) may be represented more than once in the membership.

## Membership Types

- 1 **Full membership:** Cohorts actively collecting data and complying with the membership criteria. They will be entitled to attend annual general meetings and have voting rights in the Member Council.
- 2 **Candidate membership:** Cohorts that will only meet the definition of a population cohort on full implementation and are still in the process of completing the membership requirements but have shared the core information about the cohort. They will be entitled to attend annual general meetings but will not have voting rights in the Member Council.
- 3 **Legacy membership:** Cohorts that would have complied with membership requirements in the past but are no longer actively collecting data. They will be entitled to attend annual general meetings but will not have voting rights in the Member Council.
- 4 **Network membership:** Networks/consortia/multisite studies which are not responsible in themselves for primary data collection and may include cohorts that are already members, but where the network otherwise meets the definition of a large population cohort. Network members will not have voting rights in the Members Council but will be able to participate in APCC activities

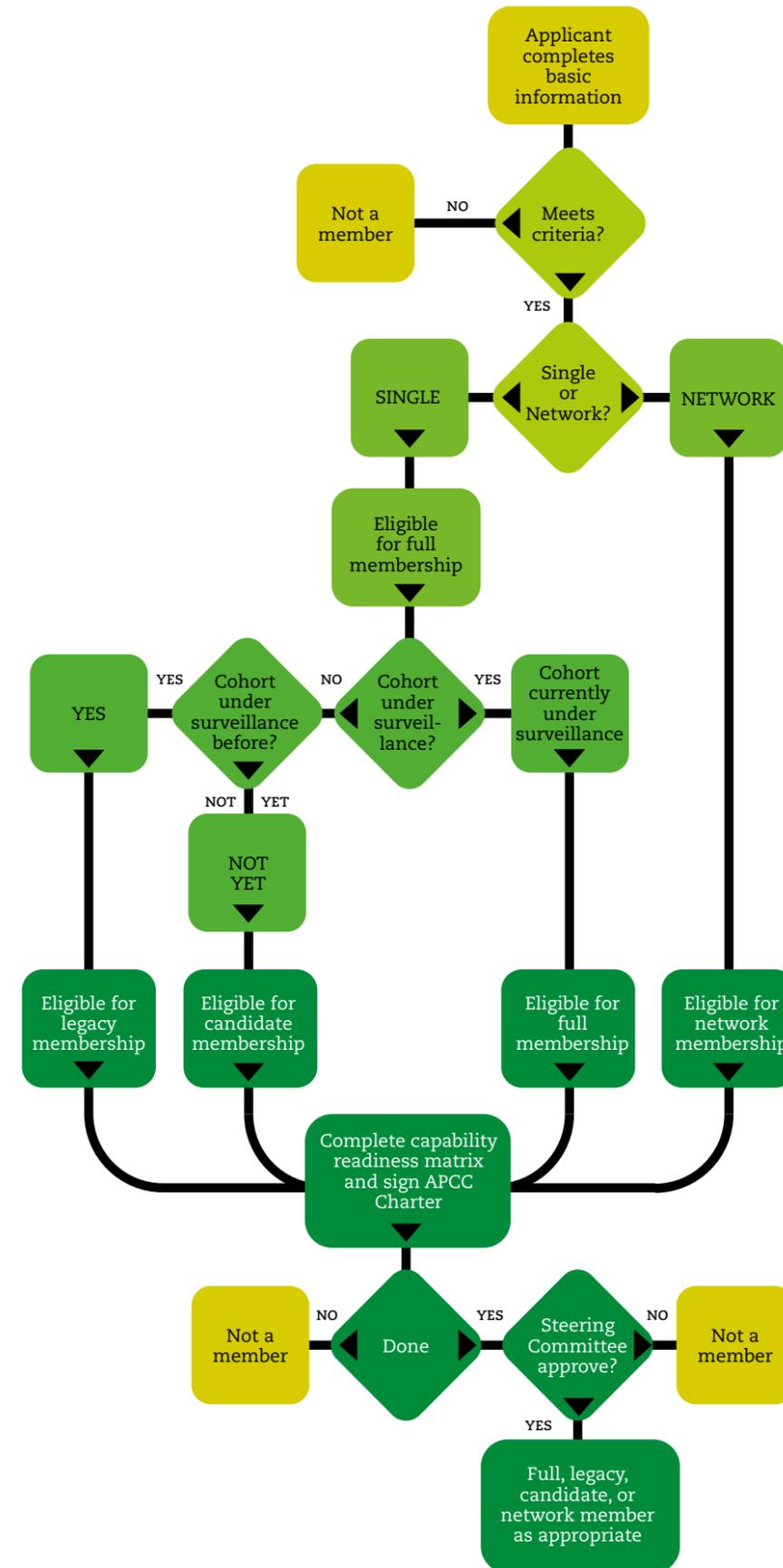


Figure 8: Membership process

### Population Cohort Definition

- 1 Location:** Located anywhere on the African continent, including the African islands.
- 2 Methodology:** Eligible individuals followed-up on more than one occasion. Minimum frequency: Annually. Documented informed consent information as well as inclusion/exclusion criteria for membership must exist.
- 3 Size:** Enrol or intend to enrol a minimum of 10,000 individuals for population cohorts or minimum of 2,000 individuals in the case of a birth cohort.
- 4 Source:** Must be population-based (i.e. the place of residence [preferably geocoded] of each cohort member is known). It could be a health facility-based cohort provided the catchment area is well defined.
- 5 Duration:** Minimum of two years follow-up (or intention/funding to follow-up for at least three years).

### Membership Responsibilities

Full members have the following responsibilities:

- 1** Participation in the Members Council.
- 2** Completion of the core information about the cohort and Capability Readiness Matrix at baseline with annual updates.
- 3** Commitment to APCC data and sample sharing policy.
- 4** Participation in collaborative research that matches with cohort capabilities and interests.  
Upholding the APCC values in their interaction with fellow APCC members.

### Membership Rights

- 1** Representation on the Members council.
- 2** Access to standard data collection tools.
- 3** Preferred access to datasets and samples.
- 4** Preferred access to grant applications coupled with opportunities to motivate for APCC research activities.
- 5** Capacity strengthening based on the Capability Readiness Matrix.
- 6** Invitation to the Annual Meeting.
- 7** Access to cohort preservation funding.

### Cessation of Membership

Cohorts will cease to be full members if they:

- 1** Request cessation of membership.
- 2** Do not update the required information annually.
- 3** Have not been actively collecting data for more than 12 months. They may be recategorised as legacy members if they so wish.

### Regional Groups

Recognising that some research goals might be better achieved within specific areas of the continent, or that it might be easier for groups of people to work together if they are located near each other, the APCC Membership can organise into regional groupings. When approved by the Steering Committee regional groups will receive support from the Secretariat.

## PART 7

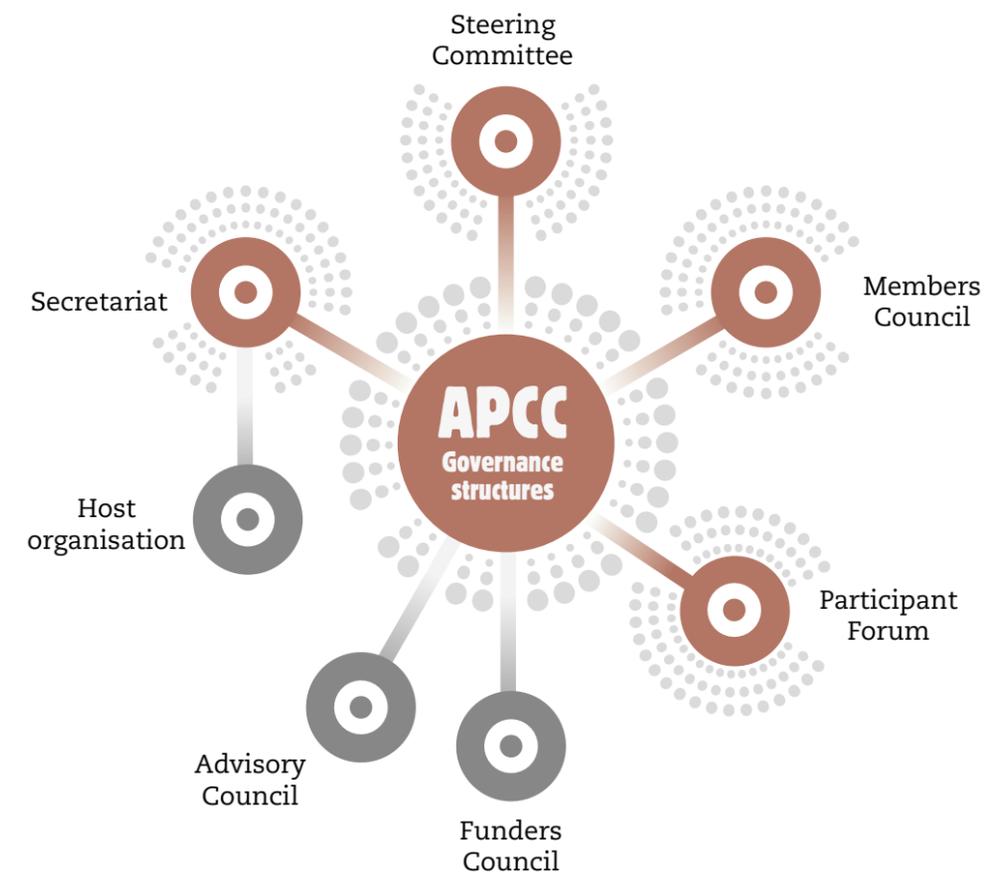
# APCC Governance

## Members Council

The Members Council is the ultimate governance structure of the APCC to which the Steering Committee as well as research leadership will regularly report and account. Each full member cohort of the APCC is eligible to nominate one delegate to the Members Council.

