THE EU-AFRICA PerMed FIRST STAKEHOLDER WORKSHOP REPORT (Deliverable D2.3)

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EXECUTIVE SUMMARY

Personalized Medicine (PM) also referred to as precision medicine, is a medical model that uses characterisation of individuals' phenotypes and genotypes to provide interventions and/or products tailored to the individual patient based on their predicted response or risk of disease. If embraced, this field could revolutionize health care in Africa which has a high burden of disease. The Europe-Africa Personalized Medicine (EU-Africa PerMed) Project is a four-year project funded by the EU with the objective of facilitating the participation of African countries in the global PM agenda.

The Kenya National Commission for Science Technology and Innovation (NACOSTI) on behalf of the EU-Africa PerMed project organized a two day virtual workshop which took place on the 9th and 10th of February 2022 and which brought together over 200 key PM stakeholders from Africa. The workshop participants had been identified through a mapping exercise from six stakeholder groups, that included Health Research Organizations, Research and Innovation Funders, Health System Policy Makers, Healthcare Providers, Industry and Private Businesses, and Civil Society Organizations. The aim of the workshop was to discuss the perception of PM in Africa, the main challenges and opportunities of PM in Africa, and the potential advantages of a closer collaboration with Europe.

The programme involved keynote presentations, group discussions, guided impulse talks, roundtable discussions, and questions and answers sessions. The opening ceremony was graced by Irene Norstedt, Director of the "People" Directorate within DG Research and Innovation, European Commission and Prof. Walter Oyawa, the Director General, Kenya National Commission for Science, Technology and Innovation. In the opening remarks, the importance of PM in dealing with health care situation in Africa was highlighted, how Africa can benefit from collaborations with Europe and the willingness of European Commission to support such initiatives. First day discussed the global overview of PM, showcasing the ICPerMed framework and EU-Africa PerMed project as existing collaborative platforms for PM. Personalised Medicine initiatives in the different African regions were also presented, highlighting the status of PM these regions. The second day focused on identifying and prioritizing PM needs in Africa as well as analysing the potential and advantages of collaboration in the field of PM between Africa and Europe. To achieve this, there were small group discussions with each group discussing an important aspect that should be considered in pursuit of PM in Africa. South Africa was presented as country that has prioritized PM agenda, and shared lessons on implementation of PM that included building a knowledge base through training, setting up infrastructure and platforms for PM implementation, funding initiatives and integration into clinical practice. Impulse talks given by eminent PM stakeholders provided further insights on the PM situation in Africa and its potential in revolutionizing health care in the continent.

It was agreed that no country can achieve the benefits of PM without collaborating with other countries or regions. The meeting therefore recommended the following: Application of a multipronged PM approach in order to advance PM in Africa, with continental/regional efforts guiding in agenda setting, while countries are left to set priorities, implementation and allocation of resources; Strengthen, as well as harmonize the ethical and regulatory aspects, at least at regional level; Advocate for PM focused funding to support training and infrastructure development; Awareness creation and communicating the value of PM to the society as well as engaging and empowering the community; Channel efforts towards characterizing African Genome, in order to bring to light the genetic diversity of the African population and foster genomics of infectious diseases; and EU-Africa PerMed project to work towards strengthening the collaboration in PM

between Africa and Europe considering the regional/national differences across African countries, focusing on real African needs and demands that will be identified together with African stakeholders, and contribute towards advancing in the development of PM in Africa and its integration in the global PM agenda.

Contents

LIST OF FIGURES

ABBREVIATIONS AND ACRONYMS

AU	African Union
AUDA NEPAD	African Union Development Agency- NEPAD
CSA	Coordination and Support Actions
EAHRC	East Africa Health Research Commission
EU	European Union
GDP	Gross Domestic Product
ICPerMed	International Consortium for Personalised Medicine
NACOSTI	National Commission for Science Technology and Innovation
NGS	Next Generation Sequencing
PM	Personalised Medicine
R&I	Research and Innovation
SAMRC	South Africa Medical Research Council
ST&I	Science, Technology and Innovation
TB	Tuberculosis
WAHO	West Africa Health Organization
WHO	World Health Organization

1.0 INTRODUCTION

1.1. Background

According to the Horizon 2020 and European Council Conclusions on Personalised Medicine (PM) for patients (2015/C 421/03, PM refers to a medical model using characterisation of individuals' phenotypes and genotypes (e.g. molecular profiling, medical imaging, and lifestyle data) to tailor the right therapeutic strategy for the right person at the right time, and/or to determine the predisposition to disease, and/or to deliver timely and targeted prevention. Personalised medicine relates to the broader concept of patient-centred care, which considers that, in general, healthcare systems need to better respond to patient needs. Personalised Medicine relies on data and knowledge about individual patients or populations, particularly that which relates to genetic, phenotypic and the environment, and successful implementation would require to be supported by robust infrastructure for research, skilled personnel among others.

Africa continues to experience a comparatively high burden of disease, particularly in TB, Malaria, HIV/AIDS and neglected diseases, affecting an estimated one billion people, and leading to annual productivity loss of over USD 800,000 Billion (World Bank, 2020). There is need for a paradigm shift in the approaches being employed by the African continent in addressing the disease burden. Technology advancement being experienced today has brought about change in the practice of medicine, particularly in diagnosis and treatment of diseases, hence the need to embrace new models and tools brought about by these advances in technology in addressing the disease burden in Africa. Personalized medicine has been shown to revolutionize health care due to its precision, and patient centered focus. For Africa to benefit from this model, more data from the African population and necessary infrastructure will be needed. Africa has been reported to be home to a population with greatest genetic diversity, yet there continues to be dearth of data required to fully benefit from PM (Mulder N., 2017). The near lack of genomics studies on African populations has led to concerns that genomics may widen, rather than close, the global health inequity gap (Munung et. al., 2018).

1.2. Europe-Africa Personalized Medicine (EU-Africa PerMed) Project

The project, titled 'Building Links Between Europe and Africa in Personalised Medicine' and acronymed EU-Africa PerMed, is funded by the European Commission under the European Union's Horizon 2020 Research and Innovation programme, grant agreement No 964333. The final aim is to facilitate the participation of African countries in the global PM research agenda. This initiative is expected to contribute to shortening 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 initiative will also foster the integration of African organizations into the International Consortium for Personalised Medicine (ICPerMed), support joint PM projects and programmes between Europe and Africa, as well as strengthen bilateral EU-AU science, technology and innovation (STI) relations in the area of health.

The EU-Africa PerMed project is a four-year project which commenced in February 2021. It is being executed by a transnational consortium of 13 organisations, 6 from Europe and the other 7 from Africa. These are AUDA-NEPAD; the East, Central, and Southern African Health Community (ECSA_HC); the South African Medical Research Council; the Institute for Health Research, Epidemiological Surveillance and Training from Senegal; The African Population & Health Research Centre (APHR) and the National Commission for Science, Technology and Innovation (NACOSTI) from Kenya and the

Egyptian Center for Innovation & Technology Development (ECITD). The project is coordinated by a Spanish company (Innovatec), and other European partners which include: the Italian Ministry of Health, The French National Research Agency, the Spanish Carlos III Health Institute and the French National Institute of Health and Medical Research (INSERM). More information about the project and the consortium is available in the webpage: https://www.euafrica-permed.eu/

1.3. General Organization and Objectives of the First Stakeholder Workshop

The National Commission for Science Technology and Innovation (NACOSTI), with contribution from other consortium members organized a two-day virtual stakeholder workshop which took place on the 9th and 10th of February 2022. The stakeholder workshop brought together over 200 key stakeholders from Africa, targeting those from health system policy makers, research and innovation funding agencies and councils, health care providers, researchers, scientific societies, industry, regional, technology developers and international organizations to discuss PM agenda in Africa. French to English and English to French language interpreters were available to take care of the language differences among stakeholders that attended the workshop.

The workshop was organized to discuss the perception of PM in Africa, main challenges and opportunities of PM in Africa, and the potential advantages of a closer collaboration with Europe in integrating local knowledge and practice. At the same time, the workshop served as a first opportunity of disseminating the project to African stakeholders, making them aware of the International Consortium of Personalized Medicine (ICPerMed) and how activities planned for the project in the remaining 3 years could be best implemented considering the needs and expectations of African stakeholders.

The programme was structured around targeted keynote presentations, discussions around PM initiatives in Africa, group discussions addressing topical issues and guided impulse talks. There were presentations of the pre-workshop survey that had been carried out in order to understand PM health needs and priorities in Africa

2.0 METHODOLOGY

2.1. Stakeholder Identification

The workshop participants were identified through a stakeholder mapping exercise that sought to identify stakeholders involved in PM or related initiatives. Consortium partners were also requested to assist in identification of relevant stakeholders, particularly in countries where numbers of mapped stakeholders were low. These efforts led to identification of over 500 PM stakeholders from Africa, who were then invited to register to attend the workshop.

The project, through the mapping of stakeholders work that was carried out (see project deliverable D2.2), had identified 6 major stakeholder groups that were relevant for the project work and for the development of PM in Africa. These 6 groups are indicated below:

Group 1: Innovation enablers/Health Research Organizations

Group 2: Research and Innovation Policy and Funders

Group 3: Health System Policy Makers

Group 4: Healthcare Providers

Group 5: Industry and Private Businesses

Group 6: Civil Society Organizations

2.2. Participants

Registration of participants was launched in November 2021, where they were requested to register through an online process. The registration link was shared to all identified stakeholders who provided details such as their name, language, position, organization, country, contact details including email, LinkedIn and twitter accounts, stakeholder group, role in the workshop, whether they agree that EU-Africa PerMed contacts them in future (e.g. for newsletters, events, project activities, etc.). During registration, stakeholders were required as a formality to consent , that EU-Africa PerMed may use, process and share submitted information within the context of the event and that the information be processed according to EU-Africa PerMed privacy policy (https://www.euafrica-permed.eu/web-privacy-policy/). Informed by the rising numbers of COVID-19 infection that was being experienced globally, a decision to change the workshop from hybrid to 100% virtual was made in December, 2021, and the same information was communicated to all invited stakeholders via email and also by, posting the same on the project website. The registration form was revised to capture this important information. Two hundred and Forty Eight (248) participants had registered by 8th of February 2022.

Majority (75%) of the registered participants were from English speaking countries while 22% were French speaking countries. However, there was 2% and 1% participants from Spanish and Portuguese speaking countries respectively who registered. Participants were drawn from 43 countries (Figure 1), with 88% coming from the 31 African countries represented (Figure 1). Though all five African regions were represented, approximately 50% of the workshop participants came from South Africa, Kenya and Egypt. Those from outside Africa such as Spain, France and Italy were mostly consortium members. Research organizations recorded the highest number of participants (53%) from among

the identified clusters of stakeholders (Figure 2). The least were from civil society organization with less than 1% representation (Figure 2).

All participants who attended the meeting consented to recording of the discussions and were further informed during the meeting that there would be audio-visual recording of the proceedings. The workshop targeted to have at least 200 participants. This target was almost achieved as day one had 199 attendees, while day two had 137 participants.

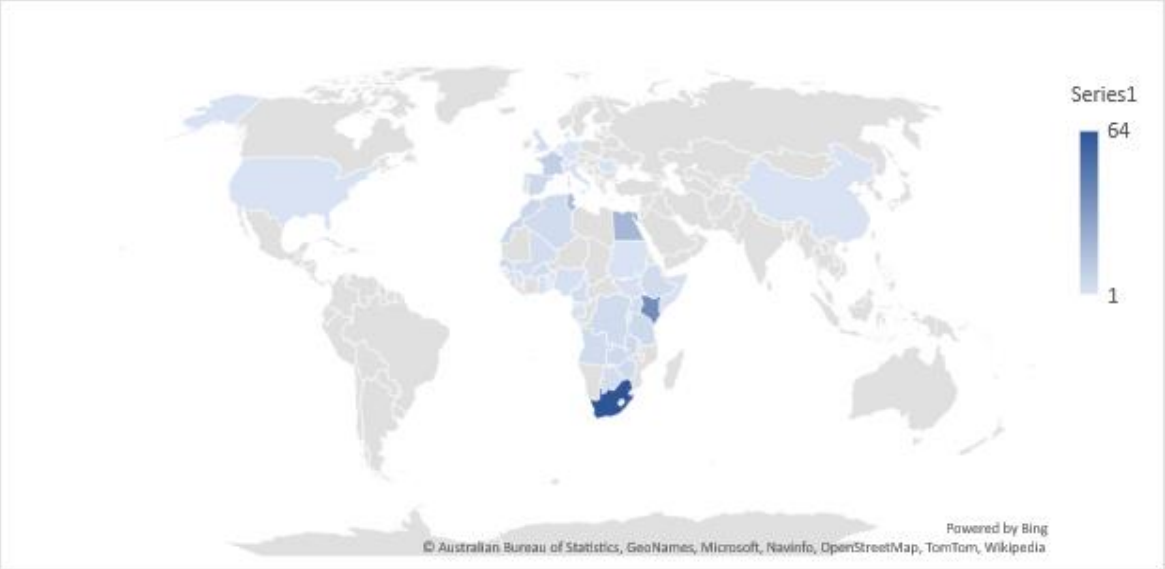


Figure 1: *Registered Participants by Countries*

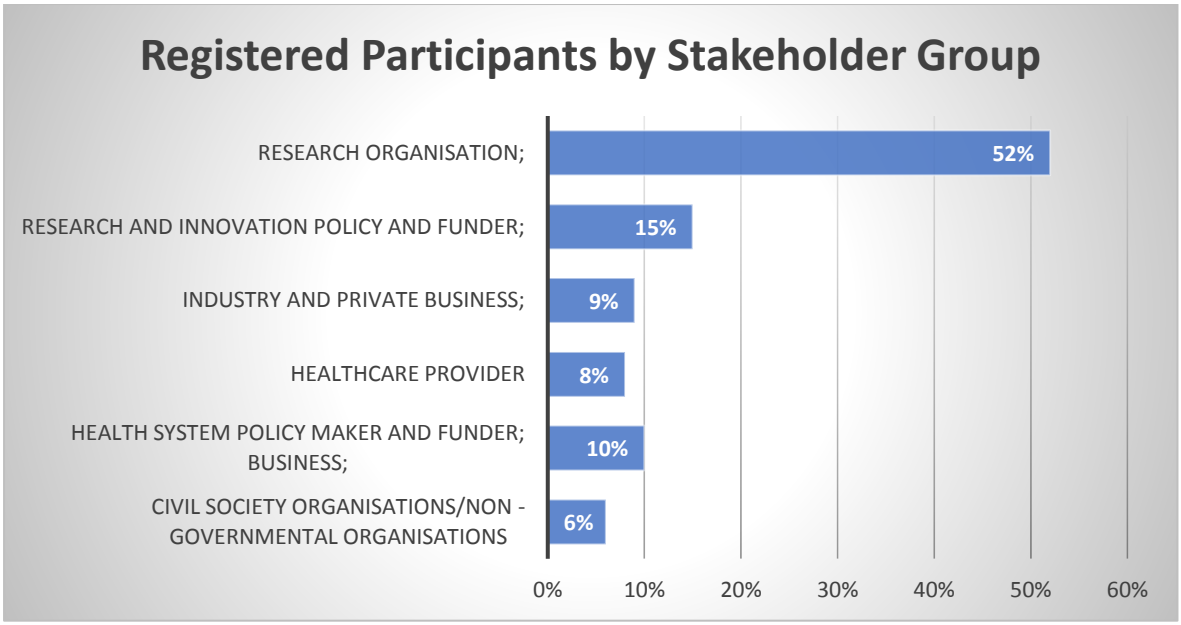


Figure 2*: Distribution of registered participants by stakeholder group*

3.0 PRESENTATIONS: DAY ONE – 9TH FEBRUARY 2022

3.1. Opening Remarks

By Irene Norstedt, European Commission and Prof. Walter Oyawa, NACOSTI, Kenya

The opening ceremony was presided over by Irene Norstedt - Director of the "People" Directorate within DG Research and Innovation, European Commission and Prof. Walter Oyawa, the Director General, Kenya National Commission for Science, Technology and Innovation.

