# POLICY BRIEF No.1



# Opportunities to Advance Personalised Medicine in Africa

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### The context and problem

Africa continues to experience a comparatively high burden of disease, particularly infectious diseases such as malaria, HIV/AIDs, and non-communicable diseases like cancer, hypertension, cardiovascular and diabetes, affecting an estimated one billion people (WHO, 2019). According to the World Bank (2020), Africa's disease burden leads to over USD 800 billion in annual productivity loss. There is a need to explore new models and tools for managing the disease burden on the continent. One such model is Personalised Medicine (PM), which refers to a medical model using the characterisation of individuals' phenotypes and genotypes (e.g., molecular profiling, medical imaging, lifestyle data). This helps in tailoring the right therapeutic strategy for the right person at the right time, determining the predisposition to disease, and delivering timely and targeted prevention (European Commission, 2015).



Figure 1: The six regions of the African Union

NORTH	Algeria, Egypt, Libya, Mauritania, Morocco, Tunisia, Western Sahara	
EAST	Burundi, Djibouti, Eritrea, Ethiopia, Kenya, Rwanda, Somalia, South Sudan, Sudan, Tanzania, Uganda	
SOUTH	Angola, Botswana, Comoros, Lesotho, Madagascar, Malawi, Mauritius, Mozambique, Namibia, Seychelles, South Africa, Eswatini, Zambia, Zimbabwe	
CENTRAL	Cameroon, Central African Republic, Chad, Congo, Democratic Republic of Congo, Equatorial Guinea, Gabon, São Tomé and Príncipe	
WEST	Benin, Burkina Faso, Cape Verde, Côte d'Ivoire, Gambia, Ghana, Guinea, Guinea- Bissau, Liberia, Mali, Niger, Nigeria, Senegal, Sierra Leone, Togo	
DIASPORA	"People of African origin living outside the continent, irrespective of their citizenship and nationality and who are willing to contribute to the development of the continent and the building of the African Union" Definition of the African Union	

Personalised Medicine has four main components. First, it is about understanding genetic differences and how they relate to people and their interaction and responses to diseases. Secondly, it is about the access, understanding, and use of technology. Africa needs to enhance access to technology so that researchers can do complete DNA analysis. Thirdly, it is about generating population-level data. There is a need for more data on African population genomics, which is accessible and usable compared to other established population genomic profiles. Finally, PM relies on adequate infrastructure in the health system to accommodate research and implement targeted diagnosis and treatment processes. Personalised Medicine is an umbrella term (Figure 2) used to make healthcare more intelligent and better by using multiple sources of information about an individual.



Figure 2: Personalised medicine as an umbrella term (Source, Benediktsson I, 2019).

This may include their environment and lifestyle data, focusing on prediction and prevention, and shifting from treating disease to managing health (Benediktsson I, 2019).

This policy brief is based on findings of the EU-Africa PerMed project activities, which include mapping the scientific research and policy landscape of PM in Africa. It also contains two stakeholder-based surveys that sought to understand the situation concerning PM in Africa and a virtual stakeholder workshop that was held on 9-10 February 2022. The workshop brought together over 200 key PM stakeholders from research, health care providers, policymakers, funders, industry, private sector, and civil society from across the African continent. The main objectives of the project are: 1. To identify policies, programmes, initiatives and infrastructure supporting research and implementation of personalised medicine in Africa; 2. To understand the perception and potential of PM in Africa and its relevance for the different countries/stakeholder groups; 3. To discuss with African Stakeholders the main challenges and opportunities of PM in Africa, and identify areas of mutual interest between Africa and Europe in PM research; and 4.To explore and analyse the potential and advantages of collaboration in R&I in the field of PM between Africa and Europe.

### **Key findings:**

# i. Limited research activities related to PM.

There is limited research and information from the existing data on African populations for informed interventions and decision-making on PM.