## Terms of Reference

- The Members Council meets during the Annual Meeting.
- Elects eight members to the Steering Committee
- Adopts key policy documents of the APCC



## Annual Meeting

The APCC hosts an annual meeting that provides an opportunity for APCC members to connect, share ideas, build relationships, and present their research. At this event, members can also interact with key APCC stakeholders to ensure that their research aligns with the needs of the cohort participants and policy development. Additionally, this is an opportunity to address the interests of research sponsors and the industry. The meeting will double as a platform to discuss APCC’s strategic direction and convene the annual Members Council meeting.

## Steering Committee

A Steering Committee (SC) of 15 members made up as follows:

- Eight **elected members** elected by the Members Council from their own ranks.
- Seven **nominated members** appointed by the elected members of the SC. A candidate member must be nominated by at least two SC members and must be a scientist of good standing involved in population cohort research. Nominated members should be selected to take diversity requirements and regional representation across all Africa regions into account. Appointments are approved by a simple majority.
- SC members serve a two year term, and can be re-elected for only one consecutive term. There is no limit to the number of non-consecutive terms a SC member can serve.
- The SC meets bi-annually.

### Co-chairs

The SC elects three of their own members as co-chairs. At least one of the co-chairs must be a SC member elected by the Members’ council.

### Executive Sub-Committee

The co-chairs and four additional SC members (elected by the SC) form the executive sub-committee. The executive committee meets regularly (fortnightly/ monthly) with the head of the Secretariat and provides operational guidance to the Secretariat.

### Responsibilities and Functions

The SC of the APCC has several key responsibilities and functions:

- 1 Values and Guidance:** The SC is bound by the APCC values and promotes these values in their decision-making and actions. The SC will appoint an Independent Scientific Advisory Group.
- 2 Strategic direction:** The SC develops and refreshes the APCC strategic objectives, and presents these to the Members Council for ratification. The SC will develop and maintain a risk register of risks that could negatively impact the achievement of its strategic objectives.

## Steering committee: APCC Interim Governance Structure

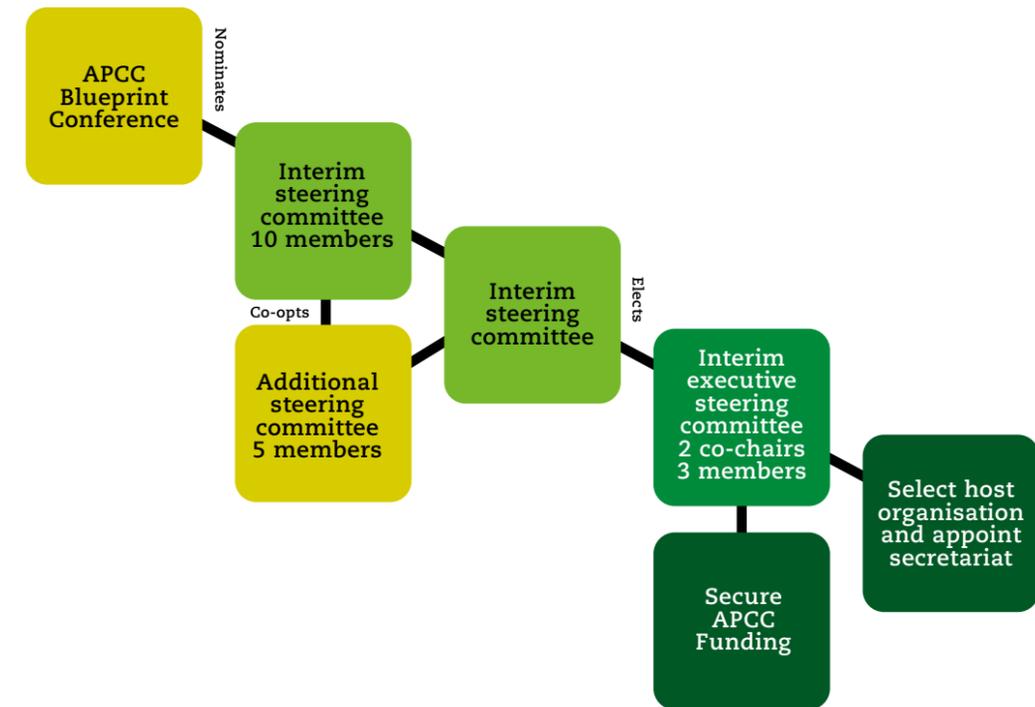
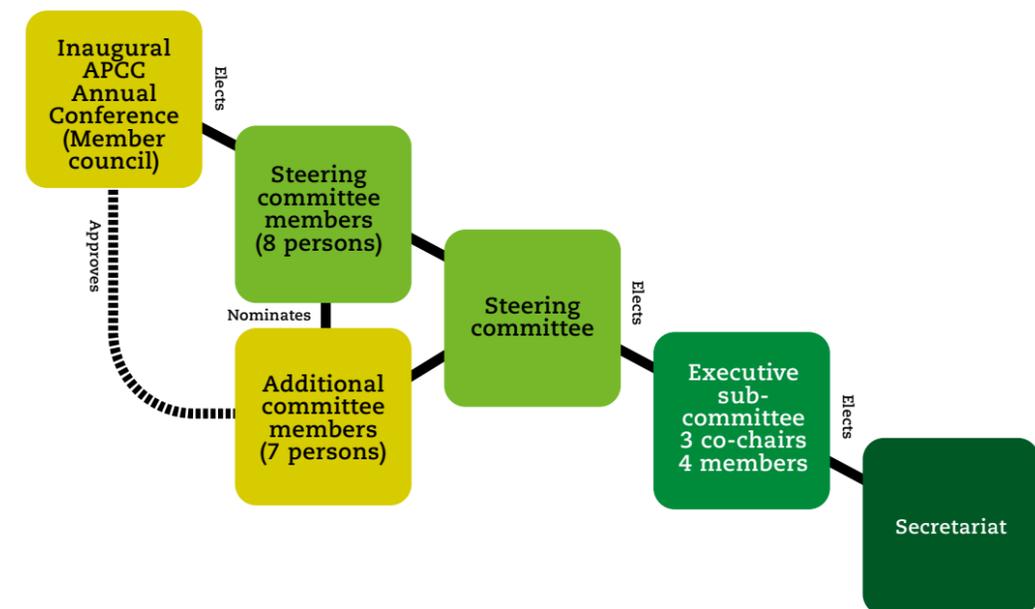


Figure 9: Steering Committee nomination and election

## Steering committee: APCC Final Governance Structure



- 3 APCC Membership:** The SC is responsible for evaluating membership applications and deciding on the membership status (full, candidate, or legacy) of applicant cohorts.
- 4 Scientific Programmes:** The SC oversees and drives multi-cohort research programmes within the APCC and ensures that these programmes align with the APCC's mission and objectives. It does this through the identification of strategic research programmes and the approval of working groups in topical areas for support by the APCC. The SC will convene a subgroup of PIs and working group leaders to enable discussion of research underway and planned, as well as ideas in development, and troubleshooting. This subgroup can foster discussion of common themes such as multicentre research, implementation and processes, contextual/cultural challenges, innovations etc.
- 5 Stakeholder Engagement:** The SC engages with key stakeholders to increase the impact of APCC science and to promote the APCC's vision and mission.
- 6 Participant Engagement:** The SC engages with the Participant Forum to ensure that cohort participants have a voice in the activities of the APCC.
- 7 Sustainability:** The SC is responsible for the sustainability of the APCC and engages with funders to develop funding opportunities for cohort-based science. It actively encourages and facilitates the involvement of member cohorts in funding applications.
- 8 Operational Oversight:** The SC, through the Executive Sub-Committee, provides oversight and guidance to the Secretariat who is responsible for the day-to-day operations of the APCC. They work closely with the Secretariat to ensure the effective and efficient functioning of the APCC. The SC is involved in the recruitment of Secretariat staff and must approve all appointments at programme director and manager levels.
- 9 Host Organisation:** The SC selects and submits the Terms of Reference/Memorandum of Agreement with the Host Organisation to the Members Council for approval the Host Organisation.

In summary, the SC has a vital role in shaping and guiding the activities and direction of the APCC. They select and approve new members, provide support to working and regional groups, drive strategic programmes, and oversee the operational aspects of the APCC.

### Interim Steering Committee

At the APCC Blueprint Conference ten persons will be nominated to form an Interim Steering Committee (ISC). These ten people will in turn co-opt an additional five persons to the ISC. A co-opted member must be nominated by at least two SC members and must be a scientist of good standing involved in population cohort research. The ISC will elect two co-chairs and three members to form an interim executive committee.

### Terms of Reference - Purpose

To provide leadership, direction, and decision-making during the consortium's implementation phase, ensuring effective management and inclusive development of the APCC.

### Terms of Reference - Key Functions

- 1** Provide leadership up to the formal establishment of the APCC and its inaugural annual meeting.
- 2** Secure funding for the implementation of the APCC.
- 3** Confirm the Host Organisation of the APCC.
- 4** Recruit and appoint the APCC Secretariat.
- 5** Coordinate the initiation of the strategic programmes of the APCC.
- 6** Recruit and approve the founding APCC member cohorts.
- 7** Finalise a conflict resolution mechanism with the Host Organisation.
- 8** Communication and reporting: Regular communication of decisions and updates to interim stakeholders.

## APCC Secretariat

The APCC Secretariat is responsible for the day-to-day activities of the consortium. The secretariat is based in and employed by the Host Organisation. The APCC Steering committee will be involved in the recruitment of candidates at programme director and programme manager level. The APCC Steering committee must approve all appointments at programme director and programme manager level. Secretariat members cannot be investigators of APCC research studies.

### Staff

- **Programme Director:** Secretariat executive. Ex officio member of the APCC-SC.
- **Research Programme Manager:** Responsible for managing the research function
- **Capacity Strengthening Programme Manager:** Responsible for maintaining the Capability Readiness Matrix and managing cohort self-assessment.
- **Data Science Programme Manager:** Responsible for supporting the Trusted Research Environment as well as the data harmonisation and sharing activities of APCC
- **Administrative Support:** Provide administrative support to the Secretariat and handle communications.