Photo 1. *Irene Norstedt - Director of the "People" Directorate within DG Research and Innovation, European Commission*

Photo 2. *Prof. Walter Oyawa – Director General, National Commission for Science, Technology and Innovation, Kenya*

Figure 3: *A photo showing the officials from EU-commission and NACOSTI who opened the workshop*

In her remarks, Irene Norstedt gave a description and benefits of PM, and the need for global collaboration in this field. She noted that personalized medicine has been applied in treatment of diseases such as different types of cancers, pharmacogenomics, with a steady development which have received approval by European Medicines Agency. Owing to the benefits of PM, the European Union has identified it as a priority area of focus. She further explained that PM has a historical perception that is limited to pharmacogenomics but, is a much wider concept that includes information gathered around an individual's environment, gender, and medical history, genetic information among others. This information is generated data from patient records, environmental and social context, and utilizes data analytics with artificial intelligence to extract patterns that would identify optimal intervention for individual patients. She however, noted that PM is not just about treatment, but also includes personalized disease prevention, early diagnosis including reduction of harmful side effects from drugs. Because of its effectiveness, it has been embraced as a revolutionary way of maintaining people's health and delivery of health care. Personalized medicine has therefore been widely regarded as medicine of the future, and therefore the need to prepare to make healthcare accessible and affordable for all.

Irene Norstedt further gave some highlights in regard to the establishment of the International Consortium for Personalized Medicine in 2016, by member states with the support of the European Commission, now commonly known as ICPerMed, with an objective of coordinating activities and set priorities in this field. ICPerMed brings together health research funders, health ministries and other

policy bodies. She informed participants that the European Commission has funded several coordination and support actions and has relied on ICPerMed to develop other aspects of PM, including its international dimension. The European Commission is pleased to have the African countries integrated into PM discussions, which is an initiative of the EU-Africa PerMed project, thereby extending the international collaboration on PM approaches to the African continent. Personalized medicine can help address the challenges of high burden of diseases and the resulting pressure on healthcare systems, and is cost effective in terms of prevention, healthcare outcomes and use of resources. These outcomes brought about by PM are desirable for the African continent just like in any other continent. Personalized medicine relies on different metrics in population diversity to interpret and validate health data, and therefore improve the understanding of diseases from a global perspective, a case so well demonstrated through the COVID 19 pandemic. She however, noted the existence of obstacles in implementation of PM, but acknowledged that challenges can be overcome, through collaboration in scientific research and innovation, such as capacity building and benchmarking to ensure implementation of best practices. Given the current advances in genomic medicine and the digitization of health as well as the reduction of the cost of the relevant technologies, and the development of PM in Africa as a conceivable positive prospect. She noted that the coordinated approach of a partnership between the EU and other countries of the world can foster implementation of best practices, as well as harmonization and standardization of approaches between different actors for the benefit for all.

The Director General, NACOSTI recognized the importance of PM as a revolutionary health care model that needed to be prioritized by African countries, while recognizing the cultural and social context such as the traditional medicine that is popular in Africa. He noted that the African health care system has immense challenges. The African continent shoulders 25 percent of the global disease burden, particularly TB, Malaria, HIV/AIDS and neglected diseases, and with high number of resources going towards healthcare needs. Africa needs to pursue pro-innovation, pro-science, and pro-technology policies and practice, dedicated to overcoming the disease burden. There is need to explore new models and tools brought about by advances in technology to address disease burden in Africa. This has been shown to work with COVID_19 and can equally work with other diseases. He acknowledged that we live in a global village, and this has been demonstrated by the COVID-19, where the infection started in one locality, and within a short time had spread across the globe. Equally, its now much easy to benchmark for best practices anywhere across the globe. There is need to strengthen cross-sector collaborations, and creating partnerships across sectors, region and global to ensure ability to respond to health and even economic needs of the citizens. Efforts to balance between health care prevention and promotion as well as utilize digital technology, data science, and innovations to step up productivity in the health sector. All these can be achieved through pursuing personalized health care. He advised that the workshop which is being attended by over 30 African countries should aim to create a scene for a more vibrant discussion on the agenda of PM in Africa, and how Africa can collaborate not only with Europe but also regions, in ensuring that we enjoy the fruits that come with this model.

3.2. Global Overview of Personalised Medicine

The first day of the workshop had the objective of presenting EU-Africa PerMed and ICPerMed to African stakeholders, as well as to discuss with them the main challenges and opportunities of PM in Africa, and to better understand the perception and potential of PM in Africa and its relevance for the different countries/stakeholder group. The first session of day 1 included a set of 4 presentations that gave the participants a short overview of the EU-Africa PerMed Project (including what were the expected objectives for the workshop), a vision from the European Commission of what was PM and the benefits for collaboration with Africa in this area, what is ICPerMed and a key-note presentation from Prof. Michele Ramsay (one of the most renowned Africa PM researchers) of the vision of PM in Africa. The second part was focused on learning about PM initiatives in Africa, what is the situation in the different regions and countries, is PM a known concept, is research informing policy action to develop PM within the health care systems and what are the main challenges and opportunities for PM in Africa.

3.2.1 EU-Africa PerMed Project and the Objectives of the Workshop

By Joaquin Guinea and Erika Sela from Innovatec

Figure 4: *Photo of Joaquin Guinea presenting on the EU-Africa PerMed Project*

The project and its overall objectives were presented by the project coordinators Joaquin Guinea and Erika Sela from Innovatec which is the coordinating institution. They highlighted the project's overall objective as being integrating African countries into International Consortium for Personalised Medicine (ICPerMed) activities, thus contributing to a successful implementation PM in the global context. ICPerMed is expected to foster joint PM projects and programmes between Europe and Africa, as well as strengthen bilateral Europe and Africa science, technology, and innovation (STI) relations in health, especially in supporting EU-AU policy dialogues relevant to research and health. Implementation of this project is expected to contribute to reducing global inequities in PM research for better disease prevention, diagnosis and treatment, as well as contribute towards the United Nations Sustainable Development Goal 3 of ensuring healthy lives and promoting well-being for all at all ages.

They further presented the main objectives of the stakeholder workshop as being aimed at presenting the EU-Africa PerMed project to African stakeholders and initiating an interaction, setting up the basis for future collaborations, as well as introducing ICPerMed to African stakeholders. The specific

objectives of the workshop were: To understand the perception and potential of PM in Africa and its relevance for the different countries/stakeholder groups; Discuss with African Stakeholders the main challenges and opportunities of PM in Africa; Identification of areas of mutual interest between Africa and Europe in PM research and explor;e and analyze the potential and advantages of collaboration in R&I in the field of PM between Africa and Europe.

To achieve these objectives, the workshop had thematic based presentations, which included: Challenges and opportunities for PM in Africa, identifying and prioritizing PM needs in Africa; and Potential and advantages of collaboration in the field of PM between Africa and Europe. The expected outcomes of the workshop included Stakeholder workshop report, a policy brief on challenges for EU-Africa collaboration in PM, a report of the Pre-Workshop survey and a list of African stakeholders interested in the project that could collaborate with the project in future activities such as the second stakeholder workshop, training events, and participating in project LinkedIn groups.

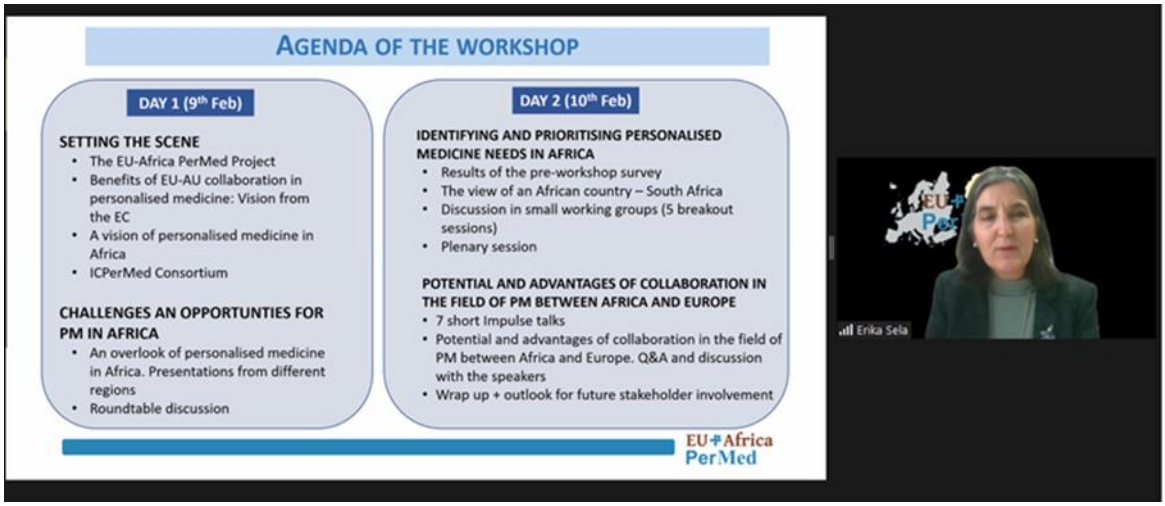


Figure 5: *A Photo of Erika Sela presenting the objectives of the stakeholder workshop*

3.2.2. Cooperation with Africa in Personalized Medicine: A Global Approach to Research, Innovation and Health

By Jean-Luc Sanne, Policy Officer, Directorate-General for Research and Innovation, European Commission

The European Union has taken a global approach to R&I through the Europe's strategy for international cooperation in a changing world. This is aimed at preserving openness in R&I international cooperation while promoting a level playing field supported by fundamental values as well as strengthening the multilateral partnerships to deliver new solutions to green, digital, health and innovation challenges.

The understanding is that none of the current and future challenges for PM can be solved by any one player alone. All key players in the field need to work together across borders in order to solve the problems and progress in delivering PM to the citizen. The ICPerMed was initiated in 2016 as a collaboration of research funders and policy makers from EU Member States and beyond, aimed at establishing Europe as a global leader in PM research and at supporting the PM science base through

a coordinated approach to research and providing evidence to demonstrate the benefit of PM to citizens and healthcare systems. The European Commission support of ICPerMed was through a Call under Horizon 2020. In 2018, the focus was on the Community of Latin American and Caribbean States, 2019 was focused on China, while 2020 the focus was on Africa, and it is through this arrangement that EU-Africa PerMed Project was supported. The European Commission has several other multilateral cooperation on health R&I which have either been launched, joined or supported over recent years. These are based on three thematic matters which are strategic issues for biomedical progress and uptake of innovation in healthcare (Heads of International Research Organizations in health R&I, International Coalition of Medicines Regulatory Authorities and International Consortium for Personalised Medicine); Non-Communicable Diseases (International Rare Diseases Research Consortium and Global Alliance for Chronic Diseases) and Communicable diseases, including epidemics preparedness and response (Global Research Collaboration for Infectious Disease Preparedness, European and Developing Countries Clinical Trial Partnership, Coalition for Epidemic Preparedness Innovations and Joint Programming Initiative on Antimicrobial Resistance)

3.2.3. Keynote Presentation on Vision of Personalised Medicine in Africa

By Prof. Michèle Ramsay, Sydney Brenner Institute for Molecular Bioscience, University of the Witwatersrand, South Africa

Figure 6: *A Photo of Prof. Michele Ramsay making a keynote presentation on the vision of PM in Africa*

The African continent is a complex and home to a population with great diversity. Africa holds roughly 15% of the world population, has 54 countries, over 3000 different ethnic linguistic groups, with four main language groups that transcend political boundaries. However, there are variations in terms of health infrastructure, climate, genetics among other areas. For example, in genetic diversity, African genomes are different in terms of having high genetic variations, structural differences, low linkage disequilibrium across the genome which presents both advantages and disadvantages when looking at linkages to health and disease. A study published in 2020 reported on just over 400 whole genome sequences from 50 different ethnic linguistic groups in Africa which identified 3.4M novel variants from such a small number. A whole genome of an individual from Africa has about 5 million variants that are different to the reference genome, as compared to Europe or Asia which has only about 4 million differences. So, you can see more diversity, even at an individual level. A phylogenetic analysis

across world population also reveals that majority of the variation resides in Africa with relatively little in non-African populations.

A lot of factors contribute to the spectrum of health and disease, some of which include not only genetics but also the environment, host factors and microbiome among other important factors. Even with all this diversity, there is no much data from Africa to support a PM agenda, yet there is a population explosion being experienced that make PM important for Africa. Among the challenges that are faced by African countries and people in terms of PMis that there is not enough data to be able to fully benefit from PM, yet Africa is disproportionately burdened with disease, particularly non communicable diseases and infectious diseases. Additionally, there is insufficient infrastructure in terms of laboratories that can do diagnostic tests as well as healthcare infrastructure. This challenge is compounded by the fact that Africa does not have enough skilled people in different areas that are important in terms of PM. Personalised medicine has four main components: First, it's about understanding genomic variation and how that relates to the phenotype, and in terms of infectious organisms. Secondly, It is about the technology, and about strengthening technology across the African continent so that we are able to do high throughput whole genome sequences. Thirdly its about data, especially big data for large cohorts, and data which is, accessible and interoperable especially with other data sets in the world, as well as appropriate consent and ethical oversight, so that these data is reusable. Finally, a strong clinical infrastructure which currently needs strengthening in many African countries.