Country	Publications Count	Country	Publications Count	
South Africa	1346	Gabon	22	
Egypt	1147	Congo	20	
Tunisia	350	Mauritius	18	
Nigeria	270	Rwanda	18	
Kenya	205	Madagascar	17	
Ghana	201	Niger	15	
Uganda	180	Democratic Rebublic	13	
Morocco	171	Congo		
Tanzania	141	Guinea-	13	
Ethiopia	111	Bissau		
Cameroon	109	Burundi	11	
Malawi	94	Namibia	8	
Gambia	76	Seychelles	7	
Algeria	71	Angola	6	
Burkina Faso	64	Sierra Leone	6	
Sudan	58	Swaziland	6	
Zimbabwe	50	Тодо	5	
Zambia	46	Chad	4	
Senegal	43	Liberia	4	
Mali	39	Mauritania	4	
Mozambique	38	Somalia	3	
Botswana	29	Central African	2	
Benin	25	Republic		
Guinea	25	Cape Verde	1	
Libyan Arab Jamahiriya	25	Equatorial Guinea	1	
Cote d'Ivoire	23	Eritrea	1	

Figure 3: Total number of PM publications per African country for the period 2011-2020 (Source, Sela et al., 2021)

The mapping of PM's scientific and policy landscape in Africa gave the level of research for the different countries as reflected by publications (Figure 3). South Africa and Egypt had more publications. Both countries have research programs focused on PM, with Egypt having more collaborations with Europe and South Africa, which has more research supported by their national budget. Algeria, Cameroon, Ethiopia, Ghana, Kenya, Morocco, Nigeria, Tanzania, Tunisia, and Uganda have also shown initiatives in PM research.

# ii. Different levels of PM adoption and implementation.

Implementation of PM across the regions within the continent was at different levels. The status of PM implementation across Africa divides the countries into five categories based on their strength in six dimensions: Governance of health research, financing of health research, resources for health research, health research outputs, international collaborations in health research, and PM/genomic research, as explained in Figure 4.



# Figure 4: Representation of the PM/genomic capacities in African countries (Source: Sela et al., 2021)

GROUP	HEALTH RESEARCH GOVERNANCE, FINANCE, RESOURCES, OUTPUTS AND INTERNATIONAL COLLABORATION	PM/ GENOMIC RESEARCH	COUNTRIES
1	Countries performing very well in health research. There is an important governmental commitment for health and PM research	VERY HIGH	South Africa and Egypt
2	Most countries have governance structure and funding for health research, and well-established international collaborations. There is already an important research activity in PM	HIGH	Algeria, Cameroon, Ghana, Kenya, Morocco, Nigeria, Tanzania, Uganda, Tunisia, Zimbabwe
3	This group of countries have, in general, a good performance in health research, but their capacity in PM/ genomic research is not as high as group2, there is potential/capacity to improve.	HIGH/ MEDIUM	Botswana, Burkina Faso, Ethiopia, Gambia, Malawi, Senegal, Zambia
4	These countries seem to be in a lower level of PM/genomic research capacity. They have an average performance in STI/ health research. In some countries data are not available to score some dimensions.	MEDIUM/ LOW	Benin, Mali, Mozambique, Congo, Cote D'Ivoire, Congo Dem. Rep., Eswatini, Gabon, Guinea Guinea-Bissau, Mauritius, Namibia, Rwanda

GROUP	HEALTH RESEARCH GOVERNANCE, FINANCE, RESOURCES, OUTPUTS AND INTERNATIONAL COLLABORATION	PM/ GENOMIC RESEARCH	COUNTRIES
5	This group includes countries with very low performance in PM/ genomic research, but also with very low values in general for the rest of the indicators. In some cases, scoring has not been possible for some countries for which there are no available for major STI indicators.	LOW	Angola, Burundi, Cabo Verde, Central African Rep., Chad, Comoros, Djibouti, Equatorial Guinea, Eritrea, Lesotho, Liberia, Libya, Madagascar, Mauritania, Niger, São Tomé and Príncipe, Seychelles, Sierra Leona, Somalia, Sudan, Togo

#### iii. Opportunities that Africa can explore to strengthen the development and implementation of PM

This section presents results that specifically identified opportunities that would create a good foundation for implementing PM in Africa.