Figure 10: Programme Director organogram

## Host Organisation

The APCC Host Organisation is the legal entity that will host the Secretariat. It is selected by the SC which will consult widely with key stakeholders and funders. The role of the Host Organisation is formalised in a Terms of Reference/Memorandum of Agreement (ToR/MoA) drawn up jointly by the SC and the host organisation and submitted for approval to the Members Council. The ToR/MoA will specify the term of the Host Organisation, with a minimum term of five years. The Members Council can terminate the appointment of the Host Organisation prior to the expiry date of the appointment term via a two-thirds majority.

The Host Organisation will provide at least the following functions:

### Functions

- Financial and grants management.
- Human resource management.
- Legal services.
- Links to policy makers.
- Links to funding organisations.
- Manages an independent conflict resolution mechanism for the APCC.

### Criteria

The criteria for an ideal host organisation includes:

- Africa-wide footprint.
- Robust and mature governance structures and long-term sustainability.
- Impeccable financial management credentials.
- Any conflict of interest to be declared.

## Conflict Resolution

In the rare event that conflicts cannot be resolved within APCC structures, members can seek mediation, arbitration, appeals process, or involve a Conflict Resolution Committee. External mediation or arbitration services can also be utilised for complex or unresolved conflicts. Fairness, transparency, and respect are essential throughout the resolution process to promote a collaborative and harmonious environment within the APCC. The conflict resolution mechanism could be situated in the Host Organisation and will be finalised by the ISC.

## Independent Advisory Council

This council will develop out of the existing Independent Scientific Advisory Group with a similar membership and terms of reference.

The APCC Steering committee will invite a panel of ten members to constitute an Independent Advisory Council. The members will be internationally acknowledged experts in the fields of the APCC's work.

## Terms of Reference

- Meets annually. Reviews the scientific content of the APCC's main functional areas and identifies gaps and opportunities to enhance the impact of the APCC's work.
- Reviews the scientific strategy of the APCC and advises on its relevance and opportunities to strengthen it.

## Participant Forum

The APCC aims to create a forum where participant delegates from member cohorts can interact with APCC activities such as Research and Capacity strengthening, for example, and provide their perspective on research questions being discussed, or the measures being used to gauge the community and participant dimension readiness. The Participant Forum does not replace or supersede the structures that member cohorts use to engage with their own cohort participants.

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## APPENDIX 1

# Work Leading up to the APCC Blueprint

## Background

The journey to establish a collaborative African Population Cohorts Consortium (APCC) started with a meeting in Uganda (March 2020) attended by African scientists and funders where the need, vision, and ambition for a research population data platform to address the Continent’s most pressing health and socioeconomic needs was agreed to. This was followed by a consultative process to write a scoping paper, involving African scientists doing cohort-based research, research funders, and led by Dr Nicki Tiffin. The result of the scoping phase was an agreement on the need for a vision and broad structure of an APCC, and clear areas were identified for further exploration in the formative phase as set out in the scoping phase report.

In March 2021 the Wellcome Trust published a Request for Proposals (RFP) for a African Population Cohort Consortium (APCC) Formative phase Delivery Team. A team co-lead by JP Ochieng’-Odero and Kobus Herbst submitted a proposal under the auspices of the African Population Health Research Centre (APHRC) with Evelyn Gitau as the institutional lead. This proposal was successful and in October 2022 the Collaboration for the Establishment of the African Population Cohorts Consortium (CE-APCC) commenced work funded by the Wellcome Trust, Bill & Melinda Gates Foundation, and UKRI Medical Research Council.

The lead institution was the African Population and Health Research Centre (APHRC), collaborating with the Africa Health Research Institute (AHRI), Africa Research and Impact Network (ARIN), Malawi Epidemiology and Intervention Research Unit (MEIRU), and African Institute for Development Policy (AFIDEP).

The CE-APCC co-leads **Kobus Herbst** and **Evelyn Gitau** were supported by the co-applicants of the different workstreams and their team members which are as follows:

- **Stakeholder & Community Engagement:** Maame Peterson and Joanes Atela, assisted by Leah Aoko. Tumaini Malenga was an early member of this workstream
- **Ethics:** Dorcas Kamuya is assisted by Alex Hinga, Michael Ogutu, and Jane Kahindi
- **Existing cohorts:** Mia Crampin and Jim Todd are assisted by Edith Chikumbu and Jethro Banda
- **Research Vision & Objectives:** Anjali Sharma, Mercy Wanjala, and Jacques Emina, are assisted by Samuel Ugbaja (postdoc). Shabir Moosa was an early member of this workstream

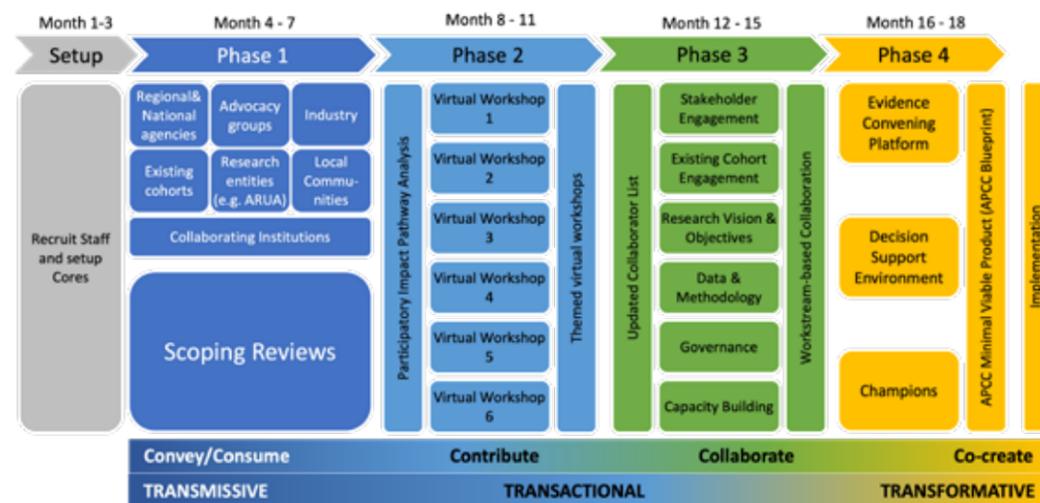
- **Data & Methodology:** Agnes Kiragga and Sikhulile Moyo are assisted by Samuel Ugbaja and Verrah Akinyi (postdocs)
- **Governance:** Umberto D'alessandro, Stephen Tollman, and Jude Igumbor
- **Omics:** Michele Ramsay, Gerald Mboowa, and Emily Wong assisted by a postdoc Samuel Ugbaja
- **Capacity Building:** Evelyn Gitau, assisted at various points by Damazo Kadengye and Marylene Wamukoya. The original convenors were Ayaga Bawah and Samson Kiware.

The following individuals were involved in the earlier parts of the CE-APCC work:

- **JP Ochieng'-Odero:** Co-lead until March 2023.
- **Shabir Moosa:** Co-applicant until Oct 2022
- **Samson Kiware:** Co-applicant until May 2023
- **Ayaga Bawah:** Co-applicant until July 2023

The CE-APCC adopted the CSCCE Community Participation Model to structure its approach to stakeholder engagement (see Figure A). This approach enabled us to build an intensive stakeholder engagement effort to provide the basis for APCC blueprint development.

Figure A: Stakeholder engagement approach



### First Phase: Scoping Review and Stakeholders Identification (January-July 2023)

In the lead-up to the first phase of this process, co-leads of the CE-APCC, Kobus Herbst and Evelyn Gitau, made presentations on the formation of the APCC across various conferences and meetings including at the International HundredK+ Cohorts Consortium (IHCC) conference in December 2022, H3Africa 20th Consortium Meeting, International Conference on Human Genomics (ICHG) in February 2023, where Kobus Herbst gave an overview of the APCC, Michele Ramsay presented the Omics Workstream and objectives, and Jude Igumbor introduced approaches to governance.

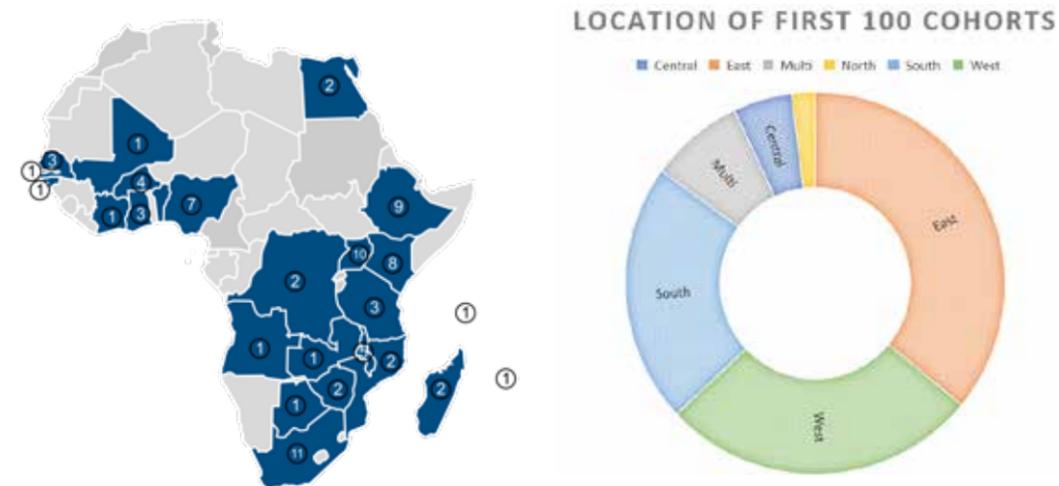


Figure B: Surveyed population cohorts in Africa

Figure C: Breakdown of cohort locations

**Existing cohorts workstream:** The main activities during this phase include preliminary criteria consultation, listing of existing cohorts, and cohort survey designing. The report is briefly summarised in Figures B to C.

**Ethics workstream:** The activities in this phase include mapping countries with and without data protection legislation (Figure E) and the implications for data sharing in APCC; mapping ethical issues for data and sample sharing in African cohort studies including a review of frameworks in use; reviewing consent processes and nature of consent and propose a template for APCC work; and reviewing of ethics approval of current multi-site studies.