The presenter highlighted a study carried out in 2021 which revealed that majority of African countries, either have no genetic services, or have very limited services, or are focusing only on diseases like sickle cell anemia, that are very common in some parts of Africa. This shows that there is need to strengthen capacity for genetic services which is an important aspect underpinning PM. Some examples given indicated the importance of Africa based data for African solutions. One of the examples is Cystic Fibrosis. The mutation causing this condition is different in European populations when compared with African populations. An essay that detects this condition amongst the European populations does not apply in African populations. Huntington's disease is the other case in point where mutations differ between the European and African populations. Also important in the PM discussion is the gene- environment interactions because different genetic variants are predisposed to disease in different contexts. This underscores the importance of research that focuses on the African population without relying on available data which mostly is from other populations.

3.2.4.A dedicated European multi-stakeholder framework for Personalised Medicine: The ICPerMed

By Monika Frenzel, Agence Nationale de la Recherche (ANR), France

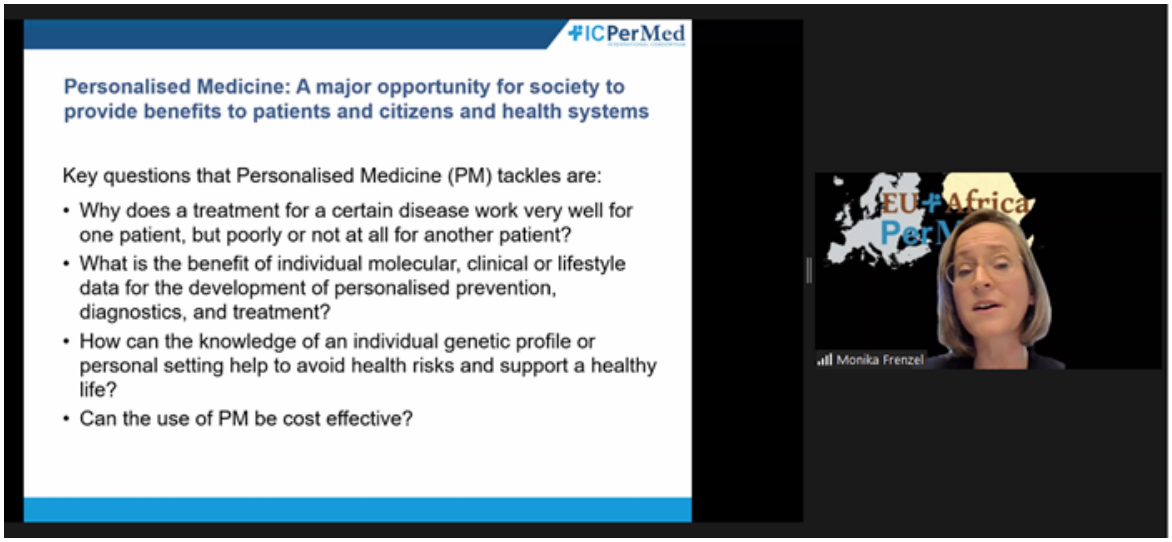


Figure 7: *A Photo of Monika Frenzel presenting ICPerMed to workshop participants*

The International Consortium for Personalized Medicine (ICPerMed) is comprised of a membership of almost 50 European and international partners, which include public and private `not-for-profit` health research funding and policy organisations and the European Commission. Member organizations of ICPerMed are high level policy organizations which include research funders, Ministries of Health, and Ministries of research and innovation which align and encourage joint efforts in implementation of PM initiatives across the globe.

She pointed out one important aspect of PM as being a common understanding of what it is. According to Horizon 2020 and European Council Conclusions on PM for patients (2015/C 421/03), it is known as *" a medical model using Characterisation of individuals' phenotypes and genotypes (e.g. molecular profiling, medical imaging, lifestyle data) for tailoring the right therapeutic strategy for the right person at the right time, and/or to determine the predisposition to disease and/or to deliver timely and targeted prevention"*. This concept deviates from the "one size fits it all" model. Personalized medicine answers questions such as why a treatment for a certain disease work very well for one patient, but poorly or not at all for another patient; the benefit of individual molecular, clinical or lifestyle data for the development of personalised prevention, diagnostics, and treatment; how the knowledge of an individual genetic profile or personal setting helps to avoid health risks and support a healthy life; and whether the use of PM can be cost effective.

To develop and embrace PM, it is important to embrace the contributions of the different key players by first bringing them together and getting them involved in discussions and agenda. These key players include citizens and patients, industry, funders, researchers, ethics and data committees, insurance firms etc., with a goal of coordinating and promoting research along the full value chain and to develop and evaluate PM approaches. Also, these key players need to address issues to do with research efforts, market access, health systems, data and ICT. ICPerMed current focus is on five topics which are Clinical Studies in PM; PM in healthcare; Patient empowerment; Education & Curricula in PM; and Health economic value of PM. All this is being done through five working groups comprised of ICPerMed members and external experts. The effectiveness of ICPerMed is based on its collaboration

with other associated initiatives, such as stakeholder forums. Achievements include increased efforts in the PM field for PM research and implementation on regional and national level but also in collaborations across countries. Ministries or funding organizations can become members or observers in ICPerMed, or joining the stakeholder group or even participate in ICPerMed recognition which is open worldwide.

3.2.5 Question and Answer Session

The session on global overview of PM was concluded by a question and answer session where participants were allowed to ask presenters questions or clarify certain aspects of PM as presented. Below is a summary of some of the answers or comments given during this session.

1. Precision public health seems to be a buzzword nowadays, and PM is part of the task of public health, and cannot be viewed outside the confines of public health system. Even as we think about how to invest in health, we should be looking at how to invest in individuals' health hence having stratified and individualized interventions in parallel and at the end, its all about personal health care

2. Commenting on blood group variants in relation to diseases, and the great migration - some of them do have phenotypic impact and have changed through evolution, either through selection, or just by random drift, but it's a fascinating area of research not enough is known about blood group variants in Africa

3. Ethical, legal, and social perspective is an important aspect of PM. Genomic data is very sensitive whether for primary use in treatment of patients or secondary use in medical analysis and research. Its even much more complex in international collaborations where such data must be shared across borders. It will require some level of trust, assessment and reflections. First is the need to work within the legal and regulatory framework, ensure that participants are well informed, administer informed consents, and ensure data is completely deidentified and not linked to a particular individual (even though genetic data is unique to individuals, it can still be deidentified).

4. African population also seem not to be benefiting from genomic data that is available because its not accessible in a form that can be used at clinical level. Its not just about collecting more data, but it's about optimal use of the data that is already available

3.3. An Overview of PM in Africa

The second session of the first day of the workshop was focused on learning about the situation of PM in Africa, at both continental and regional level, and also the view from the WHO-Regional Office for Africa. The first part had presentations from representatives from 4 African Regions (North, South, West and Central), from AUDA-NEPAD representing the views of the African Union and a vision from WHO-AFRO. These were followed by a roundtable discussion, where participants were able to question and comment about the challenges and opportunities of PM in Africa, at national, regional and continental levels

3.3.1. Personalized Medicine in Africa: A Vision From WHO

By Joseph Okeibunor, WHO Regional Office for Africa, Brazzaville, CONGO

Personalised Medicine is an old, but a very relevant concept. It is about creation of medical treatments unique to patients. It can be prevention, or therapeutic strategies where individual vulnerabilities are taken into consideration. It also refers to tailoring of treatments to individuals considering their unique genetic background and considerations. This concept is very relevant, because WHO supports case management, looking into the specific realities of the different cases as they arise. To support case management of diseases, especially the priority diseases, such as tuberculosis, HIV, cancer, and malaria, reports are reviewed periodically and the treatments are adjusted based on the data to ensure that they meet the needs of individuals. Indeed, all WHO treatment guidelines for case management of priority diseases consider the individual needs and realities of the cases in determining what treatment suits the individual. WHO therefore welcomes collaborations to address priority diseases including multi disease resistant tuberculosis, HIV and AIDS, malaria, among others, particularly when focusing on genetic factors and issues of their metabolism. Though WHO is not an implementing agency, it supports such collaborations with member states as evidenced by the EU-Africa PerMed project. He explained that WHO facilitates collaboration by presenting such intentions before the Member states in the regional committee, and then follow up by supporting member states in implementation of their strategies. WHO also encourages empowerment of the countries to take lead in terms of developing policies for implementation of PM, and to improve health outcomes at country level. There is also need for coordination at international and sub regional levels because strong coordination is needed to minimize transactional costs.

3.3.2. Precision Medicine in Africa

By Paul Tanui, African Union Development Agency -NEPAD

In 2015, the AU Specialized Technical Committees (STC) on Health Population and Drug Control which brings together all the ministers of health from Africa, reviewed the African Health Strategy (2007-2015) which provided an opportunity to relook at the health research section (continental position paper on health research in Africa), and guided that research and innovation should be integrated into the revised African Health Strategy (AHS) with technical support from the NEPAD agency and other interested parties. The AHS recognizes the role of Health Research in providing evidence for policy- and decision-making at all levels, emphasizing the direction given on health research and responding to challenges identified by the Abuja and Accra High Level Ministerial Meetings on Health Research. It also emphasizes the need for content of research to go beyond determining prevalence and to consider that social and psychological factors are behind health choices. This has provided for the development of a continental position paper on health research in Africa.

He gave some highlights of the AHS 2016-2030 as focusing on health research and innovation that emphasizes the need to institutionalize mechanisms for defining, producing and utilizing African research in ways that can transform the health sector as well as the African economy and society as a whole. Achieving health goals and targets requires matched investment in research and innovation to improve access to medical technologies and products. Furthermore, data from health research and innovation should be collected and analysed to inform policy and decision-making at all levels of the healthcare system. Member States should encourage locally driven and financed research through the empowerment of local research institutions, setting up of innovation hubs and allocation of 1% of the national GDP for research and innovative as envisioned in the Science, Technology and Innovation Strategy for Africa (2014 – 2024). Building regional expertise in research should be supported where

it offers more returns through strengthening regional research centres, building research networks and sharing results across countries.

Another initiative of the AUDA-NEPAD is the development of Framework for the Implementation of Genomic Medicine for Public Health in Africa in collaboration with Africa Academy of Sciences. "Precision Medicine" describes the use of specific information about an individual to facilitate a more precise approach to their healthcare. The term is very broad with wide reaching approaches and implementations. One of the more specific approaches is genomic medicine, where knowledge about a person or population's genetic makeup can be used to derive the most appropriate diagnosis, treatment and, where possible, disease prevention strategy. Genomic medicine has been applied to a number of areas of healthcare, including perinatal testing and newborn screening for monogenic diseases, cancer screening and treatment, rare disease diagnosis and treatment, pharmacogenomics and sequencing of pathogen genomes. However, most of these activities have been restricted to developed countries.

Some of the key barriers to the implementation of genomic medicine world-wide and which are more pronounced in developing countries, include clinical and data infrastructure, regulatory environments, integration of new technologies into clinical practice, and cost. Knowledge and evidence generation are also essential elements which are constantly evolving as new genomes are sequenced and genome wide association studies are undertaken. In Africa, due to under-representation of African populations in such studies, knowledge and evidence for actionability on genomics data are lagging behind the developed world. This, along with poorer resources and infrastructure limitations, mean that African countries need to overcome greater barriers to implement genomic medicine, but this is by no means an impossible task, as challenges can be addressed in a stepwise manner. The aim of the Framework for the Implementation of Genomic Medicine for Public Health in Africa is to highlight these elements within the African context and provide some recommendations on how African countries can work on putting them in place by building on existing infrastructure. This will enable resource limited countries to start implementing appropriate genomics-based health-related interventions, drawing on experiences from elsewhere, but adapting to the African context where necessary.

Elements of the framework are: Clinical facilities for patient counselling, screening, treatment and monitoring; Sample collection, processing and data generation facilities; Data storage, curation, analysis, interpretation and sharing infrastructure; Knowledge bases with up to date information on genotype-phenotype link and actionability; Research facilities to increase knowledge on genomics in African populations; Genomic medicine training programmes for healthcare professionals; and Regulatory, data governance and ethics consent processes governing all the above activities

3.3.3. Translational Research to Precision Medicine: The North African Experience

By Dr. Yosr Hamdi, Institute Pasteur, Tunisia

A lot of effort have been dedicated to the implementation of PM in different countries in the world, including Africa, and genomics and PM are in the first wave of scientific priorities in the continent. The presenter informed participants that some of the efforts in which she has been part of include contribution to development of "A Framework for Implementation of Genomic Medicine for Public Health in Africa" which was published in 2021. Secondly, are the recommendations on how to make research and innovation a driver for sustainable development in the AU-EU relations which proposes measures to implement AU-EU cooperation in health systems. This was done through a policy study by an advisory group on research and innovation for AU-EU cooperation. Thirdly, is the development of a policy brief on the implementation of PM in Tunisia health systems (2021).

There is no doubt of the need to implement PM in Africa. In North Africa the roadmap being followed to implement PM has four steps. The first being a kind of situation analysis where over 400 genetic related diseases have been identified. Followed by capacity building and getting own omics experts through training activities such as genetic and molecular diagnosis, NGS data analysis, Implementation of genomics database and NGS platforms. Thirdly, is analysis of the ecosystem and in-depth stakeholder evaluation which include health care providers, clinicians, pathologists, radiologists, oncologists, academic researchers, knowledge societies, pharmaceutical companies, bioinformaticians, diagnostic companies, policy makers, advocacy groups and patients. Finally, is about implementation of PM. An example was given about the Tunisia Genome Project, where over 9 institutions are involved. Sequencing facilities have been built for research and clinical use, worked on a Reference Sequence of the Tunisian Genome, which has supported efficient Diagnosis, Personalized Treatment, and reinforced preventive care.