# a) Investing and building on current research efforts in PM

It was noted that significant work on pharmacogenomics had been done in South Africa, Egypt, and Nigeria through the African Pharmacogenomics Network (APN). The network undertakes research, training, and translation. Most African countries can leverage the existing African genomes for better health. Achieving health goals and targets requires matched investment in research and innovation to improve access to medical technologies and products. Investing in locally-driven research by empowering local research institutions and establishing innovation hubs in African countries is essential. Similarly, building on ongoing research on disease surveillance, especially at the genome level, is of essence to creating core capabilities in genomics research required for a PM ecosystem.

#### b) Generating and Utilizing genomic data on African Population

There are some available genomic data on the African population. However, it is not accessible in a form that can be used at the clinical level. Therefore, the data gap is not just about collecting more data but also about converting and analyzing the already available information for optimal use. Therefore, African countries have great opportunities to invest and build capacities and platforms to generate and synthesize available data into information that can be used in PM. Such data can support case management of diseases, especially the priority diseases, such as tuberculosis HIV, cancer, and malaria, where reports are reviewed periodically, and the treatments can be adjusted based on the data to ensure that they meet the needs of individuals.

#### c) Establishing collaborations through the available platforms to strengthen PM implementation at the Continental level

There are already some forms of collaborations, including south-south collaborations, private sector, civil society, and foundations to invest in PM, which will allow the sharing of scarce resources such as DNA sequencing infrastructure. Therefore, individual countries have an opportunity to initiate such collaborations to strengthen the development and implementation of PM in their respective territories.

It is essential to recognize that the African continent comprises various economic communities, with each of these communities having commissions/bodies handling the health component. It would be necessary to loop in these regional communities to develop the PM agenda but have individual countries implement the agenda with the support of available platforms. An opportunity also exists to strengthen the collaboration in PM between Africa and Europe, focusing on real African needs and demands identified together with African stakeholders, and contribute towards advancing the development of PM in Africa and its integration in the global PM agenda.

#### d) Developing skills locally and tapping into the diaspora-trained and skilled human resources to enhance PM

A wide array of skilled personnel is needed to support the implementation of PM. These include researchers, doctors, nurses, clinical geneticists, genetics counselors, pharmacists, bioinformaticians, technicians, data scientists, and data security personnel. Brain drain was noted as a significant challenge in implementing PM in Africa. Hence, as PM is being prioritized, bringing back, the skilled diaspora community should be prioritized as a resource in PM development. Deliberate efforts to attract them back home by creating opportunities and favorable terms such as investment in infrastructure where they can work and encouraging them to stay in Africa can be pursued.

Another way to invest in PM skills and capacity is to establish and encourage centers of excellence whose focus will be to understand and control the transmission of infectious diseases in Africa and foster human genomics in the continent by leveraging networks and collaborations with laboratories and academic and public health institutions to advance disease surveillance and research in Africa.

There are several large-scale training programs on genomics surveillance and data across Africa through various funded initiatives such as Human Heredity and Health in Africa (H3Africa), International Network for the Demographic Evaluation of Populations and Their Health (INDEPTH) to form the Africa Wits-INDEPTH partnership for genomic studies on cardiometabolic diseases (AWI-Gen project), Network for Genomic Surveillance in South Africa (NGS-SA,) the Square Kilometre Array (SKA) Programme among others. These centers of excellence and cross-sector initiatives continue to invest in capacities required for PM on the continent.

# e) Establishing and implementing the policy and ethics frameworks

Continentally, the World Health Organization and the AUDA-NEPAD stand out as leading in promoting the health agenda for Africa. The AUDA-NEPAD has led efforts to develop a framework for implementing Genomic Medicine for Public Health in Africa. This essential document will guide PM adoption and implementation in the continent. The stakeholders' meeting proposed using regional platforms to promote PM in Africa. The regional economic blocks are suitable for leading the formulation of policy to govern PM and create awareness of the value of this module to the African people and the enhancement of resilient health systems.