**Governance workstream:** The activities in this phase involve reviewing the governance principles which include strategic vision, participation & consensus orientation, transparency, equity and inclusion, accountability, risk management, decision-making, data protection, training & capacity development, reporting & feedback mechanisms, and rules of law. Case studies were conducted on the Human Heredity and Health in Africa (H3Africa) Consortium, the European Open Science Cloud (EOSC), the Innovative Medicines Initiative (IMI), and the eMERGE (electronic medical records genomics) network.

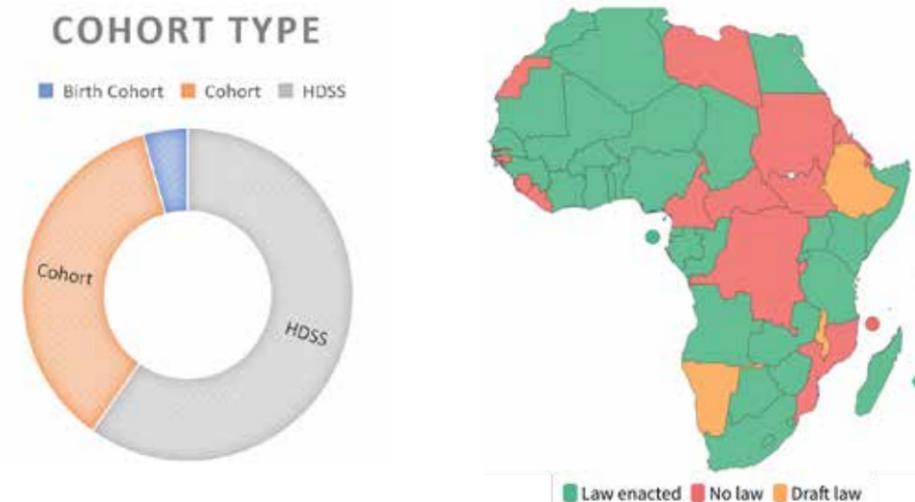


Figure D: Breakdown of cohort type

Figure E: Status of protection of personal information legislation in Africa

**Findings:** Based on an extensive scoping review, it was found that traditional academic partnerships are the most common model, where two or more organisations collaborate to share expertise, resources, and intellectual capital to benefit both individuals and their respective organisations. Therefore, an APCC will foster research collaborations and partnerships that provide numerous benefits, including cost savings from resource sharing, access to talent and expertise, speed of discovery, enhanced credibility, increased visibility and recognition, and improved coordination amongst multiple entities (cohorts).

**Omics & Data and Methodology Workstreams:** The data and methodology group, in collaboration with the omics working group, was tasked to document current standards for phenotypic, genomic, and other omics data generated in African cohorts and to assess which international standards were applied. The aim is to provide guidelines for standards to cohort producers and users to enable uniform datasets for collaborative and comparative analyses and interventions for improving population health in Africa.

**Findings:** The two workstreams identified a need for the development of recommendations for cohorts in terms of international best-practice standards and approaches to data collection, storage, access, sharing and biobanking, and omics. This involves establishing a consensus set of guidelines for data collection, data management, and data sharing, enabling efficient and reliable collaboration among participating cohorts, as well as promoting data harmonisation, and enabling large-scale investigations into African population health and disease patterns.

**Research, Vision, and Objective:** Summarised research aims, objectives, countries of affiliations, and research focus areas for select cohorts included in longitudinal population studies and their networks. They identified gaps in research domains/areas in existing cohorts and their core indicators vis-à-vis primary health care (PHC) and universal health coverage (UHC).

**Findings:** While the vision and objectives inherent in the consortium and population studies have applications for primary health care (PHC), they do not explicitly meet its requirements on aspects such as social determinants of health, intersectionality, primary healthcare service delivery, integrated care, and interprofessional collaboration, comprehensive and preventive services, quality of care, precision medicine, precision public health, health systems strengthening, health workforce development, health information systems, building resilience/mitigating climate change, financial protection and health financing, intersectoral collaboration, policy and programme impact evaluation. Therefore, a strong PHC system is a prerequisite for universal health coverage (UHC) that aims to increase access to quality care without financial hardship for the most underserved and marginalised populations.

During this phase, an Independent Advisory Group (IAG) was constituted (Table A).

## Second Phase: Thematic Workshops and Nairobi in-person meeting (August-December 2023)

Following the **Scoping Review & stakeholder identification**, the CE-APCC engaged a range of stakeholders through a series of thematic workshops (Table B). These virtual workshops engaged a range of stakeholders to explore and focus on the findings of the scoping review. Stakeholders were drawn from the existing cohorts survey, a stakeholder landscape review done by the stakeholder engagement workstream, the network of co-applicant researcher contacts, and contacts made at scientific meetings where the CE-APCC co-leads and others presented the initiative.

The objectives of this phase were:

- 1 Explore themes identified during the scoping phase with a range of stakeholders.
- 2 Identify aspects of establishing the APCC that were not elucidated during the scoping phase.
- 3 Identify and encourage individuals and institutions to engage with the CE-APCC during the blueprint development phase.

### Findings/Outcomes from the Thematic Workshops: Existing Cohorts Workstream

- **Data harmonisation and sharing:** Stakeholders emphasised the need for APCC to develop harmonised and standardised data collection instruments and surveillance methodologies.
- **Capacity strengthening:** Participants saw capacity building as a key role for the APCC, especially in supporting the unique challenges related to the sustainability and impact of longitudinal cohorts.
- **Governance:** There is a strong sense that cohorts should play an active role in the governance of the consortium with involvement both in the running of the organisation and the development and implementation of research projects.
- **Stakeholders:** It is important to understand who the key stakeholders in cohorts are, ranging from regional entities such as Africa CDC and WHO AFRO to in-country policymakers, hosting academic institutions, local government, and communities.

Member	Country	Designation
Alash'le Abimiku (Chair)	Nigeria	Virology, biobanking
Charles Mwansambo (Co-chair)	Malawi	Chief of Health Services
Andrew Haines	UK	Environmental Change & Public Health, LSHTM
Ronald Sinkala	Zambia	Legal and Governance
Alex Ezeh	Nigeria/US	Global and population health
Nicki Tiffin	South Africa	Computational biology, Bioinformatics
Sonia Abdelhak	Tunisia	Genetics
Oumar Gaye	Senegal	Parasitology (malaria)
Daniel Mwai	Kenya	Health Economics, UHC, PHC
Simisola Akintola	Nigeria	Legal and Governance

Table B: Thematic workshops			
Date	Thematic Workshop	Workstream	Participants
2 Jun 23	Existing Cohorts Workshop	Existing Cohorts	18
9 Jun 23	Existing Cohorts Workshop (repeat)	Existing Cohorts	18
16 Jun 23	Existing Cohorts Synthesis Workshop	Existing Cohorts	23
26 Oct 23	Existing Cohorts Workshop	Existing Cohorts	8
27 Jul 23	Data Standards & Omics Virtual Stakeholder Engagement Workshop	Data Standards & Omics	76
19 Oct 23	Omics and Data Methodology follow-up workshop	Data Standards & Omics	17
28 Sept 23	Data Sharing in African Population Cohorts	Ethics	78
12 Oct 23	Ethics review, consent, and governance structures	Ethics & Governance	40
11 Oct 23	Understanding opportunities and barriers towards inclusive population research and action in Africa: Towards an APCC Blueprint	Stakeholder Engagement	24
21 Nov 23	Building Consensus for Research Vision and Objectives for Population Studies in Africa	Research Vision and Objectives	24

Note: A total of 194 different individuals attended the 10 thematic workshops from 21 different African countries.

- **Cohort sustainability:** Maintaining cohorts beyond relatively short-term study-specific research funding is a long-term challenge. Consideration needs to be given to bottom-up (cohorts to consortium) development of research priorities. National governments can play a role in supporting cohorts' sustainability with the South African Population Research Infrastructure Network (SAPRIN) as a prime example.

### Findings/Outcomes from the Thematic Workshops:

#### Stakeholder Engagement Workstream

- **Community Engagement:** The importance of ethical, transparent, and accountable community engagement in the APCC process to document community needs, and build long-term trust was highlighted.
- **Research Questions and Evidence Needs:** Stakeholders, particularly academia and research policy influencers, are keenly interested in identifying priority research questions and evidence needs.
- **Communication and Engagement Strategy:** Stakeholders are keen to shape the communication and engagement strategy of the APCC: This involves developing effective channels and platforms for collaboration, interaction, and knowledge sharing among stakeholders.
- **Effective Channels/Platforms for Engagement:** Leverage virtual platforms, such as webinars, online forums, and in-person workshops and conferences as collaborative tools, to facilitate real-time interactions and knowledge sharing among stakeholders.

#### Governance Workstream

This workstream identified the following approaches:

- Prioritise maximising efficiency to attract funding and identify and approach relevant funders.
- Establish a framework for identifying and resolving disputes before collaboration starts and allocate responsibilities and leadership roles.
- Provide skills development and capacity-building opportunities, such as grant writing training and access to funding sources.
- Ensure adequate funding, impartial leadership, equitable distribution of resources, and address perceptions of dominance within the collaboration.
- Focus on effective governance, resource allocation, accountability, and inclusivity in the organisational structure.

#### Ethics Workstream

This workstream reached the following conclusions:

- Explicitly acknowledge the legal, socio-economic, and ethical differences across cohorts in terms of data sharing, consent, and ethics review.
- Given that most participants felt that they would not trust reviews conducted in other countries, it seems multiple ethics reviews in cohorts might be inevitable.
- There is a need for a careful process of harmonising and standardising data sharing, consent, and ethics review processes in the APCC.
- The APCC is likely to adopt collaborations of entities with varying levels of capacities and powers, including the capacities and powers to give valid informed consent, review protocols obtain approvals, and share or use data.

