



**African Population and  
Health Research Center**



## **THE IMPLEMENTATION NETWORK FOR SHARING POPULATION INFORMATION FROM RESEARCH ENTITIES (INSPIRE 2.0)**



# **LAUNCH REPORT**

**Date:** February 27 – 28, 2025

**Venue:** Novotel, Dakar Senegal

**Participants:**

- African Population and Health Research Center
- Health and Demographic Surveillance Site Representatives
- Malawi University of Business and Applied Sciences



# Table of Contents

## **DAY 1: FEBRUARY 27, 2025**

- Session 1: Opening Remarks
- Session 1.1: Opening Remarks
- Session 1.2: Keynote Address from APHRC
- Session 1.3: Introduction to INSPIRE 2.0 (Demonstration Project Launch)
- General Feedback & Questions
- Session 2: Health and Demographic Surveillance System Sites Presentations

## **DAY 2: FEBRUARY 28, 2025**

- Session 1: Group presentations
- Session 1.1: Harnessing AI and LLMs in HDSS
- Session 1.2: Sustainable Approaches to Maintaining HDSS Operations
- Session 1.3: How to Leverage HDSS for population and health research.
- Session 2: Introduction to the Gates Family Planning Program
- Session 3: Data Harmonization, Standardization and Analytics
- Session 4: Assessment of LPCs and HDSS - Data capability maturity assessment
- Session 5: Way Forward

## **Annex 1: Presentations**

## **Annex 2: Launch Photos**

## **Annex 3: HDSS Participants**

# DAY 1: FEBRUARY 27, 2025

## Session 1: Opening Remarks

**Time:** 09:00 - 10:00

**Session Chair:** Dr. Damazo Kadengye

### Session 1.1: Opening Remarks

- **Speaker:** Dr. Malick Sylla
- **Summary Points:** Dr. Malick Sylla highlighted one of the key objectives of INSPIRE 2.0, i.e., strengthening health and population data systems across Africa. He outlined existing challenges hindering this goal, including the insufficient utilization of available data, the lack of harmonized and standardized datasets with varying formats that hinder global integration, and limited access to datasets. To address these challenges, he emphasized the need for data standardization and harmonization. He also underscored the unique opportunity INSPIRE 2.0 presents in leveraging HDSS datasets to facilitate discussions on improving data collection methodologies and maximizing data utilization. Additionally, he stressed the importance of translating dataset outputs into understandable insights for policymakers, ensuring data-driven decision-making.

### Session 1.2: Keynote Address from APHRC

- **Speaker:** Dr. Andre Kengne
- **Summary Points:** Dr. Kengne outlined the mission and vision of APHRC and its diverse research themes. He highlighted the Data Science Program (DSP) as the host of the INSPIRE 2.0 project and acknowledged the presence of HDSS representatives and partners. He noted that HDSS sites are evolving to bridge critical gaps in data availability and discussed key themes, including challenges such as the lack of standardized data across countries and the need for sustainable funding. He emphasized the necessity of modernization, particularly through the integration of AI and data science tools to enhance dataset utilization and outputs. He also stressed the importance of strengthening collaboration among HDSS sites to improve data systems. Concluding his remarks, he underscored INSPIRE 2.0's role in enhancing the understanding of major health conditions and positioning population health as a catalyst for improving lives in Africa.

### Session 1.3: Introduction to INSPIRE 2.0 (Demonstration Project Launch)

- **Speaker:** Dr. Agnes Kiragga
- **Summary Points:** Dr. Kiragga provided an overview of the INSPIRE 2.0 project and its goals, emphasizing the use of longitudinal data to generate evidence. She highlighted INSPIRE's achievements, including leadership in data standardization through OMOP CDM, vocabulary modifications, HDSS collaborations, and capacity-building efforts. She also addressed key challenges such as data quality, skills gaps, infrastructure limitations, and sustainability. Additionally, she discussed the intersection between INSPIRE and the African Population Cohort Consortium (APCC) in harmonizing population cohort data across Africa and enhancing data FAIRness, i.e., making it Findable, Accessible, Interoperable, and Reusable. Concluding her remarks, she stressed the importance of collaboration in ensuring the project's success.