Some of the recommendations for promoting PM in Africa as presented by the speaker, include 1) **Awareness creation, and communicating the value** of PM to the society as well as engaging and empowering the community, particularly, patients; 2) Getting knowledge and understanding of the background information on healthy states of our population; 3) **Infrastructure** which include 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, facilities for clinical action and clinical trials.;4) **Training to enhance human resource** (researchers, healthcare professionals, bioinformaticians, technicians, data protection officers etc), data Analysis skills, genomic medicine training for health care professionals and genetic testing /counselling among others; 5) **Strengthen ethics and governance structures which is important to strengthen ethical and regulatory framework, as well as harmonize the ethical aspects at least at regional level** to be able to collaborate and to work together especially on data governance; 6). Quality monitoring and evaluation; 7) Funding by African governments investing more on PM and encourage south-south collaborations, private sector, civil society and foundations to invest in this field; 8) **Clinical translation** so that the result of all the efforts trickles down to patient centred care, and other benefits that come with implementation of PM approaches in health care.

3.3.4. A Southern African Region Overview of Personalized/ Precision Medicine

By Prof. Collet Dandara, Division of Human Genetics, University of Cape Town

An overview of South Africa PM was presented by Prof. Collet Dandara, who gave the history of Pharmacogenomics in Africa which started in August 2003 with the African Pharmacogenetics workshop held in Nairobi, Kenya, followed by another one in December, same year in Accra, Ghana for The African Society for Human Genetics (AfSHG). In the same year, the 1st Draft of the complete Human genome was finalized after its release in 2001. However, he noted that though there has been, major funding inflows into Africa, from both domestic and international funders, no serious attempt

has made to provide funding focused on pharmacogenomics. However, in 2018/2019 SAMRC released a Pharmacogenomics focused call.

Pharmacogenomics is important because, drugs do not always work, and patients can respond differently to the same medicine. The highest percentage of failure is in cancer drugs at 75%. Africa has to do more in pharmacogenomics, because there is more genomic differentiation of African populations compared to European or Oriental populations.

He noted that significant work on pharmacogenomics has been done in South Africa, Egypt and Nigeria, but most African Countries have done very little or nothing. This dream is however being realized through the African Pharmacogenomics Network (APN). The network undertakes research, training and translation. They had a meeting in Nairobi, Kenya in 2018 with a vision of exploring and leveraging African genomes for better health. Their objectives are Awareness of pharmacogenomics among Africans; Research & Training on Pharmacogenomics in Africa; and Clinical Implementation of Pharmacogenomics in Africa. The Network has been consolidating pharmacogenomics knowledge, research capacity and translation in Africa through introduction of Masters in Genomic Medicine (AiBST & Chinhoyi University), Masters/PhD in Genetics (South Africa Universities), and collaborative platforms and support for regional Centers of Excellence. South Africa has adopted several methods to catalyse pharmacogenomics. These include dedicated funding in pharmacogenomics; Identification of genuine pharmacogenomics researchers with a track record and dedicated funding; Creation of consortia, networks or training hubs; and Collaborative regional focus on pharmacogenomics translation.

3.3.5. An Overview of Personalized Medicine in West Africa

By Dr. Badara Cisse, Institut de Recherche en Santé, de Surveillance Epidémiologique et de Formation, Senegal

The presenter summarized PM in West Africa region as being slow in its development and adoption. The region is made up of a community of 15 countries. These are Benin, Burkina Faso, Cabo Verde, Ivory Coast, Gambia, Ghana, Guinea, Guinea-Bissau, Liberia, Mali, Niger, Nigeria, Senegal, Sierra Leone, and Togo. It is home to approximately 220 million inhabitants, with a regional GDP of 106.7 billion USD. The speaker acknowledged that although PM is unique to certain populations, West Africa as a region has its specificities and special needs for effective development of PM. Though PM as a concept has been in existence for decades, there is growing knowledge and interest especially on application of human genetics in prevention, diagnosis and treatment of many diseases. Personalized medicine is growing in the region courtesy of Human Heredity and Health in Africa (H3Africa) consortium. However, the region still experiences limitations such as lack of adequate infrastructures and equipment, few skilled specialists, limited experience, isolated collaborations, and inadequacies in the regulatory framework. To promote PM in the region, therefore, there is need, firstly, to characterize the African Genome to bring to light the genetic diversity of the African population and foster genomics of infectious diseases. Secondly, pool efforts in establishing strong and capable Centers of Excellence. Thirdly**, make the concept of PM better known to political decision-makers and other key stakeholders in medical research** in West Africa and finally, integrate PM into the health system agenda.

The speaker informed participants that at the moment, there are a number of Centers of Excellence in genomics In West Africa, that will be key in promoting PM agenda in the region. These include H3Africa Consortium, ACEGID (Nigeria), MRC/LSHTM (The Gambia), Pathogens Genomic Diversity

Network Africa (Mali), IRESSEF (Senegal) and Centre International de Recherche et de Formation sur les Agents Infectieux et le Génomique (Senegal). The focus of these institutions in regard to PM should be to understand and control transmission of infectious diseases in West Africa in order to save lives and protect an already fragile health system and foster Human Genomics in the continent. This can be achieved through establishing networks of collaborations with laboratories, academic and public health institutions to advance outbreak surveillance and research in West Africa.

3.3.6 An Overview of Personalized Medicine in Central Africa

By Dr. Peggy Raymonde Conjugo-Batoma, Communauté Economique des Etats d'Afrique Centrale as presented by Rizwana Mia, the session moderator

The presentation gave an overview of PM from the perspective of the Commission of Economic Community of Central African States (ECCAS), which is a regional commission. This commission is amongst the six recognized by the African Union Commission. It was set up in 1983 but started operations in 1985 through the establishment of office of the General Secretary and three Deputy Secretary General's. The 11 countries that are part of ECCAS, are Angola, Burundi, Cameroon, Central African Republic, Congo, the Democratic Republic of Congo, Gabon, Equatorial Guinea, Rwanda, Sao Tome and Principe and Chad.

The President of this community is Angola, while the Vice President is Equatorial Guinea. There are five different subcommittees of ECCAS whose affairs are managed by different countries. The Environment and Natural resources, Agriculture and Rural Development by Congo; Development of the territory and infrastructure by Cameroon; Political cooperation, peace, and security by Chad; Monetary and financial affairs by Rwanda; and Promotion of agenda for human and social development by the Democratic Republic of Congo. The priority for the region to develop and implement PM lies within this Commission's mandate, because the Commission has a mandate to ensure equality in healthcare as well as gender promotion, human and social development. Indeed, health is one of the eight sectors captured in the 2021-2025 strategic plan.

Though PM is not a priority for now, the Commission aims to set up the Central African Health Organization which will implement all health actions in the region by bringing together all the organizations in the sector. They are also seeking to establish collaborations especially with international and private funding agencies who can support biomedical and health research in this area. Those they are looking forward to having such collaborations are the Human Science Research Council and the Global Partnership for Effective Development Cooperation.

3.4. An Open Discussion on the Challenges and Opportunities of Personalised Medicine in Africa

(Moderated by Rizwana Mia, South Africa Medical Research Council)

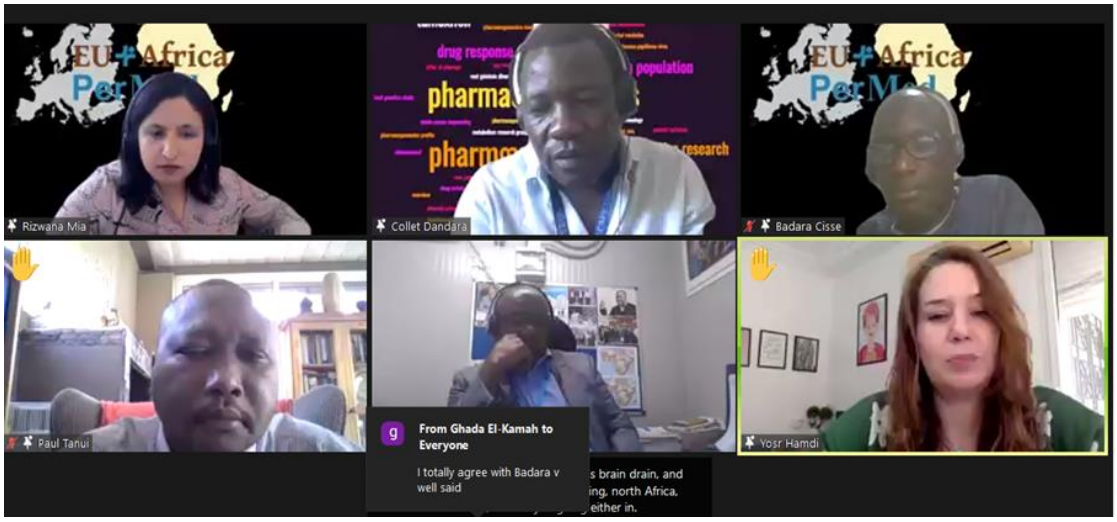


Figure 8: *A Photo of the panelists and moderator during the open discussion.*

Upper row from left to right: Rizwana Mia (session moderator), Prof. Collet Dandara, Dr. Badara Cisse; Second row left to right: Paul Tanui, Dr. Joseph Okeibunor and Dr. Yosr Hamdi

The moderator of the roundtable discussion commenced the dialogue by posing the two questions: One *on how Africa should pursue PM agenda development and the second one was whether there was a scope in development of PM approaches in diagnosis and treatment of infection diseases*. Only 44% of the participants responded to the first question out of which approximately half of the respondents preferred a regional focus of the PM agenda development with 35% and 17% opting for a continental and country focus respectively. In the second question, 27% of participants responded and 100% agreed that there is a scope to develop PM approaches in the diagnosis and treatment of infectious diseases. The answers from respondents informed the discussion, on how Africa can pursue development of PM agenda, in the different regions and the scope of developing PM approaches in the diagnosis and treatment of infectious diseases.

In the discussion, the following highlights were noted:

1. Platform for countries to interact at Continental level - World Health Organization has a platform for supporting member states to implement recommendations, strategies, and frameworks through regional committees. Once a decision is passed by a regional committee, it is the onus of individual country to carry on with the implementation of the recommended strategies. The level of implementation depends solely on capacity and infrastructure available in these countries. Majority of stakeholders prefer a regional focus; the best way would be to develop a strategy that would be presented to Ministers of Health. Once they adopt the strategy, this gives a political push for the agenda to be implemented. The World Health Organization has the technical advisors on matters that relate to health. The flow of activities works well if they move from WHO, to the regional community such as WAHO, and then to the individual countries for implementation. Regional networks need to be strengthened to foster cooperation and collaboration.

2. Diversity within African countries and populations- It's important to recognize that African continent is made up of various economic communities, with each of these communities having commissions/bodies handling related health component. It would be important to loop in these regional communities in development of PM agenda, but have individual countries implement the agenda with the support of WHO. Another aspect of importance to consider in the regional focus of PM agenda development is the difference between the confines of the geographical regions and genetic distribution which does not follow the geographical boundaries. An example is Egypt, the most interesting country in the world in terms of genetics because of historical aspects, and which is closer to the Middle East than African. There is therefore needed to differentiate between genetical component and geographical boundaries.

3. Limitations in skilled human capacity and funding - Africa needs to set up Centers of Excellence for purposes of skills development. As we think of priorities in PM, we also need to think of ways to bring back diaspora community, that would be a resource in PM development. For example, Senegal is about to complete its Human Genomic Platform, but funding has been an issue, and would require support. EDCTP should consider creating a dedicated grant call for PM. In the Northern Africa region, it has well trained people in PM, but the gap is twofold. First is the brain drain component that has affected PM implementation in the North Africa region. There is need for deliberate efforts made to attract them back home, by creating opportunities and favorable terms such as salaries and infrastructure where they can work and encourage them to stay in Africa. Secondly, a lot of effort has been spent in training, and it's time to think about application of this knowledge which is already available. Even as we look at the brain drain and its effects, Africa should not lose sight of replenishing those who leave to create a balance. Centres of Excellence are also key in training. Countries which are lagging in PM can be assisted by having them train in these Centres of Excellence. The African Union has recognized the diaspora community as the 6th African region, in addition to South, East, West, North and Central Africa. African Union has gone ahead and convened a high-level dialogue meeting with the diaspora community engaging with them on how to contribute to development back into the continent. For PM agenda, this 6th region should also contribute, in terms of availing their expertise for PM development in Africa. In addition, even non-Africans willing to support Africa should have a platform for engagement such as the STISA strategy. There is need for more advocacy for funding in PM and other emerging fields. Targeted training in aspects that are lacking, having programmes that attract trained human capital so that they don't leave their countries after training, and setting aside and dedicating funds would help in alleviating the endemic skills gap being experienced currently. Also relooking at the curriculum used in training of physicians so that PM is incorporated. Another aspect is involving the private sector. In Tunisia for example, the private sector is applying PM in clinical setting, and therefore need to be supported, even as the public sector is supported in implementation of PM

4. Approaches to development of PM diagnosis and treatment of infectious diseases- Hundred percent of the respondents agreed that there is a scope to develop PM approaches in the diagnosis and treatment of infectious diseases. It's known that infectious diseases are an underlying cause in almost all diseases such as diabetes, coronary heart disease, and cancer. Treating the infectious disease would also serve to reduce burdens of other diseases. There is however need for training and practical experience in application of PM in treatment of infectious disease. There is evidence that some well-known treatments for infectious diseases should not be applied to some communities with certain genetic composition. This could be a low-lying fruit because of the already available skills and competencies in Africa.

In conclusion the discussants further emphasized that regional focus is a good way to proceed, though there is need to recognize the inequalities that exist even within the regions. An example is South Africa that has a well-developed PM ecosystem, yet within the same economic community, we have countries where PM concept is not well known. **There is need for a multipronged approach, with regional and continental efforts guiding in agenda setting, while countries are left to set priorities, implementation and allocation of resources for PM.** There is a need to develop Centres of Excellence dedicated to building skills in PM in Africa. Funding support for training and infrastructure development that would even serve to attract trained diaspora community back to Africa was proposed. This could be through deliberate efforts such as specific grant calls to support training in PM and finally Infectious diseases can be a starting point in PM implementation in Africa.