#### Research Vision and Objectives Workstream

This workstream developed the following recommendations:

- Explore the relationships between megatrends and the incidence of chronic and infectious diseases across geographies (Megatrends include technological advancements, demographic shifts, socio-economic changes, climate change, pollution, and urbanisation).
- Identify best practices for integrating health considerations into policies and actions across various sectors and their impact on public health.
- Identify effective policies, programmes, and interventions through population-level research and evaluation.
- Investigate strategies to enhance the resilience and adaptability of health systems to cope with emerging challenges and disruptions, and how they can be redesigned to be more responsive to the changing needs of populations.
- Develop skills and frameworks for effective cross-sectoral collaboration to address the multifaceted determinants of health such as education, environment, and urban planning.
- Develop communication strategies that encourage clear, transparent, and culturally sensitive engagement with stakeholders and communities through various communication channels, including social media, community meetings, and public forums, to reach a wider audience.

- Develop strategies for sustaining engagement and participation beyond the lifecycle of individual projects or initiatives.

### Data and Methodology Workstream

- **Mismatched Data Standards:** The workstream created data standards guidelines that will be used to adapt and modify data standards to better meet the characteristics of LPC datasets in the African setting. This modification can enable smoother interoperability and improve data compliance with worldwide research standards.
- **Data Standards Awareness Gap:** The workstream plays a critical role in creating awareness and providing training on the significance of data standards in the African research setting. This includes conducting seminars, and training sessions, and collaborating with research institutes to encourage data standard adoption.
- **Interoperability with Omics Data:** To enable the smooth integration of these different data types into research endeavours, it is critical to create standards that can efficiently manage them through collaboration with specialists in genomes and omics research to develop a unified data architecture that incorporates all essential data types.

### Omics Workstream

- **Skills Gap and Capacity Development:** Comprehensive training programmes were proposed to bring all stakeholders to a level of confidence in dealing with mixed data to create successful partnerships among subject matter experts and data scientists.
- **High Cost of Generating Omics Data:** Stakeholders suggested looking into cooperation with industry players to secure funds for massive omics data initiatives. Local knowledge development was also emphasised as a requirement for effective omics research within specific cohorts.
- **APCC Futureproofing for Omics Research:** Participants proposed the establishment of accessible hubs around the continent to assist institutions and academics with data gathering storage, analysis, and usage. These centres would boost involvement in phenotypic and mixed data gathering for further omics research.
- **Infrastructure and Sample Collection:** A key concern was the disparity in infrastructure between cohorts for sample collection before data gathering, DNA analysis, and data processing. Some locations lacked the adequate infrastructure to do these duties, and addressing this shortcoming was deemed crucial before moving on to analyse the data and capacity building.

### Capacity Strengthening Workstream

The workstream identified capacity-building gaps in cohorts that include data harmonisation to enhance data access and data sharing, cohort management (stakeholder engagement, funding, developing, and implementing research strategy and agenda, among others) to ensure the sustainability of cohorts, and ensure that the capacity-building exercises are geared towards filling gaps identified through the existing cohorts survey.

Capacity-building models should be leverage through collaborations/ partnerships to avoid duplication of efforts. Where it is not possible to leverage existing models, establishing new programmes and specialised short courses to deliver identified skills is recommended.

Capacity building should be at both the pre-and post-doctoral levels including embedding higher degrees in the cohorts, while including partnerships with universities.

Exchange programmes between cohorts would be important for building capacity in best practices in cohort management.

### Nairobi In-Person Meeting

The Nairobi in-person meeting of the CE-APCC team members took place on 10-12 December 2023. The meeting which was hosted by the African Population Health Research Centre (APHRC) was attended by the afore-mentioned Co-Chairs, Co-Applicants, and their teams. Discussions were had on the different workstreams' activities and this culminated in a discussion document which formed the basis for what is now the APCC Blueprint document.

### Third Phase: APCC Blueprint Discussion Document, Collaborative Workshops and Draft Blueprint (January-April 2024).

To get the thoughts of the cohort leads on the CE-APCC blueprint document, the existing cohorts' workstream coordinated three 3-hour collaborative workshops on March 11th, 13th, and 14th. Several concerns were raised during the workshops which will be included in this document. Apart from CE-APCC team members, the three workshops were attended by 40 cohort representatives. In line with the APCC Blueprint discussion document, CE-APCC representatives presented several sections which were followed by the responses outlined in Table C.

**Table C:** Summary of the existing cohorts' workstream coordinated three 3-hour collaborative workshops on 11th, 13th, and 14th March 2024

Category	Cohort's Queries	CE-APCC Response
APCC	Similarities/differences to INSPIRE? Is it replacing INSPIRE?	INSPIRE will advise APCC, ensure FAIR data, and train data managers. APCC is not replacing INSPIRE.
	Who funds APCC and its functions?	The current funders are Wellcome Trust, BMGF, and UKRI MRC. The intention is to increase the funding base in the future.
Membership	Differences between candidate/full members? Legacy cohorts' status?	Candidate members work towards full membership; legacy cohorts need not resume data collection.
APCC Membership	Can embedded/nested cohorts be members? Criteria for membership?	Embedded cohorts can join if not shared with parent cohort in APCC. Networks of cohorts membership criteria outlined in Blueprint document.
Governance	Who can be on the steering committee? Role of rural/urban groups?	Secretariat members cannot be investigators. Urban/rural considerations depend on membership.
Capacity Strengthening	How will capacity strengthening be provided? Stabilisation fund details?	Based on Capability Readiness Matrix with funding prioritisation based on need.
Scientific Networking	How will stakeholder engagement be handled? Strategic programmes' design and funding?	Collaboration with regional organisations. Funding support via Secretariat. Strategic programmes will evolve.
Ethics	AVAREF model and multi-country ethics reviews? Broad consent forms?	AVAREF facilitates multi-country ethics reviews. Broad consent forms and ethics guidelines are evolving.
Cohort Methodology (Data/Samples)	Data standardisation challenges? TRE use and data access? Authorship guidelines?	APCC to ensure data standardisation and TRE use. Authorship guidelines in place.
Cohort Methodology (Biosamples)	Biosample ethics and sharing considerations? Handling of pre-consortium bio-specimens?	Ethics guidelines and consent crucial for biosample sharing. Pre-consortium samples considered based on consent.

## APPENDIX 2

# Existing Cohort Research Organisations – Websites, Selected Publications

Name of cohort	Country • city/ district	Website	Bio
ACCME	Nigeria;	<a href="https://h3accme.com">https://h3accme.com</a>	Studies NCDs including cancer and cardiometabolic diseases in a rural and urban population of over 11,000.
Agincourt HDSS	South Africa; Mpumalanga Province, Ehlangeni District, Bushbuckridge sub-district.	<a href="http://www.agincourt.co.za">www.agincourt.co.za</a>	Managed by SA MRC and Wits, the cohort currently has about 116,000 on follow-up. The rural cohort primarily focuses on mental health, mortality and CVDs.
AHRI HDSS	South Africa; District of Umkhanyakude	<a href="https://www.ahri.org/">https://www.ahri.org/</a>	Independent research institute focussing primarily on TB and HIV intervention studies and clinical trials with secondary interests in mental health, climate change and non-communicable diseases in association with HIV. Operates a 150000 person HDSS as a node of the SAPRIN network
AL-SEHA: A Longitudinal Study of Egyptian Healthy Aging	Egypt; National	<a href="https://www.aucegypt.edu/research/src/sdg-health-equity/eastern-mediterranean-aging/al-seha">https://www.aucegypt.edu/research/src/sdg-health-equity/eastern-mediterranean-aging/al-seha</a>	Has 3,000 of targeted 20,000 adults under follow-up. The cohort studies aging and dementia in rural and urban Egypt.
Arba Minch HDSS (AM-HDSS)	Ethiopia; South Nations	<a href="https://amu.edu.et/research-offices/research-and-publications-research-centers/arba-minch-demographic-surveillance-and-health-research-unit-am-hdss">https://amu.edu.et/research-offices/research-and-publications-research-centers/arba-minch-demographic-surveillance-and-health-research-unit-am-hdss</a>	Managed by Arba Minch University, following over 138,000 rural and urban participants. It monitors and records vital events, pregnancies, and migration among others.
AWI-Gen (Africa Wits-INDEPTH partnership for Genomic studies)	Ghana, Burkina Faso, Kenya and South Africa	<a href="https://www.wits.ac.za/research/sbimb/research/doi:10.1080/16549716.2018.1507133">https://www.wits.ac.za/research/sbimb/research/doi:10.1080/16549716.2018.1507133</a> ( <a href="https://pubmed.ncbi.nlm.nih.gov/30259792/">https://pubmed.ncbi.nlm.nih.gov/30259792/</a> )	Multi-country research cohort targeting 12,000 rural and urban older adults. Studying genomics, cardiometabolic traits - genetic epidemiology- and population genetics among others.
Bamako HDSS	Mali; Quartier of Banconi and Djicoroni Para	<a href="http://www.cvd-mali.org">www.cvd-mali.org</a>	Managed by centre for Vaccine Development- Mali, following 203,043 urban population since 2007
Bandafassi HDSS	Senegal; Bandafassi District	<a href="https://academic.oup.com/ije/article/43/3/739/2949552">https://academic.oup.com/ije/article/43/3/739/2949552</a>	Established in 1970, it has just under 14,000 participants in 2011. It monitors household compositions and records vital events and causes of death.
Bandim Health Project	Guinea-Bissau; Bissau	<a href="https://www.bandim.org/about-bandim-health-project/">https://www.bandim.org/about-bandim-health-project/</a> <a href="https://www.measureeffects.org/hdss">https://www.measureeffects.org/hdss</a>	Household level longitudinal cohort. The American University in Cairo with 20,000 participants being followed up. It does not collect biosample data.