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### General Feedback & Questions

1. **Plans for INSPIRE to conduct training on the use of AI:** Training will be conducted based on identified needs, with capacity building being one of the key goals of INSPIRE 2.0
2. **Clarification on the intersection between APCC & INSPIRE:** APCC is exploring various data-sharing models, including a federated approach and Trusted Research Environments (TRE).
3. **Plans to include data sharing:**
  - i. A needs assessment will be conducted and will include questions on data sharing and trust.
  - ii. Data sharing and governance remain key concerns, with a need to align institutional policies, particularly within HDSS-hosting institutions.
4. **Navigating data sharing for HDSS-generated datasets funded by different organizations**

## Session 2: Health and Demographic Surveillance System Sites

**Presentations Time: 10:00 – 16:00**

**Session Chair: Dr. Ivan Busulwa**

- **Summary Points:** This session featured presentations from all 13 HDSS sites in attendance on Day 1. The sites were: Magu, Hararghe, MEIRU, Ruwenzori, MRC The Gambia, Niakhar, Bandafassi, Taabo, Nanoro, Ouagadougou, Iganga-Mayuge, Manhiça, Ruwenzori, and the MRC Uganda General Population Cohort. Each presenter highlighted an overview of the HDSS sites, key demographic characteristics, research objectives, data collection methods, key findings and impact, challenges & lessons learnt, innovations, and future recommendations to Strengthen HDSS.

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### Key Takeaways

- **Funding & Sustainability:** Funding constraints were identified as a widespread challenge across most HDSS sites, with only a few exceptions such as Hararghe, which benefits from government support. To secure additional funding, some sites have introduced taxation on nested projects, a strategy recommended as a sustainable funding model. Strengthening government buy-in was also discussed as a key approach to increasing long-term sustainability by showcasing the impact of HDSS and aligning its activities with national policies.
- **Data Collection & Linkage:** Whereas data linkage between HDSS and health facilities is progressing at some sites, it remains a challenge in others due to financial and skills gaps. To improve data collection, there is a need to scale up the incorporation of AI in HDSS data collection systems – this can help mitigate survey fatigue and enhance data quality. Reducing the intervals between demographic surveillance rounds was also recommended to improve reporting accuracy. Additionally, political and cultural sensitivities were identified as barriers to participation, making data collection more difficult. Strengthening community engagement was highlighted as a crucial strategy for building trust and improving participation, ultimately enhancing the quality and completeness of the data collected.

- **Capacity building, Strengthening HDSS Networks & Collaboration:** The need for knowledge exchange, networking, and collaboration across HDSS sites is becoming increasingly important. To support this, the establishment of a steering committee was proposed to help coordinate and facilitate these efforts. Strengthening partnerships and enhancing knowledge sharing can be achieved through technical workshops and the promotion of open data practices. Additionally, capacity-building initiatives should be guided by thorough needs assessments, ensuring that HDSS personnel receive targeted development of their skills based on the specific gaps identified at their sites.

## General Questions & Comments

### Magu HDSS

- Inquiry about expanding record linkage tools beyond HDSS to include hospital facility data, emphasizing the need to enhance the capacity to integrate HDSS and hospital records effectively

### Hararghe HDSS

- Greater clarity is needed on the distinction between add-on data and routinely collected data (explained that add-on data was gathered less frequently, i.e., every two years).
- The integration of a family planning module and tracking contraceptive use at the individual level remains a challenge, as data is currently collected only at the general population level.
- The introduction of the family planning data collection module faced barriers, primarily due to cultural norms that led to a focus on married individuals during data collection.
- Funding sustainability efforts include securing government support and establishing Memorandums of Understanding (MOUs) with university management, allowing PhD and MSc students to utilize the data for research.