Implementing policy frameworks covers data and sample protection and use in research. This also covers data sharing protocols and the provision of existing data identities of individuals whose data is collected. Further, strengthening the capacity of institutional review boards (IRBs) in terms of skills and diversity, especially for reviewing protocols in genomics and other PM-based research, is essential. Another important aspect is the integration of national regulatory authorities for medicines, involved in approving products before they come to the market at the regional level.

#### f) Citizen education

Discussions during the stakeholder meeting pointed out the need to educate African people and communities about PM's value, which would create demand for individualized healthcare, better regulation, and ethics on data and sample management. Improved literacy enables the establishment of political frameworks to tackle effectiveness, efficiency, equity, and ethical issues underlying the development and implementation of PM approaches.

## **Policy Recommendations:**

From the reflections shared above, **African governments**, **ministries of health**, **research**, **science**, **and technology agencies**, as well as **regional bodies**, are urged to consider the following priorities:

- 1. Support research, data generation, mining, and translation into clinical care: Building and supporting infrastructure for genetic data generation from African populations is also important. It informs the development of accurate and affordable tests that provide an accurate diagnosis, informing targeted individualised treatment. Clinical translation of generated data to ensure informed patient-centered care and other benefits of implementing PM approaches in health care needs to be considered. This can also contribute to capacity building in genomic research.
- 2. Skills and infrastructure development: Training and educating sufficient people in specific areas to perform and interpret tests and support health systems is crucial as it results in a new generation of informed, empowered, engaged, and responsible healthcare providers and actors. There is a need to invest in sequencing and genotyping facilities, biobanks for samples and their associated data, data infrastructure and information management systems (data generation/storage/ analysis pipeline), electronic health records, internet connectivity, and facilities for clinical action and clinical trials.
- 3. Ethical and regulatory framework development, strengthening, and harmonization: It is essential to establish, strengthen, and harmonize a cohesive legal and regulatory framework that will cover data and sample protection and use in research. It further enhances the capacity of institutional review boards (IRBs) in terms of skills and diversity, especially for reviewing genomics and other PM-based research protocols.
- 4. Awareness creation: Creating awareness and communicating the value of PM to the general public, policymakers, and researchers, as well as engaging and empowering the community, is essential. This will boost the demand for individualized healthcare, better regulation, and data and sample management ethics.

## Call to action:



African leaders are encouraged to prioritize investing resources in collaborations, partnerships, and networks to enhance capacity building, genetic testing, health electronic record systems, and health economic research at continental, regional, country, and institutional levels. Furthermore, leaders are encouraged to strengthen the relationship with

the European Union to learn and identify opportunities to advance research and policy that facilitates progress in the advancement of PM in Africa.

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#### Additional Contributions:

- A. Radwan (ECITD) and J. Guinea (Innovatec) carried out the scientific mapping (bibliometric analysis) of PM in Africa (Ref. Sela et al., 2021)
- N. Mulima (ECSA-HC), P. Tanui, and N. Moiloa (AUDA-NEPAD) have also contributed to the preparation of the document.
- M. Frenzel and P. Debre contributed to preparing the pre-workshop survey and the discussions in the stakeholder workshop.

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# About the EU-Africa PerMed project:



The project (Building Links Between Europe and Africa in Personalised Medicine) aims to integrate African countries into the International Consortium for Personalised Medicine activities, thus contributing to a successful implementation of Personalised Medicine (PM) globally. It will foster joint PM projects and programs between Europe and Africa and strengthen bilateral EU-AU science, technology,

and innovation (STI) relations in health. It is expected to contribute to the shortening of the existing health disparities between developed and developing countries, as well as facilitate the access of African countries to new tools and technologies that have the potential to make healthcare more efficient and equitable. The project will run for four years, starting on the 1st of February, 2021.

This is the first among other policy briefs that the project team will develop. A second policy brief will be prepared with recommendations for a sustainable EU-AU collaboration in PM based on an analysis of the potential and advantages of EU-AU collaboration in PM.

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