Name of cohort	Country • city/ district	Website	Bio
Basse, Farafenni and West Kiang HDSS operated by The Medical Research Council Unit The Gambia	Gambia; Upper River Region - Basse North Bank Division - Farafenni Lower River Region - West Kiang	<a href="https://www.lshtm.ac.uk/research/units/mrc-gambia/locations">https://www.lshtm.ac.uk/research/units/mrc-gambia/locations</a>	A set of research cohorts (HDSSs) run by MRC Gambia with over 200,000 participants being followed up. It serves as a platform for clinical trials, collecting social, clinical and biosample data.
Birth to Thirty	South Africa; Gauteng province	<a href="https://bt30.org/the-bt30-study/">https://bt30.org/the-bt30-study/</a>	Followed 3,273 singleton births (early 1990s) from pregnancy, and collecting data since then on key issues affecting them at their ages during each data collection phase. Continues to follow-up subsequent generations (from 2005).
Bukavu Observational Study	Democratic Republic of Congo; South Kivu	<a href="https://osf.io/yrv6c">https://osf.io/yrv6c</a> <a href="https://pubmed.ncbi.nlm.nih.gov/31393877/">https://pubmed.ncbi.nlm.nih.gov/31393877/</a>	Managed by Catholic University of Bukavu-UCB (DRC) and Flemish Universities, observational study in both rural and urban. Designed to follow 12,00 people for 12 years from 2012 to investigate cardiovascular issues.
Butajira HDSS	Ethiopia; Meskan, Mareko and Silti Districts	<a href="https://atelim.com/butajira-hdss-ethiopia.html">https://atelim.com/butajira-hdss-ethiopia.html</a> <a href="http://www.indepth-network.org/dss_site_profiles/butajira.pdf">http://www.indepth-network.org/dss_site_profiles/butajira.pdf</a>	Located in 10 randomly sampled villages with combined 54,096 population as of 2007. Conducts epidemiology studies on top of annual censuses capturing vital events.
C-SHARP (Cape Town Systematic Healthcare Action Research Project)	South Africa; Cape Town, Western Cape	<a href="https://saprin.mrc.ac.za/csharp.html">https://saprin.mrc.ac.za/csharp.html</a>	An urban HDSS established in 2023 to understand "community oriented primary healthcare". Plans to enrol and follow-up 130,000 people.
Centro de Investigacao em Saude da Manhica / Manhica Health Research Centre	Mozambique; Manhica	<a href="https://www.cismmanhica.org/">https://www.cismmanhica.org/</a>	Managed by Manhica Health Research Centre, following over 155,000 of targeted 212,305 rural population. Conducts research on Malaria, TB and HIV and MNCH.
Chokwe HDSS	Mozambique; Chokwe district	<a href="https://www.indepth-ishare.org/index.php/catalog/176">https://www.indepth-ishare.org/index.php/catalog/176</a>	Established in 2010, with a population of 56,727, and had a population of just under 100,000 in 2016. Collected vital events, and verbal autopsy data among others.
Cross River HDSS	Nigeria; Calabar and Akpabayo Municipalities	<a href="https://crhdss.org/">https://crhdss.org/</a>	Established in 2012, has one rural and one urban site with a combined population of over 33,000 by 2016. Generates data suitable for understanding population dynamics, MNCH, and NCDs among others.
Dabat Research Center (Dabat HDSS)	Ethiopia; Region: Amhara Districts: Dabat, Gondar and Gorgora	<a href="https://drc.uog.edu.et/">https://drc.uog.edu.et/</a>	Established in 2021 currently enrolled 70,000 out of a targeted 110,000. Collects data on vital events among others, providing a platform to "develop and evaluate a system for continuous registration of health and health-related, and socioeconomic indicators".
Dale-Wonsho HDSS	Ethiopia; Sidama Region, Ethiopia	<a href="https://nu.edu.et/index.php/center-of-excellence/hdss-research-center">https://nu.edu.et/index.php/center-of-excellence/hdss-research-center</a>	An open cohort established in 2017, registering births and deaths and data on causes of birth, immunization and antenatal care follow-up among others. Currently has 72,000 out of targeted 215,000 under follow-up in rural and urban Ethiopia.
Dande HDSS	Angola; Dande, Bengo province	<a href="https://academic.oup.com/ije/article/46/4/1094/3852149">https://academic.oup.com/ije/article/46/4/1094/3852149</a>	Established to provide timely data on causes of morbidity in Angola. Covered a population of 58,645 in 2014.
DIMAMO Population Health Research Centre	South Africa; Capricorn District, Limpopo Province	<a href="https://saprin.mrc.ac.za/dimamo.html">https://saprin.mrc.ac.za/dimamo.html</a>	Rural HDSS covering approximately 116,000 individuals. Conducts population health research in a rural and socioeconomically disadvantaged area. Areas include NCDs, maternal health and HIV.
Dodowa HDSS	Ghana; Shai-Osudoku and Ningo-Prampram Districts	<a href="https://www.dodowa-hrc.org/index.php?option=com_content&amp;view=article&amp;id=276&amp;Itemid=314">https://www.dodowa-hrc.org/index.php?option=com_content&amp;view=article&amp;id=276&amp;Itemid=314</a> <a href="https://www.dodowa-hrc.org">https://www.dodowa-hrc.org</a>	Established in 2005, it has a population of over 117,000. Through censuses and key informants they monitor vital events and health indicators to inform healthcare decisions.
Entebbe Mother and Baby Study (EMaBS)	Uganda; Entebbe municipality and Wakiso district	<a href="https://emabs.lshtm.ac.uk/">https://emabs.lshtm.ac.uk/</a>	A birth cohort initially designed as a trial investigating work infections during pregnancy, now provides a platform to research health impacts of early life experiences.

Name of cohort	Country • city/ district	Website	Bio
General Population Cohort (GPC)	Uganda; Kalungu district (Rural southwestern Uganda)	<a href="https://www.lshtm.ac.uk/research/centres-projects-groups/general-population-cohort">https://www.lshtm.ac.uk/research/centres-projects-groups/general-population-cohort</a>	A rural research cohort established in 1989, primarily focused on studying NCDs and infectious diseases including HIV and epidemics. Has 23,000 participants out of targeted 25,000. It generates clinical, social and biosample data.
Generation Malawi	Malawi; Lilongwe and Karonga	<a href="https://www.meiru.info/generation-malawi/">https://www.meiru.info/generation-malawi/</a>	Targets 5,000 participants in rural and urban Malawi to study "longitudinal course and pregnancy, early-life and intergenerational effects for chronic mental and physical health conditions". The study collects biosamples.
Gilgel Gibe HDSS	Ethiopia; Kersa, omonada, Tiro Afeta and Sekuro Districts	<a href="https://ju.edu.et/gilgel-gibe-field-research-center/">https://ju.edu.et/gilgel-gibe-field-research-center/</a> <a href="http://www.indepth-network.org/Profiles/Gilgel%20HDSS.pdf">http://www.indepth-network.org/Profiles/Gilgel%20HDSS.pdf</a>	It monitors and registers vital events. Also collects data on pregnancies, migration, child growth and morbidity among others. Had a population of 54,538 (rural and urban) in 2011.
GRT-INSPIRED	South Africa; Gauteng (Hillbrow, Atteridgeville, Melusi)	<a href="https://grt.ac.za/wsg">https://grt.ac.za/wsg</a> <a href="https://saprin.mrc.ac.za/grtinspired.html">https://saprin.mrc.ac.za/grtinspired.html</a>	An urban HDSS of with a population close to 50,000 out of a target of 100,000, established in 2020. Investigates changes in demographic and health indicators within a changing socio-economic environment.
H3Africa ACCME	Nigeria, Zambia	<a href="https://h3africa.org/index.php/accme/">https://h3africa.org/index.php/accme/</a>	A study involving 12,000 women to investigate genomic risk of vaginal microbiome and their association with high risk HPV infections and progression of cervical cancers.
HAALSI (Health and Aging in Africa)	South Africa; Mpumalanga Province, Ehlangeni District, Bushbuckridge sub-district.	<a href="https://haalasi.org/">https://haalasi.org/</a>	Following about 5,000 (aged 40+) people since 2012 to research how chronic diseases interacts with social, family, and economic conditions in order to generate evidence on determinants of health and functional status for the elderly.
Hararghe (Kersa) HDSS; have three site namely Kersa, Harar, Haramaya HDSS	Ethiopia;	<a href="https://www.hararghe.org/research-sites">https://www.hararghe.org/research-sites</a> <a href="http://researchaffairs.haramaya.edu.et/wp-content/uploads/2017/09/18-Kersa-Harar-HDSS.pdf">http://researchaffairs.haramaya.edu.et/wp-content/uploads/2017/09/18-Kersa-Harar-HDSS.pdf</a>	Comprises three HDSSs covering a population of over 310,000. Provides a platform for different kinds of research including maternal and child health.
HDSS Polana Canico	Mozambique; Maputo City	<a href="https://ins.gov.mz/wp-content/uploads/2020/10/HDSS-Polana-Canico%CC%A7o-Relato%CC%81rio-Avaliac%CC%A7a%CC%83o-de-base-19102020.pdf">https://ins.gov.mz/wp-content/uploads/2020/10/HDSS-Polana-Canico%CC%A7o-Relato%CC%81rio-Avaliac%CC%A7a%CC%83o-de-base-19102020.pdf</a>	A peri-urban HDSS which had about 15,000 participants in 2017. Provides a platform for cross-sectional studies including on COVID-19 and HIV and clinical trials.
Heart of Soweto cohort study	South Africa; Soweto	<a href="https://www.hefssa.org/static/heart-of-soweto-study">https://www.hefssa.org/static/heart-of-soweto-study</a>	Studying causes and consequences of cardiovascular diseases, by prospectively enrolling 12,000 men and woman presenting with heart disease at Chris Hani Baragwanath Hospital.
IDI Research cohort	Uganda; Kampala	<a href="https://idi.mak.ac.ug/programs/research/">https://idi.mak.ac.ug/programs/research/</a> <a href="https://idi.mak.ac.ug/research-units/">https://idi.mak.ac.ug/research-units/</a>	This 1,000 person urban cohort focuses on HIV and issues relating to ART usage. It generates social clinical and biosample data. With over 70,000 patients at IDI, many of the nested cohorts created per need fall under the Longitudinal cohorts units.
Ifakara HDSS	Tanzania; Kilombero and Ulanga Districts	<a href="http://indepth-network.org/member-centres/ifakara-hdss">http://indepth-network.org/member-centres/ifakara-hdss</a> <a href="http://indepth-network.org/sites/default/files/content/centres/files/Ifakara%20HDSS.pdf">http://indepth-network.org/sites/default/files/content/centres/files/Ifakara%20HDSS.pdf</a>	Located in the southern part of Tanzania, by 2007 it had close to 170,000 people under surveillance. Apart from generating data on key health and demographic indicators, it also served as a platform for testing tools and evaluating interventions.
Ifakara Millennium Birth Cohort	Tanzania; Kilombero and Ulanga Districts	<a href="http://www.ihl.or.tz">http://www.ihl.or.tz</a> <a href="https://ihl.or.tz/our-events/170/details/">https://ihl.or.tz/our-events/170/details/</a>	The birth cohort currently has 5,400 people from the 1998-2000 birth cohort under follow-up. It looks at long term impact of childhood malaria infection and climate change, livelihood and health.
Iganga Mayuge Health and Demographic Surveillance Site (IMHDSS)	Uganda; Iganga and Mayuge	<a href="https://muchap.mak.ac.ug/">https://muchap.mak.ac.ug/</a>	IM-HDSS currently has about 100,000 urban and rural participants. Among others they register births, deaths and population movements in their catchment area.