3.5. Wrap up for Day One

By Erika Sela, Innovatec Spain

Figure 9: *A Photo of Erika Sela -project coordinator wrapping up day one of the workshop*

Erika Sela, coordinator of the EU-Africa PerMed project, summarised the key messages from day one These included:

1. Personalized Medicine is a steady evolution towards a new way of delivering health care.
2. The importance of overcoming global health challenges through collaboration, as the COVID-19 has shown.
3. The European Commission takes PM as a priority area for long term collaboration between EU and Africa.
4. Personalised Medicine should be tailored to the African context, how we translate from research into practice, the need to have more skilled workforce, more understanding of PM by the population and the policymakers, and the need for more data.
5. There is need for more political will to advance PM in the continent.
6. Regional Economic/Health Communities in Africa can play an important role but countries need to take the leadership at country level.
7. World Health Oorganisation can help to give the vision for Africa on PM, which can then be implemented by countries and the regions.
8. Some countries are ready for PM but others need more time, and this should be taken into account when we seek a regional approach. There is also a difference in terms of genetic

9. diversity within regions (e.g. Egypt in North Africa). So, it should be taken into account, not only the geographical distribution of Africa by regions but also the genetic differences.
10. Cross country collaborations (networks) have also been mentioned as important to advance in PM, and not all countries have this type of networks.
11. Education, training and funding are important aspects to advance in PM. There is lack of adequate skilled individuals in Africa.
12. Platforms exist and they need some focused funding, special calls for PM in programmes such as EDCTP.
13. Skilled personnel from North Africa exist but they are leaving the countries, have funding specifically to bring them back.
14. In North Africa, we need to stop training people but start applying what we are learning: Implementation and application in real settings.
15. Countries that are more developed in PM can offer the possibility to train PM for researchers from other countries or incorporate them in research groups. WHO-Afro is looking for dedicated funds to cover funding to dedicated training.
16. Continuous training on PM of physicians, clinicians and health care providers, outside the University.

PRESENTATIONS: DAY TWO – 10TH FEBRUARY 2022

The second day of the workshop focused on two important issues for the EU-Africa PerMed project, which were i) Identifying and prioritizing PM needs in Africa and ii) Exploring and analyzing the potential and advantages of collaboration in R&I in the field of PM between Africa and Europe.

The first part of the day included two presentations, one with the results of a survey administered to all participants understand PM health needs and priorities in Africa and a presentation of the PM programme in South Africa, as an example of an African country that is already carrying out research developing and implementing PM in their health system. This was followed by 5 small group discussions for Identifying and prioritising PM needs in Africa, each one focused on one important aspect of PM.

- GROUP 1: Scientific and technological needs
- GROUP 2: Scientific and technological application fields
- GROUP 3: Operational needs for better integrating PM into healthcare and clinical practice
- GROUP 4: Governance / regulatory / ethics needs to make personalised medicine a reality
- GROUP 5: What is/are the need/s to improve healthcare?

After the presentation of the results of the small groups in the plenary, the second part of the day focused on the potential and advantages of collaboration in the field of PM between Africa and Europe. The session started with 7 short impulse talks followed by a question-and-answer session and discussion with the speakers forming a round table and open exchange between the participants

3.6. Identifying and Prioritizing Personalized Medicine Needs in Africa

3.6.1. Preliminary Results of the Pre-Workshop Survey on Personalized Medicine Health Needs and Priorities in Africa

By Lynette Kamau, African Population and Health Research Center, Kenya

One of the consortium members, Lynette Kamau, on behalf of work package 3, presented the results of the survey, which was carried out to understand the needs and priorities in Africa, and which had received 76 responses from PM stakeholders from 19 African countries at the time of the workshop. All the five African regions were represented. South Africa had the highest number of responses (20), followed by Kenya (13). Other countries had between 4 and 1 stakeholders responding to the survey.

The stakeholders were asked to identify themselves, including research organizations, research and innovation funders, and health system policymakers. The results indicated that most respondents were from research organizations (31). Research and innovation funders, as well as industry and private business, came in third with seven respondents each, followed by health system policymakers (5), health care providers (3), and finally, civil society organizations (2). Most of the respondents (69) indicated that personalized medicine is a concept known in their region/ country. Between 54.29% - 82.86% from different sectors indicated that PM is an area of interest in their country.

Cancer emerged top (86%) as the disease where PM approaches would be most needed, followed by cardiovascular diseases (66%), infectious diseases (59%), diabetes, and other metabolism-related conditions (57%). Other outlined intervention areas were rare genetic diseases (47%), immune diseases (44%), mental health conditions (43%), other non-communicable diseases (30%). Results indicated a low level of adoption and implementation of PM across the healthcare continuum from

existing strategies. PM-related programs provided by the healthcare system and genetic testing services, biobank, and patient registries were indicated as severely lacking. When identifying PM needs in regions/countries, respondents prioritized targeted treatment, followed closely by improved diagnostics. Further, half of the respondents felt that targeted prevention and ethical, legal, and social frameworks should be prioritized. In developing the African PM agenda, 48% of the respondents noted that starting at the regional level would be the best option. However, 26% of the respondents preferred enhancing ownership globally and nationally.

Almost all respondents (99%) agreed that the genetic diversity of African populations is necessary and valuable to the global knowledge required to advance PM research and approaches, for example, the development of vaccines and drugs. Further, 90% agreed that African data is necessary to understand specific disease fields, such as the prognosis of diseases, including host pathogenesis of infectious diseases. Most respondents (87%) noted that strengthening the relationship with the European Union at the scientific level was very important to increase efforts in PM, with less than half of respondents indicating that strengthening the relationship should be focused on a policy level.

3.6.2. South Africa: A Case of PM implementation in Africa

By Rizwana Mia, South African Medical Research Council, South Africa

Figure 11: *A Photo of Rizwana Mia presenting an example of African Country Implementing PM program*

The South African Medical Research Council in South Africa was described as a typical example of an institution that has institutionalized PM in the Country. An overview of its operations and programs was described as indicated below.

The South African Medical Research Council (SAMRC) is a public organization established through legislation (SAMRC Act No. 58 of 1991). The SAMRC is the largest local funder of health research in South Africa, with a total annual revenue in 2020/21 of ZAR 1.17 billion (€ 67,6 million). Its mission is to improve the nation's health and quality of life by conducting and funding relevant and responsive health research, development, innovation, and research translation. A key focus is the translation of research into new or improved policies, practices, processes, and products to ensure health impact.

In 2016, South Africa started focusing their funding on PM, as it had identified a quadruple disease burden, while its pilot genome program (The Southern African Human Genome Program) was closing off its 1st phase. The focus of the new program was Non-Communicable Diseases. The South African PM ecosystem consists of innovation and breakthrough technologies, health infrastructure, biobanks, big data, precise diagnosis, efficacious and safe drugs, applied and/or translational research education, and integration of data to knowledge or targeted interventions with its objective being better health outcomes for all. The Country's health innovation main focus are new treatment and prevention technologies, digital health and PM. The PM strategy involves strategic partnerships, pharmacogenomics, genomics and genome mapping, and digital health. Their funding is from the government and the Strategic Health Innovation Partnerships (SHIP). The total investment in PM /genomics since 2016 to date is ZAR 210 million (€12.3M) and is increasing.

The SAMRC-DSI Genomics Centre is equipped with the state-of-the-art equipment, with a workflow which starts with a nucleic acid sample, then automated library preparation, followed by sequencing, and finally automated megaBOLT data processing. Overall portfolio of SAMRC consists of projects that aim to develop products that will one day be used in their healthcare system. They are targeting Non-Communicable Diseases, infectious diseases and malaria. The partnership model has created great momentum for PM and Genomic Science in South Africa as they are able to synergize with all programs that support PM, such as ERA-PerMed and EU-Africa PerMed Project. This will go a long way in aiding them move further in understanding PM and benefitting from its usage.

3.7. Identifying and Prioritizing Personalized Medicine Needs in Africa – Group Discussions

Figure 11: *A Photo of Rizwana Mia moderating Group 1 discussions*

3.7.1 Group 1: Scientific and technological needs

The group discussed about the e*xistence of strategic plans, programmes, actions that support PM in their countries.*

In Mali, there was no national plan for PM, but there are emerging efforts by research groups both for research and training. There was a small national budget allocated for research and innovation activities, though it was reported that a need existed for basic sequencing facilities and servers for bioinformatic activities. In Angola, they were at very early stages of setting up sequencing services and structuring biobanks, though with very low funding. The country could greatly benefit from an African network to learn from peers. Sierra Leone has no national funding for R&I activities, and they have very limited human resource capacity for PM research. Similarly, the waves of support tend to die out as there is no sustained capacity. The Ebola outbreak spurred capacity and industry linkages which could assist in developing PM research activity in the country, but there was no sufficient local capacity to sustain it.

In Egypt, there was a promising genome project though at initial stages. It was mentioned that African Society for Genetics supports collaboration between African countries and highlighted the importance of collaboration with the EU in providing additional resources. Initiatives such as EDCTP could give the impulse for countries to have the missing resources and develop PM capacity. In Kenya, the major challenge was seen as the fact that there were different regulations and navigating through them is a challenge. The Government was yet to develop a policy or program on genomic testing in hospitals, and because of that, patients were reported to pay high costs as insurance schemes do not cover such costs.

In general, biobanking as one of the infrastructure essential in PM, was identified as a challenge and operating it with research grants gives limited sustainability and ownership. Its operation needs to be permanent with constant flow of funds probably from the government. Making a case to governments to fund such initiatives with evidence of the gains from PM would stimulate funding and support at policy level.

The group also discussed issues of data sharing and harmonization. It was agreed that it is necessary to have access to existing data. They also noted that ideally databases should get to a more granular level of the African population as sometimes one needs to zoom even into a community or ethnic group; e.g. African Genome Variation Database, and its beacon service (looking at a particular variant), and filtering service (finding frequencies). An example of African genomic medicine portal (https://agmp.h3abionet.org/) was given as one that gathers data from public databases trying to improve the curation of this existing data and making it a one-stop-shop that is better adapted and curated for Africa and open access to all. It was noted that there is a challenge of international data sharing, particularly in navigating through different regulation regimes.

The link between academia -industry through collaborations and partnerships are key in growth of PM in any country. In Egypt, there is ongoing academia – industry collaboration, which propels interest and results for pharmacogenomics. In Kenya, this collaboration needs to be strengthened as its still a new concept, as well as a focus on improving relationship between researchers/developers and clinicians. It was noted that the private sector is providing services to academia for research. Members agreed that there is need for coordination at country level to ensure regulation and strategies are enabled as opposed to regional level strategies as countries do vary in terms of their policies. At regional level, there should be a way to enable networks which could assist countries within regions and leverage on programs developed at country level.

3.7.2. Group 2: Scientific and Technological Application Fields

Figure 122: *A photo of Group 2 participants*

On governance, the group highlighted the following focal areas of collaboration: Sharing of knowledge and infrastructure for research; Exchange of practices and experiences of PM implementation in the health system e.g , professional networks of researchers / clinicians / decision-makers / private actors either by disease or by discipline; Common training and education activities (any focus, e.g. healthcare providers, patients, citizens, researchers); Collaborative research projects and implementation of joint research programmes (i.e. ERA-PerMed); Common policy development; Common funding activities; Technology developments; and Development of ethical frameworks and regulation. In summary, policy-level collaborations should be promoted (high-level policy dialogue, research ethics/bioethics frameworks, forums of discussion between regulatory agencies, adoption of common standards).

Participants agreed that collaborations could either be North- South, South-South or networking at the level of National programs. However, collaborations should first be pursued at regional level which is also compatible with the EDCTP model (networks of excellence), and that disease consortia could be envisaged at the same time (following example of pharmacogenomics) as well as improve the existing models that have new structures. On the **EU-Africa PerMed Project, members agreed that it would provide a mechanism for harmonized development of PM** so that PM approaches are broadly applicable and reflect global health priorities, interest of international cooperation in pandemics response, mutualization of knowledge and technologies. Further suggestions included a more sustainable collaboration that would bring more knowledge and data which will respond to the genomic diversity and multiplicity of research questions. This will put Africa in a leading position to identify unknown individual factors (genomic and others).

The group also discussed how Africa can build accessible databases and strengthen data infrastructures, as well as harmonize regulatory frameworks to enable a secured sharing of data between countries. **Harmonization of standards to facilitate PM development was seen as a necessity**, but also difficult taking into account the diversity in countries, and the current stakeholder landscape in Africa (researchers, clinicians, patients, decision-makers, biotechs, pharmaceutical industries, NGO etc). The group gave the following as issues that would require consideration in future: Strengthening EU Africa program; Governance possibly inspired by EDCTP model, regional

structuration for platforms / scientific hubs, stakeholder networking, capacity building in relation to PM; Continental consortia based on disease / topics; Sharing of data to be envisaged though guided by policy; and participants to be ambassadors of PM and promote collaborative science and sustainable partnerships.

3.7.3. Group 3: Operational Needs for Better Integrating PM into Healthcare and Clinical Practice

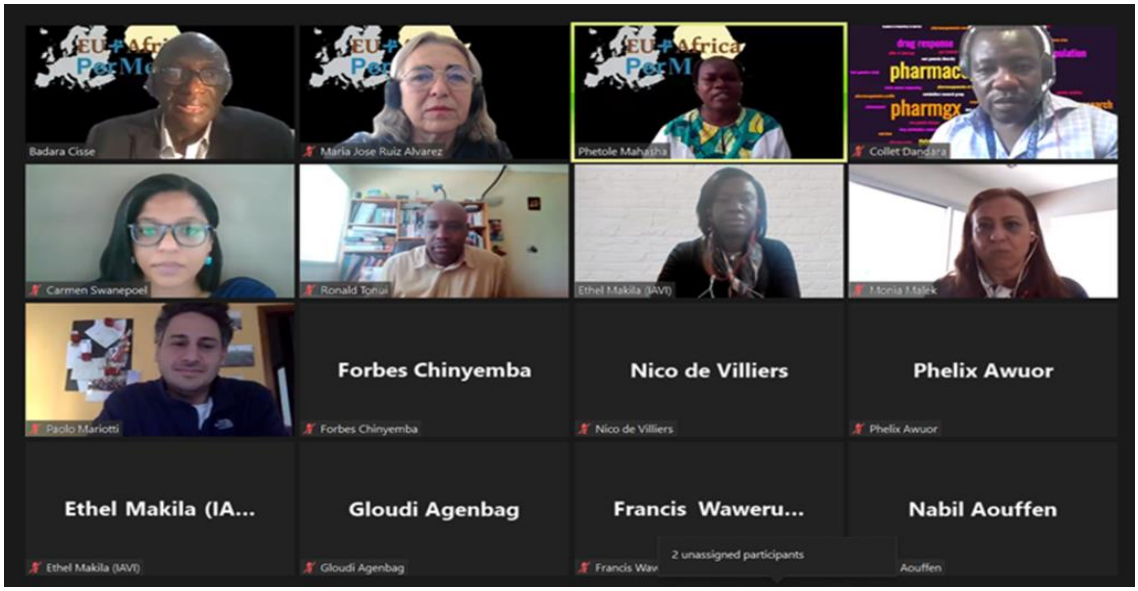


Figure 33: *A photo of Group 3 participants*

This group structured their discussion by having specific topics which participants were to contribute to. The first topic to be discussed was on access to infrastructure for genetic testing as well as centralized and sustainable databases that would serve as pool for genetic and healthcare data from hospitals. Participants agreed that these can be supported through collaborations in capacity building, genetic testing, electronic health record system and research in health economic. This would also ease the burden of access to affordable medical care. It was noted that there are difficulties in genetic testing as most testing is done by private entities or centralized labs like the case of South Africa. The consequence is that the results take so long to be analysed and there are also difficulties in accessing the results. Furthermore, the criteria for the selection of tests are not the same between private and public institutions. It is difficult to have testing facilities in individual centers. Hence, there is a need for collaboration among national research centers to enable access to genetic testing structures and receive results in appropriate time. Development of guidelines on genetic tests for different diseases to improve prevention, diagnosis, and treatment would be a great facilitator of the process. Establishment of biobanks and electronic data records was also seen as being as necessity.