## Ruwenzori HDSS

- The effectiveness of the record linkage tool and the comparison of data quality collected by Village Health Teams (VHTs) and standard data collectors are being assessed. Currently, the record linkage tool is being utilized in two hospitals, with data quality evaluation included as part of the ongoing objectives.
- The motivation for establishing the Bwera HDSS, beyond tracking migration, was to enable a comparative analysis between urban populations in Bwera and rural populations in Kagando.

## MRC Unit in The Gambia

- Clarity on the Database Management System used for storing data.

## Niakhar HDSS

- Navigating ethical standards and guidelines in conducting HDSS requires harmonizing policies to align with regulatory authorities across HDSS sites.
- In Senegal, support for HDSS extends beyond international funding through the OPSE, which ensures cost-sharing and sustainability while planning to include government stakeholders.

## Baandafasi HDSS

- The shift from village-level to household-level data collection has an impact on data quality, which requires further assessment.
- The funding strategy relies on sustaining operations through nested studies, as there is no core funder. This approach demonstrates that even small-scale household samples can drive impactful research while effectively managing costs.

## Our Partners



Gates Foundation



# DAY 2: FEBRUARY 28, 2025

## Session 1: Group presentations

**Time: 09.00 – 09.30**

**Session Chair: Dr. Ivan Busulwa**

**Session 1.1:** Harnessing AI and LLMs in HDSS

**Presenter:** Dr. Esu Stanley

### **Key Points:**

- Artificial intelligence can enhance scheduling and improve the efficiency of data collection tools such as voice-to-text technology.
- HDSS face challenges such as skills gaps, infrastructure limitations, data heterogeneity, and cost constraints. These can be addressed through knowledge sharing, increased funding, and AI-driven data reconstruction.
- AI can facilitate linkages between policies and datasets to enhance policy impact.

**Session 1.2:** Sustainable Approaches to Maintaining HDSS Operations

**Presenter:** Dr. Ivan Kasamba

### **Key Points:**

- Enhancing efficiency and scalability can be achieved through resource sharing and cross-site learning, particularly in data management and collection systems.
- Showcasing the impact of population cohorts on public health is essential for securing continued support and funding.
- Engaging stakeholders at local, national, and global levels is necessary to justify the value of maintaining long-term population cohorts.
- Establishing a shared vision and coordinated efforts will also strengthen the successful implementation of population cohorts.
- Nested studies can generate revenue by incorporating service fees for data access.
- Collaborating with the private sector can provide additional funding by leveraging cohort data for research and development.
- Utilizing technology in data collection can help reduce operational costs and improve efficiency.
- Joint grant applications between HDSS can enhance financial sustainability by securing collaborative funding opportunities.



## Session 2: Introduction to the Gates Family Planning Program

**Speaker:** Dr. Ramatou Ouedraogo

### **Summary Points:**

Key discussions included:

- **Integration of a family planning (FP) module into HDSS.** Noted that this appeared feasible with minimal structural challenges.
- **Expected challenges and mitigation strategies:**
  - Cultural sensitivity in HDSS regions can sometimes lead to non-compliance, as individuals participating in FP may fear stigmatization. To address this challenge, several strategies were proposed. These included: Using female data collectors and involving male heads of households can help encourage participation.
  - Additionally, to prevent the exclusion of unmarried women aged 15-49, community members, as opposed to external data collectors, should be engaged in qualitative assessments. Conducting community sensitizations before data collection is also crucial to emphasizing its importance and fostering trust. Collaborating with community health workers (CHWs) and Village Health Teams (VHTs), particularly by recruiting locally, can also improve FP integration. Providing feedback to communities on research findings further strengthens trust and encourages continued participation. To ensure smooth implementation, these strategies should align with best practices for introducing new data collection modules related to family planning.