Name of cohort	Country • city/ district	Website	Bio
IHOPE	Madagascar; Ifanadiana District	<a href="https://www.pivotworks.org/?popuppress=ihope-household-longitudinal-cohort">https://www.pivotworks.org/?popuppress=ihope-household-longitudinal-cohort</a>	A representative sample of geographic district, comprising all of the population (n = ~12,000) living in randomly selected households. Studying health system, and provides a platform for evaluating different interventions.
Kagando HDSS	Uganda; Kasese	<a href="http://www.karudec.ug">www.karudec.ug</a>	A semi-urban open cohort of 40,000 Uganda. Researching vaccine equity.
Kaloleni-Rabai Health and Demographic Surveillance System	Kenya; Kilifi County	<a href="https://www.aku.edu/mcea/departments/Pages/krhdss-profile.aspx">https://www.aku.edu/mcea/departments/Pages/krhdss-profile.aspx</a>	Started in 2017 with the aim of strengthening capacity of local health departments in generating and processing health and vital events data, and as a research platform to answer population level questions. As of 2022 had just over 98,000 participants under surveillance.
Kanyama	Zambia; Lusaka	Not yet	Will aim to recruit 200,000 urban participants.
Karonga and Area 25 HDSSs	Malawi; Rural -Karonga, Urban- Area 25 in Lilongwe.	<a href="https://www.meiru.info/healthy-lives-malawi/">https://www.meiru.info/healthy-lives-malawi/</a>	An open cohort, HDSS with over 78000 individuals under surveillance in rural and urban locations. Serves as a sampling frame for numerous biomedical studies including repeated cross-sectional studies of chronic NCDs. HDSS aims to cover 110000 population.
Kaya Health and Demographic Surveillance System	Burkina Faso; Kaya Health District	<a href="https://hubssr.org/kaya-health-and-demographic-surveillance-system-kaya-hdss/">https://hubssr.org/kaya-health-and-demographic-surveillance-system-kaya-hdss/</a> <a href="https://jrss.bf">https://jrss.bf</a>	Urban and rural cohort of 85,000 participants established in 2007. Collects data on vital events. Researches reproductive health including HIV and maternal and child health indicators.
Kilifi Health and Demographic Surveillance System (KHDSS)	Kenya; Kilifi County	<a href="https://kemri-wellcome.org/kilifi-health-and-demographic-surveillance-system-khdss/">https://kemri-wellcome.org/kilifi-health-and-demographic-surveillance-system-khdss/</a>	A rural research cohort of over 300,000 participants. Researches morbidity, child mortality and vaccines among others. Provides a sampling frame for numerous health projects including intervention studies.
Kilte-Awlaelo Health and Demographic Surveillance System	Ethiopia; Tigray Region (Kilte-Awlaelo, Wukro, and Atsbi Wemberta)	<a href="https://catalog.ihnsn.org/index.php/catalog/5333">https://catalog.ihnsn.org/index.php/catalog/5333</a>	Enrols over 100,000 participants. Apart from demographic surveillance including causes of death, the cohort also studies how different factors affect health of the population. Started in 2009.
Kimpese HDSS	Democratic Republic of Congo; Kimpese Health zone	<a href="https://crsk.cd/index.php/histoire/">https://crsk.cd/index.php/histoire/</a>	Established in 2017 to support evidence generation for health decision making and evaluation of health interventions. Follows about 60,000.
Kintampo HDSS	Ghana; Kintampo North and South District	<a href="https://kintampo-hrc.org/pages/khdss.html">https://kintampo-hrc.org/pages/khdss.html</a> <a href="https://kintampo-hrc.org">https://kintampo-hrc.org</a>	Rural HDSS established in 2003. Platform for clinical trials, implementation research, policy evaluations, malaria and NCD research. Had a population of 456,478 in 2020.
Kisesa observation HIV cohort study	Tanzania; Magu District, Mwanza Region Tanzania	<a href="mailto:mwanza@nimr.or.tz">mwanza@nimr.or.tz</a>	A rural HDSS collecting data on births, deaths, migration, HIV and other health and social areas. Has a population of 50,000.
Kisumu (KEMRI/ CDC)	Kenya; Rarieda, Siaya and Gem Districts	<a href="http://www.indepth-network.org/member-centres/kisumu-hdss">http://www.indepth-network.org/member-centres/kisumu-hdss</a> <a href="http://ije.oxfordjournals.org/content/41/4/977.full.pdf+html?sid=d6099d6b-a5e7-4d19-aaa0-45b6030092d8">http://ije.oxfordjournals.org/content/41/4/977.full.pdf+html?sid=d6099d6b-a5e7-4d19-aaa0-45b6030092d8</a>	Created as part of insecticide treated net trial, the HDSS covers 230,000 participants. Providing a platform for multi-disciplinary research.
Kombewa HDSS	Kisumu county	<a href="http://www.indepth-network.org/member-centres/kombewa-hdss">http://www.indepth-network.org/member-centres/kombewa-hdss</a> <a href="http://indepth-network.org/sites/indepth.mrmdev.co.uk/files/content/centres/files/Kombewa%20profile.pdf">http://indepth-network.org/sites/indepth.mrmdev.co.uk/files/content/centres/files/Kombewa%20profile.pdf</a>	Established in 2007/2011?, it has grown into a regulated clinical trials, diseases surveillance and nested studies platform. Has a population of over 180,000.
Kyamulibwa HDSS / Masaka	Uganda; Kyamulibwa, Kalungu District		Managed by UK Medical Research Council and Uganda Virus Research Institute, 20,000 population in both rural and urban areas.

Name of cohort	Country • city/ district	Website	Bio
LTC Survey (Rural)	Malawi; Karonga	<a href="https://www.meiru.info/healthy-lives-malawi/">https://www.meiru.info/healthy-lives-malawi/</a>	A rural chronic conditions cohort of 25,000 participants aged 15+ to understand the epidemiology of longterm health conditions such as diabetes, hypertension and mental health.
LTC Survey (Urban)	Malawi; Lilongwe	<a href="https://www.meiru.info/healthy-lives-malawi/">https://www.meiru.info/healthy-lives-malawi/</a>	An urban cohort of 25,000 participants aged 15+ to understand the epidemiology of longterm chronic health conditions such as diabetes, hypertension and mental health.
Magu HDSS (Kisesa?)	Tanzania; Magu District	<a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4911678/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4911678/</a>	The HDSS established in 1994 as one component of the Kisesa HIV Cohort. It monitors mortality fertility and morbidity in the general population. Mostly HIV research. Had a population of 35,569 in 2014.
Manicaland Centre for Public Health Research	Zimbabwe; Manicaland Province	<a href="http://www.manicalandhivproject.org/">http://www.manicalandhivproject.org/</a>	This cohort is targeting enrollment of 17,000 mostly rural people of all ages to mainly research issues around HIV and other sexual risk behaviours.
Manyatta HDSS	Kenya; Kisumu city	<a href="http://www.kemri.go.ke">www.kemri.go.ke</a>	Managed by Kenya Medical Research Institute, following 75,000 urban population.
Mbita HDSS	Kenya; Homa Bay County	<a href="https://academic.oup.com/ije/article/42/6/1678/739377">https://academic.oup.com/ije/article/42/6/1678/739377</a>	Managed by Kenya Medical Research Institute, the cohort is expected to be following 75,000 urban population up from 54,000 in 2013. It has capacity to be a platform for other research studies.
Mecha HDSS	Ethiopia; Mecha	<a href="https://www.bdu.edu.et/mrc/">https://www.bdu.edu.et/mrc/</a> <a href="https://www.etpha.org/publications/other-publications.html?download=479:hdss-network-policy">https://www.etpha.org/publications/other-publications.html?download=479:hdss-network-policy</a>	Established in 2013, it includes three geo-climatic conditions to investigate mortality and morbidity differences. Currently has over 74,000 people providing data on migration, vital events (including verbal autopsies), and health related conditions such as pregnancy, immunization and morbidity.
MHURAM (The Moramanga Health Survey in Urban and Rural Areas in Madagascar) Cohort	Madagascar; Region Alaotra Mangoro, District Moramanga	<a href="https://academic.oup.com/ije/article/48/6/1754/5606762">https://academic.oup.com/ije/article/48/6/1754/5606762</a>	Rural and urban cohort following up over 87,000 people. Conducts research on NCDs and infectious diseases.
Mildmay Uganda Cohort	Uganda;	<a href="https://mildmay.or.ug/what-we-do">https://mildmay.or.ug/what-we-do</a>	Primarily focuses on HIV prevention and management in Uganda. It has over 100,000 ART clients under its care.
Mlomp HDSS	Senegal; Loudia-Ouolof	<a href="https://archined.ined.fr/view/AWRIRa4ugpz89Adag6nX">https://archined.ined.fr/view/AWRIRa4ugpz89Adag6nX</a>	A rural cohort of close to 9,000 participants (2015). Collects data on vital events, migration and morbidity. Started in 1985.
Nahuche HDSS	Nigeria; Zamfara state	<a href="https://academic.oup.com/ije/article/43/6/1770/708860">https://academic.oup.com/ije/article/43/6/1770/708860</a>	Established in 2009 to provide population based comparisons for sample survey and champion research that would promote health and wellbeing. Had a population of over 125,000 at baseline in 2010.
Nairobi Urban HDSS (NUHDSS)	Kenya; Nairobi	<a href="https://aphrc.org/project/nairobi-urban-health-and-demographic-surveillance-system-nuhdss/">https://aphrc.org/project/nairobi-urban-health-and-demographic-surveillance-system-nuhdss/</a>	An urban HDSS of 90,000 participants established in 2002. Created to study impacts of urbanisation, particularly how life in slums affects health outcomes. Serves as a platform for special studies for example on education, family planning in urban slums.
Nanoro HDSS	Burkina Faso; Central west region/ Nanoro Health district	<a href="https://crun.bf/hdss/">https://crun.bf/hdss/</a>	Among other conducts clinical trials and other intervention research and other biomedical research on infectious and NCDs. Has 66,500 people under follow-up in rural Burkina Faso.
NATIONAL MUSLIM EMERGENCY RESPONSE ORGANIZATION (NMERO)	Kenya;		A rural and urban cohort focusing on disease outbreaks and surveillance and emergency response.
Navrongo HDSS	Ghana; Kassena-Nankana District	<a href="https://navrongo-hrc.org/navrongo-hdss/">https://navrongo-hrc.org/navrongo-hdss/</a>	Started in 1993, now has over 150,000 people under follow up. They routinely collect data on pregnancies, births, morbidity and mortality, migration, marriages and vaccination status.