The group also discussed mechanisms to promote access to novel drugs. It was noted that there is no uniformity of the cost of the generic drugs. To increase access to novel drugs, awareness and knowledge is needed in terms of occupational needs of the patients. It is necessary to have networks to support participation in clinical trials that can facilitate access to novel drugs. Regulation for the approval of new drugs is not standardized and sometimes these processes are prohibitive. Harmonization across regions would result in a high number of patients benefitting from drugs. This

may also address the issue of differences in access that are experienced between the private/public health systems. Harmonization should target health technology assessment following genetic and social/environmental /economic diversities.

Readiness of clinical trial sites to participate in developing prevention care PM strategies was also discussed. The group looked at the criteria for selecting clinical trial sites, whether studies should target "advanced", centralized, urban hospitals, or have a broader strategy integrating community centers from more remote areas (community medicine as well as hospital medicine). It was recommended that there should be broader representation in clinical trials, taking into consideration the social environment. The criteria for selecting clinical trials sites was seen as being dependant on the regional health system, genetic population diversity, and field of disease. However, it is based on expertise, ethics and quality internal procedures. Resources (human and economics) are needed for collaboration on networks and clinical studies. Improving the knowledge on technology transfer should be a priority as well as involvement of patients in all processes.

Advocacy for the adoption of new regulations, ethical procedures and collaboration with scientific experts should be carried out as well as strengthening the PM ecosystem and cultivate a mechanism to obtain continuous feedback among researchers, policy makers and society. Benefits need to be understood to be applied because the adoption in health care has an important economic cost implication. A dedicated budget for education and literacy of new technologies is really needed. There are different ways to induce the adoption of the PM approaches that can be implemented especially during the university's studies. This includes the curricula adaptation and a continuous training (workshops). The training must be responsive to changes in PM technologies, and it should be continuous. The target of training should focus on young professionals on health care and on research. Also, the general population needs to understand the concept of PM. There is need for continuous education (workshop, webinar) and training from different universities. Research in main diseases of focus to include cancer, malaria, TBC, HIV.

Participants agreed that transfer of research to the market can be achieved by involving industry in clinical studies. Implementation of PM at regional level and internal collaboration will increase market access. Support from the Ministry of Health (scientific and economic support) is necessary for better results.

3.7.4. Group 4: Governance/Regulatory/Ethics Needs to Make PM a Reality

The moderator of this group presented the pre-workshop survey results for the question "Which PM thematic area should be first focused on in your region/country?" The ethical, legal and social aspects were ranked as important. Other questions asked included the level of awareness and knowledge of PM, whether there was trust among citizens and patients and finally who the relevant stakeholders /bodies were in PM. The group provided inputs to each of the questions as described below.

Question 1: Are there in your view enough ethical, social, legal (regulatory) frameworks for genetic data (data ownership, privacy, security/protection, sharing)?

Members of the group agreed that the question of informed consent is often tricky as the benefits can influence informed consenting process/procedures. There are ethical and legal frameworks, but they should be strengthened, and that there is also a need to work on social frameworks. More importantly, there is a need to strengthen Institutional Review Boards (IRBs) in terms of skills and diversity, especially for reviewing protocols in genomics. National regulatory authorities for medicines, who are involved in approving products before they come to the market, should be integrated at the regional level.

Question 2: Which is the level of awareness and knowledge about PM according to your experience?

Most participants acknowledged that **there is very low awareness in most African countries**, even for policy-makers (except maybe in Egypt, Tunisia, South Africa). An example was given of nuclear medicine, which has been grappling with the problem of public perception for decades. There is a continuous effort for awareness creation, for example with the science week in South Africa, during which the center receives thousands of students to help demystify nuclear medicine. Therefore, it is important that scientists and institutions rather than government officials be trusted by the public.

Some of the reasons given for lack of awareness, included the confinement of PM to research organizations for a long time, and some policy-makers are not familiar with term. There should be a bridge between what the research community is doing and how it can benefit patients. There is need to identify key institutions in each country to ensure that PM is integrated into healthcare systems and make sure there is a wide awareness among policy makers. An example was given from Tunisia, where there has been research in human genetics for several years, hospitals doing genetic testing, and laboratories working on human genetics and yet, most policy makers are not conversant with the terminology. Many initiatives exist but there is a need for a vision at the top to integrate all values and for more funding, but scientists haven't yet succeeded to get politicians interested in the field of PM.

Question 3: Do you think there is trust among citizens and patients?

Members expressed their opinions and come into an agreement that many African countries suffer from mistrust because for a long-time sample have been taken to other countries and didn't result in capacity building, and that there is suspicion even amongst themselves. There is a need for awareness creation that should be done, to enhance trust in Africa. There are large scale PM initiatives, biobanking, databases, publications but more effort is required to communicate on the importance and benefits of these initiatives, for example by putting databases into the public domain.

Question 4: Who/what would be the relevant stakeholders/bodies in this area?

Participants acknowledged managers of biobanks are important stakeholders. A good example is the biobank in South African. Most of the donors may not be well-educated and may be coming from villages where they don't know what DNA is and what it can be used for. However, IRB acting on behalf, knowledge and make decisions that protect patients/research participants. Another important class of stakeholders is governments/policy-makers who should also be involved to protect DNA, ownership and privacy. It is very important to engage all the stakeholders who include the community as well as governments and policy-makers in making decisions regarding PM.

3.7.5. Group 5: What is/are the Need/s to Improve Healthcare

Africa needs to undertake a situational analysis to identify problems and package priorities. Participants preferred that each country identify its issues and develop strategies, however, policy frameworks needed to be at the regional level. This way, they could leverage on the developed programs which can be implemented by task forces.

Regarding platforms/infrastructures, biobank, biobanking surveillance systems and sequencing platforms, they were found to be very important but require a lot of investment, hence always compete with basic instalments. There is need to review diagnostics tools, e.g. use mammography instead of ultrasounds for better results. There is a need to build capacity in diagnostics and genomics. A platform for sharing data and initiatives on genomics need to be developed and strengthened.

Data was mentioned as being an important factor in PM yet it is limited in Africa for informed decision making. There is need to generate evidence in terms of data. Individual data may be available but intra follow-ups in biobanks vs inter-follow-ups for linkages is required. Lack of data in most diseases is even more glaring such as mental health. **Training is an important factor since human capacity is limited, especially in physicians.**

Healthcare managers, service providers, patients/clients' and policy makers need to be sensitized on available platforms for genomics, and how embracing PM can transform healthcare. This will inform effective policy formulation and regulation. Health investments should be maximized through medical insurances and diseases with most burden – such as Non - Communicable Diseases should be considered, and PM should be part of initiatives such as one health and Universal Health Coverage.

Regarding efficiency in management of healthcare, countries need to understand the cost of PM to enable them plan and set-up measures to apply it, as it is not necessarily more expensive. Affordable innovations have a huge potential for PM and traditional medicine is the best example of PM, as COVID-19 had shown, and Europe needed to learn from it, and apply new tools to traditional medicine. Countries also need to understand how the existing resources are utilized, such as expertise, equipment, and overall infrastructure to avoid mismanagement.

3.8. Potential advantages of collaboration in the field of PM between Africa and Europe: *Impulse talks, Round Table and Open Exchange Between All Participants.*

3.8.1. Lessons Learnt – How to Create Collaboration (Africa/Europe)

By *Prof. Moses Bockarie, Director of International Cooperation (Africa) and Head of Africa Office, European* & Developing Countries Clinical *Trials*

To achieve universal health coverage, there is need to integrate and coordinate research, capacity development and implementation efforts through collaborations. Researchers and policy-makers in Africa should engage in south-north collaborations and cross-sector networking to identify creative solutions to complex problems. The presenter used the EDCTP model as a perfect example of networks that have worked. EDCTP established several networks: Institutional networks, PHE networks for outbreak response, Ethics and Regulatory networks and Researcher's network. There were 26 African Countries and 9 European Countries who participated in EDCTP2 Regional Networks of Excellence. ALERRT and PANDORA-ID-NET are two multidisciplinary consortia which were established with the aim of providing accelerated evidence for the optimal clinical management of patients, and for guiding the public health response to severe infectious outbreaks. 18 African Countries and 6 European Countries are part of these consortia.

EDCTP uses a strategy for capacity development which focuses on strengthening product-focused health systems research, comprehensive fellowship programmes, regional networks of excellence, strengthening ethics capacity and regulatory framework, and site preparation for conducting clinical research. Towards collaboration and capacity development, EDCTP has supported projects involving 24 sub-Saharan African countries, accounting for 59% of its total funding. EDCTP2 has immense support for capacity building in Sub-Saharan African countries in various ways: research facilities, PhD students, researchers and support staff, regulatory and ethics review capacity building and participating in Networks of Excellence. It also has an Alumni Network which fosters excellence and collaboration among researchers.

3.8.2. Personalized Medicine Research, Infrastructure /Platforms

By Prof. Yazdan Yazdanpanah, National Agency for Research for AIDS and Viral Hepatitis and the 13M Thematic Institute

The presenter explained that PM research can take the form of basic science, clinical science or translational research, making it a continuum. It's important to understand PM as a continuum, that could start from genetic molecule and cellular mechanisms of diseases and drugs, prognostic factors of diseases, identification of biomarkers for the disease, targets identification and validation drug repurposing. It then needs to be translated to the society particularly, the patients in case of new drugs, diagnosis, pre-clinical validation, clinical trial and then stratify the response. To meet all these needs, one would require infrastructure and platforms, libraries, 'omic technologies, high throughput screening, data capture, storage and processing tools, supercomputers, but also bio banks, cohorts, preclinical and clinical trials infrastructures including clinical research platforms.

Given this wide scope of PM, there is no doubt on the existing number of challenges. One of the challenges is advanced and expensive technologies, such as omics NGS imaging and big data infrastructures for pulling various data sources and ensuring data quality for research on PM. One factor in the PM continuum is the interaction between the public and private sector. France has been looking at developing these infrastructures and these platforms for PM with a goal of developing PM in the country and integrating genetic analysis into healthcare practice. The country is also working on interactions between research and clinical practice to try to create this genomic infrastructure. The best approach however is to build on existing structures such as hospitals, national system for health data, regulatory framework, and ethics, which is extremely important. France is also working on genetics of microorganisms, the diagnostic techniques using sequencing, to understand genetic mechanisms of diseases, the genetic and molecular mechanism of drug resistance and understand individual response to pathogens. France is trying to do all this through leadership by IRS on emerging infectious diseases, which is a new agency with a funding and coordination function on infectious diseases such as HIV and AIDS, STI and TB.

3.8.3. Patient View – How to Engage the Patients and Society

(By Angela Nguku, Deputy Chief Executive Officer, White Ribbon Alliance Global)

The presenter noted that, whatever we do in practice, in research, in delivery of care, or programming, we need to involve patients. It is important that we ensure optimal engagement of patients and societies in general. In the design, delivery and evaluation of products and services, whether in health or in other sectors even in the business sector, we need to ensure that we engage clients. We know that in health, and especially in service delivery, if we involve patients by educating them and in policy formulation, we will enhance service delivery, uptake and governance. What patients have to say about the health system is a valuable source of information for planning and improvement. Providers of high-quality care, also listen to their patients, what they hear helps them diagnose and determine the best treatment approach. In research, the voices of people can inform measurement. Patient reported outcomes are increasingly important to measure the quality of care.

"Why are we not putting the patients or the clients at the center of our work?" the presenter asked. She explained that the simple reason could be that many assume these as passive consumers with no voice or valuable contribution, the truth of the matter is, these are the real experts, who hold the key to our work through their own lens and voices. Their contribution could see improved uptake of what we work so hard to bring forth through research, policy, and programs. The presenter brought to the

attention of the participants about the White Ribbon Alliance Campaign: A global advocacy movement, that was founded in 1999, and whose mission is to propel a people-led movement for reproductive rights. It was formed out of the realization that too often the voices of women in countries with poor maternal health outcomes were being unheard, resulting in slow and inequitable progress.

Two key things that a lot of health experts, researchers, policy makers, academicians never think about when they talk about services, and products is patients' respect and dignity, value of their role and involvement. Patient engagement relies on the three building blocks: patient or client literacy and data, communication by the health care provider, and satisfaction beyond the service. The Lancet Global Health Commission on health quality health systems in the Sustainable Development Report says, "The health system should measure and report what matters most to people, such as competent care, user experience, health outcomes and confidence in the system."

3.8.4. Medicine in sub-Saharan Africa: a stepwise approach

By Prof. Abdoulaye Djimdé, Pathogens Genomic Diversity Network Africa

He defined PM as 'a medical model using characterization of individuals' phenotypes and genotypes (e.g. molecular profiling, medical imaging, lifestyle data) for tailoring the right therapeutic strategy for the right person at the right time. He indicated that in sub-Saharan Africa, there is need to start with 'precision Public Health' instead. He gave an example of genetic diversity in *Plasmodium falciparum* in sub-Saharan Africa. 2263 *P. falciparum* genomes have been identified from 15 countries in East, West and Central Africa. These results were obtained through complex analyses.