### Session 3: Data Harmonization, Standardization and Analytics

**Presenter:** Dr. Amelia Taylor

**Summary Points:**

This session focused on data harmonization, standardization, and analytics, highlighting gaps in successful harmonization efforts within Africa. Dr. Amelia Taylor emphasized the opportunity for HDSS sites to enhance the value of collected data to other stakeholders by leveraging AI for standardization and harmonization. Additionally, she underscored the importance of conducting an inventory of existing data collection methodologies, storage systems and harmonization efforts to improve integration and usability.

### General Questions & Comments

- Has AI ever been used in data collection? [Yes, AI has been used to translate handwritten data.]
- What are the existing standards of data harmonization/standardization?
- How do you ensure harmonization of data within different contexts?

### Session 4: Assessment of LPCs and HDSS - Data capability maturity assessment

**Presenter:** Dr. Samuel Iddi

**Summary Points:**

Dr. Samuel Iddi presented on the HESA Toolkit Assessment, which categorizes data ecosystems and evaluates data maturity levels to help HDSS sites develop tailored roadmaps. He emphasized the importance of assessing training needs, infrastructure, and computational capacity to strengthen and unify data systems across all sites.

### Session 5: Way Forward

**Speaker(s):** Dr. Agnes Kiragga and Dr. Andre Kengne

**Key Points:**

- Appreciation to all attendees, facilitators, the APPC and funders
- Creation and adoption of working groups to drive specific objectives
- Enhance visibility with tangible outputs and products.
- INSPIRE 2.0 should ensure population level data is more accessible, more impactful and more actionable

### Session 6: Launched INSPIRE 2.0



# Annex 2: Launch Photos



## Annex 3: HDSS Participants

Names	Institution
<b>Denna Michael</b>	National Institute for Medical Research   Mwanza   Tanzania
<b>Charles Mangya</b>	National Institute for Medical Research   Mwanza   Tanzania
<b>El Hadj BA</b>	Institut de Recherche pour le Développement (IRD), UMR VITROME/ Vecteurs infections Tropicales et Méditerranéennes
<b>Abdoulaye Diop</b>	Institut de Recherche pour le Développement (IRD), UMR VITROME/ Vecteurs infections Tropicales et Méditerranéennes
<b>Albert Dube Nkhata</b>	Malawi Epidemiology and Intervention Research Unit (MEIRU)
<b>Paul Kambiya</b>	Malawi Epidemiology and Intervention Research Unit (MEIRU)
<b>Dan Kajungu</b>	Makerere University Center for Health and Population research (MUCHAP) and Iganga Mayuge HDSS
<b>Betty Nabukeera</b>	Makerere University Center for Health and Population research (MUCHAP) and Iganga Mayuge HDSS
<b>Mohamed Salama</b>	School of Sciences & Engineering (SSE), The American University in Cairo (AUC)
<b>Merga Dheresa</b>	Ethiopian Public Health Institute
<b>Ariel Nhacolo</b>	CISM Centro de Investigacao em Saude de Manhiça (Manhiça Health Research Center) Mozambique
<b>Inacio Mandomando</b>	CISM Centro de Investigacao em Saude de Manhiça (Manhiça Health Research Center) Mozambique
<b>Ivan Kasamba</b>	The Medical Research Council (MRC)/Uganda Virus Research Institute (MRC/UVRI) Research Unit
<b>Ahmad Ayub</b>	Department of Community Medicine, Faculty of Clinical Sciences /College of Medical Sciences, Ahmadu Bello University
<b>Prof. Abdramane Soura</b>	University of Ouagadougou
<b>Bruno Lankoande</b>	University of Ouagadougou
<b>Siaka Kone</b>	Taabo Health and Demographic Surveillance Site
<b>Karim Derra</b>	Clinical Research Unit of Nanoro (CRUN)
<b>Amelie Taylor</b>	Malawi University of Business and Applied Sciences (MUBAS)
<b>Asinja Kapuru</b>	Ruwenzori Demographic and Health Surveillance Initiatives Uganda, Limited
<b>Esu Ezeani Stanley</b>	MRC Unit, The Gambia

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RAPPORTEUR: PAULINE ANDESIO