Name of cohort	Country • city/district	Website	Bio
Niakhar HDSS	Senegal; Niakhar	<a href="https://dataset.osupytheas.fr/geonetwork/geonetwork/api/records/a6d9a46c-44f4-4253-b599-bd7eade06816">https://dataset.osupytheas.fr/geonetwork/geonetwork/api/records/a6d9a46c-44f4-4253-b599-bd7eade06816</a>	Surveillance started in the early 1960s. By 2013 about 45,000 people were under follow-up with data collected routinely on epidemiological, economic and environmental variables.
Nigerian 100K Genome Project	Nigeria	<a href="https://www.insideprecisionmedicine.com/news-and-features/nigerian-100k-genome-project-describes-strategic-vision/">https://www.insideprecisionmedicine.com/news-and-features/nigerian-100k-genome-project-describes-strategic-vision/</a> <a href="https://www.nature.com/articles/s41588-022-01071-6">https://www.nature.com/articles/s41588-022-01071-6</a>	Aims at understanding genetic diversity in Africa. Plans to sequence and understand NCD risk and etiology through analysing genetic samples from 100,000 adult Nigerians.
Nouna HDSS	Burkina Faso; Nouna	<a href="https://www.crsn-nouna.bf">https://www.crsn-nouna.bf</a> <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2940452/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2940452/</a>	Established in 1992, by 2007 it was covering a population of over 78,000. Collecting data on vital events including causes of death.
Nyanja	Malawi; Salima	<a href="http://www.nyanja-health.com">www.nyanja-health.com</a>	Plans to recruit 120,000 rural participants to primarily understand mortality and severe disease epidemiology
Ouagadougou HDSS (OHDSS)	Burkina Faso; Ouagadougou	<a href="http://www.issp.bf">www.issp.bf</a> <a href="http://www.issp.bf/index.php/fr/site-map/articles/244-tous-les-departements/467-catalogue-des-donnees">http://www.issp.bf/index.php/fr/site-map/articles/244-tous-les-departements/467-catalogue-des-donnees</a>	An urban HDSS with 100,000 people under surveillance. Focuses on health research including mortality, health inequality, and other urbanisation factors affect health.
PRECISE Network	Manhica District hospital and Xinavane Rural Hospital	<a href="https://precisenetwork.org/about/research-highlights/precise-supplement/">https://precisenetwork.org/about/research-highlights/precise-supplement/</a>	The PRECISE Network is a new and broadly-based group of research scientists and health advocates investigating high blood pressure, fetal growth restriction and stillbirth as key pregnancy complications.
PURE-Pro prospective Urban and Rural Epidemiological Study	Zimbabwe, Tanzania, South Africa	<a href="https://www2.phri.ca/pure/">https://www2.phri.ca/pure/</a>	An observational study of 225,000 from 27 countries (including three in Africa) on impact of urbanization on common risk factors and CVD.
Rakai Community Cohort Study (RCCS)	Uganda; Rakai	<a href="https://www.rhsp.org/research/rccs/rccs-overview">https://www.rhsp.org/research/rccs/rccs-overview</a> <a href="https://www.rhsp.org">https://www.rhsp.org</a>	Open cohort enrolling all consenting adults in rural and urban communities (~18,000). Mostly HIV studies covering incidence, prevention and treatment and sexual behaviours. Censuses are conducted to obtain demographic and socio-economic data. Cohort serves as a platform for other studies including trials and nested cohort.
Rufiji HDSS	Tanzania; Rufiji district	<a href="https://www.ihl.or.tz/our-research/">https://www.ihl.or.tz/our-research/</a> <a href="https://pure.johnshopkins.edu/en/publications/health-amp-demographic-surveillance-system-profile-the-rufiji-hea">https://pure.johnshopkins.edu/en/publications/health-amp-demographic-surveillance-system-profile-the-rufiji-hea</a>	Established in 1998, by 2012 the HDSS had over 100,000 participants. It was set up to monitor household and individual changes (including births and deaths), socioeconomic and geographic data.
Seychelles Child Development Study	Seychelles;	<a href="https://www.urmc.rochester.edu/labs/seychelles/scientific-approach.aspx">https://www.urmc.rochester.edu/labs/seychelles/scientific-approach.aspx</a>	Managed by the Seychelles MoH and Rochester University. Established in 1980s to study child development, and how prenatal and early postnatal factors affected child development. Started with 779 children tested at different ages. Other cohorts (i.e. mothers) have also been established.
SIBS-Genomics	Nigeria	<a href="https://balance.ucsf.edu/content/sibs-genomics-systematic-investigation-blacks-stroke-genomics">https://balance.ucsf.edu/content/sibs-genomics-systematic-investigation-blacks-stroke-genomics</a>	With 8,000 research participants from Africa, this study will understand genetic variants associated with ischemic stroke amongst people of African ancestry.
SIREN	Nigeria, Ghana	<a href="https://pubmed.ncbi.nlm.nih.gov/29618553/">https://pubmed.ncbi.nlm.nih.gov/29618553/</a>	Stroke cohort following 6,000 population done at 15 sites in Nigeria and Ghana. Cases were adults (aged ≥18 years) with stroke confirmed by CT or MRI with age and gender matched controls.
SIS-COVE/COMSA	Mozambique;	<a href="https://comsamozambique.org/">https://comsamozambique.org/</a>	COMSA set up a representative nationwide sample (800,000) of clusters for routine surveillance of pregnancies, birth outcomes and deaths.

Name of cohort	Country • city/district	Website	Bio
Siyakhula Cohort	South Africa; KwaZulu-Natal	<a href="https://academic.oup.com/ije/article/47/2/680/4822280">https://academic.oup.com/ije/article/47/2/680/4822280</a>	Managed by AHRI, this rural and urban cohort has 1,536 participants under follow-up. It primarily focusses on cognitive development, mental health and breastfeeding.
Survey of Young People	Egypt	<a href="https://popcouncil.org/project/survey-of-young-people-in-egypt/">https://popcouncil.org/project/survey-of-young-people-in-egypt/</a>	A longitudinal survey (four major rounds between 1997 and 2022), with 17,000 participants in 2022. Focuses on young people's needs and aspirations.
Taabo HDSS	Tiassale district	<a href="https://csrs.ch/fr/stations/taabo">https://csrs.ch/fr/stations/taabo</a> <a href="https://academic.oup.com/ije/article/44/1/87/654421">https://academic.oup.com/ije/article/44/1/87/654421</a>	Managed by Centre Suisse de Recherches Scientifiques en Cote d'Ivoire, following about 45,000 population in rural and urban. Used to generate evidence and evaluate interventions.
TASO-CAN	Uganda	<a href="https://repository.gheli.harvard.edu/repository/10727/">https://repository.gheli.harvard.edu/repository/10727/</a> <a href="https://academic.oup.com/ije/article/41/4/946/683540">https://academic.oup.com/ije/article/41/4/946/683540</a>	Managed by The AIDS Support Organization, rural clinical cohort, following 24,000 population. Largely conducts HIV research.
Tunisian Human Genome project	Nation wide		Rural and urban Genomic cohort with about 50,000 population.
Umlazi Surveillance Initiative to Nurture Grassroots Action (USINGA)	South Africa; KwaZulu-Natal	<a href="https://saprin.mrc.ac.za/usinga.html">https://saprin.mrc.ac.za/usinga.html</a>	A peri-urban HDSS interested in developing insights into population health and wellbeing, including through understanding population change and dynamics, youth, health and socio-economic issues. Started data collection in 2023.
Volta Region of Ghana cohort	Ghana; Volta region		Being established by Institute of Health Research, University of Health and Health and Allied Sciences, Ghana.
VUKUZZI	South Africa; Somkhele Umkhanyakude, KZN	<a href="https://academic.oup.com/ije/article/51/3/e131/6446138">https://academic.oup.com/ije/article/51/3/e131/6446138</a>	Urban and rural cohort following 18,000 people established in 2018. Primarily researches HIV, TB and Diabetes.
Young Lives	Ethiopia;	<a href="https://www.younglives.org.uk">https://www.younglives.org.uk</a> ; <a href="https://www.younglives-ethiopia.org/">https://www.younglives-ethiopia.org/</a>	Managed by Policy Studies Institute. Birth cohort now adult and older cohort of 1000 who were 8 years old when the study began enabling comparisons of ages 8, 12, 15 and 19.

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