For PM, the following will be required: Creating scientific ecosystem capable of generating the required data; Training specialized scientists to translate that data into knowledge, and engaging with policy makers, hospitals, patient groups and communities for optimum impact.

3.8.5. Harmonizing Personalized Medicine Research methodologies through Collaboration

By Paula Garcia, European Clinical Research Infrastructure Network

The presenter gave a brief of the PERMIT project, which is part of the ICPerMed family of projects, just like the EU-Africa PerMed project. This project is funded by European Commission through the horizon 2020 program, it's a two-and-a-half-year project which started in January 2020 and is scheduled to end in June 2022. Its focus is harmonizing PM Research methodologies through collaboration by establishing recommendations.

One important aspect of the PERMIT project is that it has managed to bring together all of the key stakeholders of the PM Research ecosystem, research institutions and infrastructures, funders, national and regional regulators, ethics committees, Health Technology Assessments agencies, scientific journals and publishers, industry, patient representatives and numerous field experts. The objective of the PERMIT project is to contribute to ensuring scientific excellence, validity, robustness, reproducibility, and acceptability of results by all key stakeholders as well as to identify standards, develop and disseminate recommendations on PM research. This is done with the aim of responding to existing challenges in the design, assessment, selection, publication and evaluation of PM research.

The PM Research pipeline can be lineal or circular and can includes High-throughput –omics / imaging data, cohort integration, multimodal data management, stratification algorithms, Preclinical models

and complex trials. Many times, the pipeline starts with generation of data, which requires working with cohorts to identify clusters of patients that have similar characteristics. This often requires working with preclinical models, to reproduce the clusters and to identify potential treatments or diagnostic tools or solutions that can better target the patient clusters. The final stage is clinical trials and testing these therapeutic solutions and seeing if they are really a benefit for the patient clusters. Having harmonized practices and standardized approaches is key in ensuring quality, reproducibility and the robustness of the research being done. Personalized medicine is an area that is picking up very fast hence the need for harmonizing and standardizing the practices with the utmost goal of upholding patient safety.

A case in point of harmonized practices is in COVID-19 pandemic, which highlights need for results that are comparable, and which can be subject to a meta-analysis for giving policy direction. Having standards contributes to generalizable results which implies a smoother mutual recognition of results, and faster adoption of these results into clinical care and practice. The broad nature of PM underpins the need for global collaborations, and international PM is a field that depends a lot on teams coming together from multiple backgrounds, multiple disciplines, but also from multiple countries as demonstrated by the PERMIT project.

The PERMIT project has a consortium a broad representation including organizations from eight different countries, and mainly organizations that are international in their composition. One challenge that the project has experienced is the different regulatory landscape, because different regulations apply in different countries and navigating them when we're carrying out these large, personalised medicine research programs across different countries, is still an important challenge.

As a way forward for PM, it would be important to strengthen cross-border collaboration, harmonize practices and expectations along the entire research pipeline as well as regulatory harmonization through mutual recognition and listening to different expectations of the different stakeholders and keeping a dynamic dialogue.

3.8.6. Lessons from COVID-19 & Infectious Diseases: Potential of Personalised Medicine

By Prof. Salim Abdool Karim, Director, Centre for the AIDS Programme of Research in South Africa

The presenter reported that South Africa had been able to collect sufficient data regarding new cases, admissions and in-hospital COVID-19 deaths. With this data, they understood how the epidemic was evolving, hence they could confidently plan for a response. The public health approach for precision medicine, is for a country to understand their epidemic using data, then they would be able to plan for the response. Using this approach, South Africa, was able to identify HIV and SARS-CoV-2 Hotspots and develop mitigation measures.

The COVID-19 Prevention Toolbox with precise public health tools for each setting, came in handy in dealing with the epidemic. These measures included fresh air ventilation and avoidance of indoor gatherings, masks and cough etiquette, hand hygiene practices, symptom screening and work from home, lockdown (extreme form of social distancing), appropriate use of Personal Protective Equipment, testing, isolation, quarantine and contact tracing, social distancing and vaccines. For the Omicron variant, though it had very many cases compared to beta and delta variants, the proportion of those admitted, severe cases, those on oxygen and those who died, was significantly lower than the other two variants. Similarly, from Centre for Disease Control report, the risk of death for individuals, is significantly reduced when one is vaccinated compared to the unvaccinated and reduced still further when one gets a booster. There is an urgent need to individualize care for immuno-compromised individuals to reduce risk of variants, hence the need for PM. To stress further the need for collaboration, South Africa was able to receive 1st vaccine in 9 months due to collaborations. There is still need for stronger EU-Africa PM collaborations to help slow the Covid-19 deaths.

3.8.7. Collaboration in South Africa that Led the World on the Discovery and Characterisation of SARS-CoV-2 Variant

By Prof. Tulio de Oliveira, Director of The KwaZulu-Natal Research and Sequencing Platform, at the University of KwaZulu-Natal

There is a network of Pan African consortium in South Africa, which assist the country in reacting fast to epidemics and pandemics. The Network for Genomic Surveillance in South Africa (NGS-SA) is composed of seven institutions, including universities and research institutions. It is supported by the DSI and the SAMRC. It has assisted the country in getting major breakthroughs for the SARS-CoV-2 where 25 high impact publications were made in 2021-2022.

The speaker reported that there has also been great investment in scientific infrastructure built over a decade and recently expanded. This can accelerate SARS-CoV-2 Sequencing in Africa. There is good coordination between the: SGBC -Specialized Genomics and Bioinformatic centers, Regional COVID-19 Sequencing laboratories, and the National COVID-19 Sequencing laboratories. There exists a Genomics facility at CERI/KRISP/SAMRC to support PM in Africa. The facility can produce 200-500 Whole Human Genomes a week and negotiated prices like USA, U.K. and European large facilities. They are now setting up WGS sequencing for pediatrics case at ICU with potential for rare diseases – aiming at 24h turn-around time. They have Whole Human Exomes, RNAseq, Pathogen PM for guiding therapies for HIV, HCV, TB and vaccines for SARS-CoV-2, Human Papilloma Virus, and the CERI/CRISP [an specialized genomics facility of the Africa CDC and WHO, already supporting 21 African countries (MTAs signed, weekly/monthly transfer of samples for genomics).

3.9. Round Table with Speakers and Open Discussion Between Participants

Figure 44: *A Photo of the panelist and moderator of the session*

First low from left to right: Prof. Salim Abdool Karim, Prof. Moses Bockarie. Paula Garcia, Prof. Abdoulaye Djimde. Second row left to right: Prof. Tulio de Oliveira, Prof. Yazdan Yazdanpanah, Prof. Patrice Debre (session moderator)

The impulse talks resulted into a round table discussion whereby the presenters formed the panel for the open discussion. They included Prof. Salim Abdool Karim, Prof. Moses Bockarie, Paula Garcia, Prof. Abdoulaye Djimdé, Prof. Tulio de Oliveira, Prof. Yazdan Yazdanpanah , Angela Nguku and Prof. Patrice Debre as the moderator.

The discussion commenced with leading questions in specific areas and participants responded/contributed accordingly as indicated below.

1. How do you see a collaborative and sharing strategy regarding EU-Africa collaborations?

Members identified different platform for collaborations, some of which were in place in South Africa. These included EU-Africa collaborations. These arrangements have proved to yield good outcomes with resultant high capacities in strong institutions within South Africa. The same applies to Nigeria and Mali. In West Africa, the resources are scarce and therefore there is no impetus. Participants expressed the need to strengthen South-South collaborations which is one of the outcomes that EDCTP is trying to push. Previously, there has been many collaborations which perpetuated a colonial kind of relationship. That has been changing overtime, what is being demanded now, are North - South collaborations, where there is mutual respect, where people work as partners, and all can contribute valuably. Participants were informed that EDCTP is promoting such a collaboration. There is also need for African networks between African countries in these partnerships, especially in areas of genomic surveillance and clinical trials.

2. What can you say regarding partnerships and platforms?

Participants acknowledged that Africa has diverse pathogens and most diverse human genome in the world and is ready for a genome revolution. Pulling resources together and treating all partners equal is key in giving access to facilities and capabilities. This is likely to allow large discounts that will avail funds for constantly training people in their respective labs. The infrastructure for PM is expensive, so working together and sharing expertise may lower cost. Therefore, countries need to engage, not only Europe but with African Countries, in pathogen research, PM and high genome research. A good example is South Africa which has well established national partnerships. One of the limitations for most African Countries is luck of funding from their governments. Most of them work as individuals

making them more vulnerable to having not enough funds. EDCTP has a good model of funding for its networks and should be emulated. More collaborations such as North-South, South-south and North-North should be encouraged.

3. How do you analyse the gaps that exist in the networks of national programs?

Participants noted that there are different ways of analysing gaps especially depending on the need. It could be either regulation gaps or technical gaps. This may also be influenced by the stakeholder' perspective. Considering that these gaps are everywhere, members discussed on how they can be closed and what they think about a regional hub. They recognized knowledge hubs concept at a regional level as a good approach. It's the best attempt to optimize the scarce resources as there are similar challenges. They are more efficient. An example is Glopidor, a consortium of funders, who find coordination being better at the regional level. However, it has not worked well at either the international level or at the national level. Regional level makes a good compromise. It is an efficient way to go forward and could push PM forward. EDCTP is showing a good example. It is a good model, it could be pushed forward to be even more efficient, to include funding, building of infrastructures, platforms. This is a real strategy, which has been supported by Glopidor as an efficient way of moving forward. It was hoped that EDCTP will get a bigger scope and more funding moving forward. Other platforms include the 3 levels of pathogen genomic initiatives, National, Regional and specialized centers. The 3 levels have proved to work well for COVID-19 and could work for PM. These specialized facilities could provide genomic surveillance and sequencing at no cost. This could give more access to different projects

4. What do you think is the output of the EU-Africa Program?

The discussion proceeded by allowing members to give their views on what they think the output of the EU-Africa program will be. The respondents agreed that all collaborations in general, help many to do things beyond their individual capability (ideas, strength). Collaborations bring more energy and diversity. For example, can study a range of diseases, which we would not be able to learn in one or two settings. It brings the opportunity to be part of the solution to the underdevelopment in Africa, and in a way that brings sustainability. There was general agreement that all of us operate in vertical silos. The African and the Europeans, have specific diseases they deal with, e.g. cancer, metabolic disorders etc. The program is more transversal and more will be learn from each other. It has a component of learning geographical wise and in the different diseases.

5. How can the EDCTP model of collaboration be implemented?

Participants supported the EDCTP model of partnership. Instead of starting from scratch, they agreed that it will be wise to replicate the EDCTP experience in other regions. For example, it will be better to consider the huge efforts made by the Institute Pasteur Network that are mainly based in North and West Africa, such as Senegal, Morocco and Tunisia (French speaking countries), by enhancing the existing resources, and making them as reference hubs of PM in these African regions. While it is good to learn from existing models, example Pasteur network, it may be hard to force collaborations/networks, as they may proof difficult to work. Participants concluded that the best way sometimes is to let those individuals that can work together to initiate the collaboration from the bottom up, instead of top-down approach. The 9 regional facilities in Senegal & Morocco for Pasteur Africa-CDC-Afro have been used for a lot of collaborations. A good example of Africa working with Europe is the case of Omicron where South Africa detected it early and this greatly assisted Europe to

prepare. Europe was willing to support them. It has been very easy to collaborate with European countries as they are at the same time-zone. The case of omicron will change the landscape of future collaborations. The north now can see that the South can provide something for them to learn from. Future partnerships will now be either as equal partners or the South partners will be stronger.

Participants unanimously agreed that they must think on how Europe and Africa can work together to benefit both continents regarding PM. Europe has worked on PM for more than 15 years, and Africa needs, to pick the strengths and avoid the mistakes. The two continents can learn from each other. Instead of going into new initiatives or duplicating, there is need to make use of what we already have, as the resources are scarce. A participant noted that North Africa is excluded from several initiatives apart from the EDCTP. African countries working together, will avoid any gaps in PM due to others being left out. Let Africa work as one with all partners. However, participants recognized that, although EDCTP is a good model, it has some limitations since it covers only sub-Saharan Africa, leaving out North Africa. There is need to push to have the whole of Africa included. Similarly, the voice of the patients and the communities, cannot be ignored, and this has been shown in HIV studies.

6. ***How do we deal with the issue of data, considering the diversity and the different regulations? How to build accessible databases, share data, regulatory frameworks?***

Participants acknowledged that there are policies and regulations regarding data which has helped researchers to own their data, but at the same time, these frameworks make it difficult to share data. There is need for open and sustained dialogue and the researchers should be present at the table to give their side of the story. There is need to create a lot of data, before we focus on data flow. They recognized that more data is needed in the human genome and PM. When dealing with infectious diseases, working with ethical boards and use of MTAs are very crucial. Therefore, there is need of data security agreements. There is need to build programmes and projects that can increase the data pool. Other continents have been sequencing their populations for so long and can now offer PM solutions for their populations. There was a general feeling that Africa need to focus on getting funding to create a reference genome.

7. ***This project wants to analyze and come up with recommendations regarding PM. How do we go about the issue of policy formulation regarding PM? What are your recommendations? Should it be high level, at research level or with regulatory agencies****?*

Participants recognized that Personalized Medicine is relatively new in Africa. PM is a luxury to be accessible to all, though we should move towards PM. Africans should start to work on solutions of the problems of tomorrow. Need to consider, the political, regulator and ethical landscape. Participants contributed to the above question by providing a wide range of answers as highlighted below.

- Africa has a great potential not only in terms of genetic data but also in terms of expertise. The first step in forming collaborations is by Africans for Africans and then disseminate and on this basis launch partnership with other countries outside Africa. Actually, Africa is facing lack in almost all components of PM, but this lack is mainly due to a mis-deployment of resources and lack of policies.
- There is a difference between "Precision Population Health“and Precision Public Health“. Public Health is a task - what problems do we have in the health systems and how to solve them? Are we doing the right things (evidence-based) in the right way (quality management)?

And the task Public Health has three target groups: the population as a whole, stratified populations and individuals. And all are needed very often to be implemented in parallel. Thus, in a nutshell, public health is a task, and population health is one of the target groups.

- Policy level should create level playing fields to bring together researchers and professional from everywhere; brokering session are very useful.
- The price for CRISP is for whole human genomes, exomes, RNAseq and pathogen genomes (bacteria for antimicrobial resistance and viruses). Its aim is to run the sequencers 100% full. Running sequencers at high percentage reduce prices quite a lot as one buy in bulk and infrastructure is optimised. The genomic data generation will be open to all African countries.
- Precision médicine is a multidisciplinary domain and applicable on infectious diseases, cancer genetic diseases so we need specific consortiums to share data but also knowledge and technical platforms

3.10. Wrap Up and Outlook for Future Stakeholder Involvement

By Erika Sela, Innovatec Spain, Monika Frenzel, Agence Nationale De La Recherche France and Rizwana Mia, South African Medical Research Council, South Africa

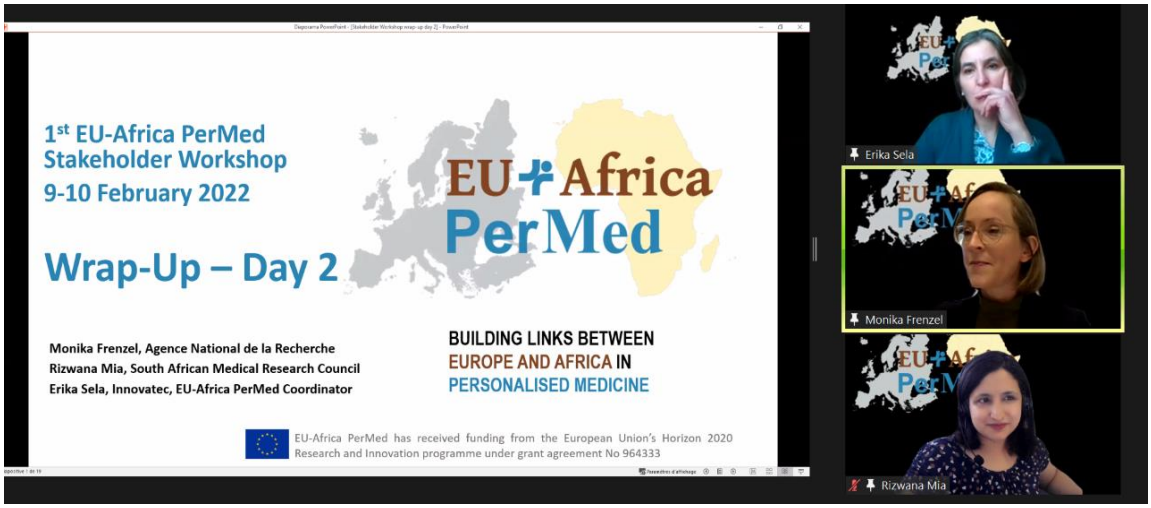


Figure 155: *A Photo of Erika Sela, Monika Frenzel and Rizwana Mia presenting a final wrap up*

The final session of the workshop served to wrap up main messages (M. Frenkel), present future actions planned by the project on stakeholder engagement (R. Mia) and close the meeting with some final words from the coordinators (E. Sela).

Some important messages that came from the workshop discussions that are relevant for the development of PM in Africa are:

1. It is important to appreciate that **Africa is diverse, and different countries are at different stages in PM implementation,** and that countries can learn from each other based on the levels of maturity in terms of PM implementation.
2. **Regional collaborations are the most preferred mode of building PM in Africa**, especially in setting the agenda, but country level would be good for implementation and allocating resources for the PM infrastructure as well as actioning priorities.
3. **Building/strengthening regulatory frameworks and developing regional strategies** for purposes of enhancing collaborations within and between regions.
4. **Setting up the infrastructure**, whether for data or clinical practice to benefit from PM.

5. **Policy makers also need to be sensitized on benefits of PM**, particularly from the point of health economics, for easy development and adoption of PM policies.

After giving a brief of the presentations made in the two days, a poll question was launched, to find out if participants understanding on PM improved during the workshop. The results of this poll showed an overwhelming majority (78%) indicating that they better understood the concept of PM. 16% percent of the stakeholders who responded to the poll indicated that maybe they understood the concept, while 6% actually said no, which means that there is need to continue closely engaging with stakeholders for better understanding of PM.

The objectives of the EU-Africa PerMed project were once again highlighted, stressing the need to continue with active engagement of the stakeholders and proposed to carry out interviews at country and regional level, hold workshops tentatively in June/July 2022, 2023 and 2024. Training activities were also lined up, surveys and discussions through platforms such as linkedin (https://www.linkedin.com/groups/14014720/) and twitter. The EU-Africa PerMed Project is also open to invitations to engage further with scientific communities either at country, regional or continental levels.

The project also had lined up upcoming training events. These are:

1. 1st EU-Africa PerMed Webinar 2nd week May 2022 on PM approaches in Oncology
2. 1st EU-Africa PerMed Summer School End 2022 on Adoption and integration of standards in PM research
3. Report on training and curriculum initiatives PM in Africa on identification of existing PM training and curriculum development. The report would be on existing and future PM training and curricular and stakeholders were requested to share their national/regional initiatives with the project for inclusion into the report.

A second poll question was launched that sought to find out if participants were willing to be engaged for future EU-Africa PerMed events which included meeting EU-Africa PerMed in interviews, training events, newsletters and participating in the surveys. Participants unanimously affirmed their willingness to be engaged by the project in future planned activities. Following this, the participants were invited to register and participate in the AERAP side event at the EU-AU summit on 17th February 2022, where the organizers had dedicated a 2-hour session to PM and was hosted by the EU-Africa PerMed project.

Since the project has the final objective of strengthening in R&I in the field of PM between Africa and Europe, the project would be counting on the participation of stakeholders in its different activities that are lined up. Since there was now a common understanding of PM as shown in the workshop, the project would collect areas of mutual interest between Europe and Africa in the area of PM, seek to further understand African needs, and contribute to actions and networks that can continue even after close of the project. All this would be done in an environment of respect and mutual trust, with a view of learning from each other.

In conclusion, the project coordinator gave a vote of thanks and appreciated all the participants, speakers, NACOSTI which hosted the meeting, Consortium partners and the European Commission for funding the project, and always being available to support activities of the project.

The workshop was officially closed by the Director General of the NACOSTI.

Figure 16: *A Picture of a slide showing social media accounts of the project for more information*

4.0 CONCLUSIONS

The workshop was organized to meet a set of objectives which included discussing the perception of PM in Africa, the main challenges and opportunities of PM in Africa, and the potential advantages of a closer collaboration with Europe, integrating local knowledge and practice. It was also an opportunity to disseminate the International Consortium of Personalized Medicine (ICPerMed) activities.

A poll carried out during the workshop demonstrated a great improvement on the understanding of PM for the participants. There was general appreciation among participants that PM can help address the challenges of high burden of diseases and the resulting pressure on healthcare systems, is cost effective in terms of prevention, healthcare outcomes and use of resources, and that it relies on different metrics in population diversity to interpret and validate health data, and therefore improve the understanding of diseases, a case so well demonstrated through the COVID 19 pandemic.

The European Commission (funder of the EU-Africa PerMed project) participated in the workshop highlighting the importance of international collaboration to overcome global health challenges and mentioning that PM is seen as a priority area for long term collaboration between Europe and Africa. This can be an opportunity for African countries to advance in in the development of PM and participating in the global research agenda.

The genetic diversity of African populations, particularly because of the historical background, can greatly contribute to enhancing the global knowledge thereby enhancing the development of broadly applicable PM approaches and efficacious drugs and vaccines among other developments. There is great potential of PM approaches in Africa, but there are underlying deficiencies and challenges that would need to be overcome for PM to become a reality. There is generally a low level of awareness of PM particularly among policy makers including low political goodwill. This could be attributed to the fact that the concept is still new and not well understood. There is also a low level of adoption and implementation of PM across the healthcare continuum, limited data from African populations that is necessary for informed decision making. Further, PM is a model that requires technologies and infrastructure which requires heavy investment hence not available in most African regions. Apart from skills gap for research and implementation of PM, funding of PM initiatives was also identified as a gap that needs to be focused on. The legal and regulatory framework requires strengthening and harmonization across the different regions in order to support PM initiatives.

Even with these challenges, there are great opportunities for PM in Africa. First, there exists an institutional framework, especially at continental and regional level, that would play a great role in facilitating PM adoption in the Africa. Continentally, the World Health Organization and the AUDA-NEPAD stand out as leading in promoting health agenda for Africa. The AUDA NEPAD for example led efforts in developing a framework for Implementation of Genomic Medicine for Public Health in Africa, a key document that will guide PM adoption and implementation in Africa. Regionally, there are bodies such as WAHO and EAHRC in Western and East Africa respectively that would equally lead in efforts in promoting PM in their regions. In fact, the workshop proposed use of a regional focus in promoting PM in Africa. Additionally, there exists regional Centres of Excellence in genomics in certain African regions, that could be used for training human capital as well as in generation of the much-needed data.

No Country can achieve the benefits of PM without collaborating with other countries or regions. Achieving benefits brought about by application of PM would require collaboration in capacity building, genetic testing, health electronic record system, health economic research among others. Cross country collaboration would facilitate important advancement of PM in Africa. Participants

agreed on the need to strengthen intercountry and regional collaborations on PM. Strengthening the relationship with the EU at the scientific and policy level was identified as very important to increase efforts in PM.

5.0. RECOMMENDATIONS AND WAY FORWARD

1. At the level of Policy, adopting a multipronged PM approach can be seen as a way to advance PM in Africa, with regional and continental efforts guiding in agenda setting, while countries are left to set priorities, implementation and allocation of resources for PM. In this regard, Regional economic and health communities in Africa can play an important role. WHO-Africa can also play an important role, linking PM with Global health issues.

2. It is important to also consider that African countries are at different level of development of PM research and implementation capacity, and that there is not a one- way approach for all. Cross country collaboration through regional networks is this seen as a useful way for more advanced countries to support those at a lower level of development. Strengthen, as well as harmonize the ethical and regulatory aspects, at least at regional level, as well as harmonize practices and expectations along the entire PM pipeline, can also facilitate the collaboration. Sharing infrastructures can also be part of the intra-regional collaboration to advance PM.

3. There is need for advocacy for PM focused funding support for training and infrastructure development. There should also be a focus on funding activities that facilitate the implementation of research into clinical practice, so that the result of all the efforts trickles down to patient centred care.

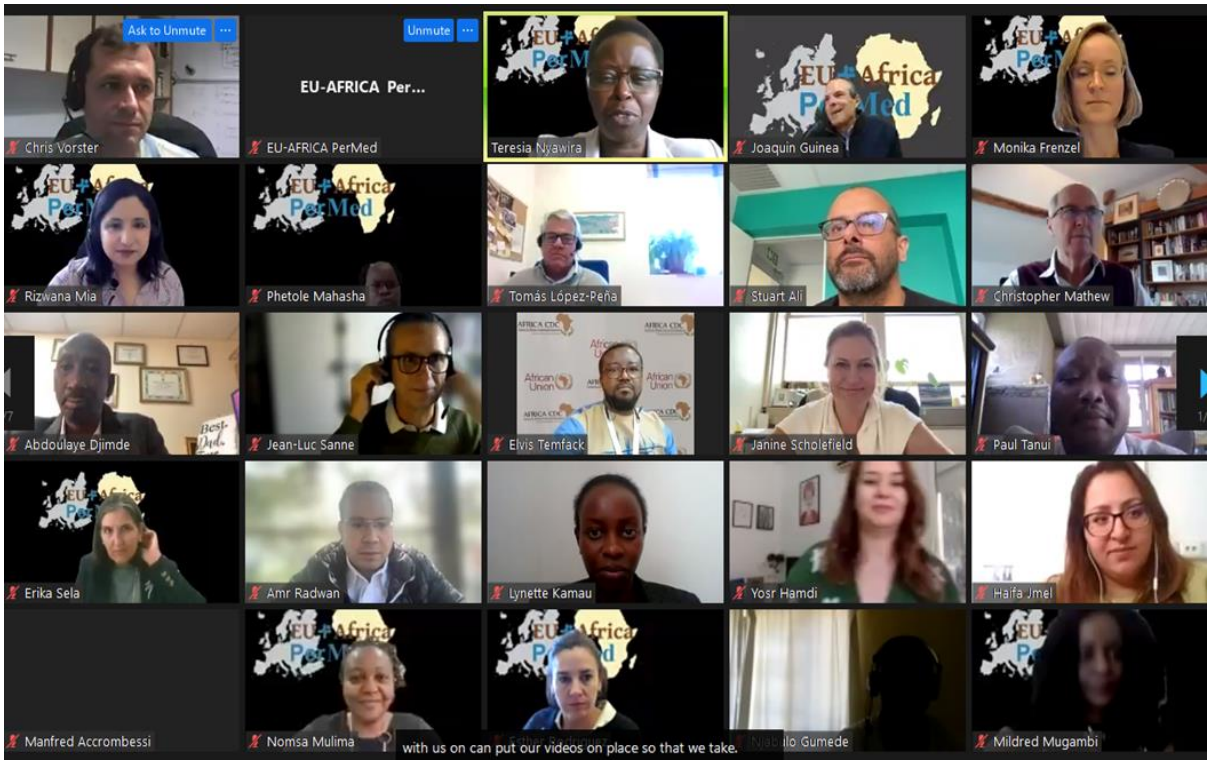
4. Capacity building was identified as one of the priorities in PM. Training and education of healthcare practitioners needs to be continuous as technology changes.

5. Important for PM development are Infrastructures focused on 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, facilities for clinical action and clinical trials.

6. Creating awareness and communicating the value of PM to the society as well as engaging and empowering the community, particularly, patients is also seen as very important. Sharing of good practices and communicating real examples of PM applications that are already improving the health of the population can be a good way of gaining political will to advance PM at country level.

7. As COVID 19 pandemic has shown, international collaboration in health research is the only way to be able to tackle global health issues and to achieve the SDG 3 to ensure healthy lives and promote the well-being for all at all ages. PM is seen a way to reduce global health inequities and all regions should collaborate and benefit from this new PM tools. Channel efforts towards characterizing African Genome, in order to bring to light the genetic diversity of the African population and foster genomics of infectious diseases, are important assets with which the African countries can contribute to the global PM research agenda.

8. EU-Africa PerMed will work towards strengthening the collaboration in PM between Africa and Europe considering the regional/national differences across African countries that have been highlighted in the workshop, focusing on real African needs and demands that will be identified together with African stakeholders, and contribute towards advancing in the development of PM in Africa and its integration in the global PM agenda.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Chris Vorster
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Teresia Nyawira
Joaquin Guinea
Monika Frenzel
Rizwana Mia
Phetole Mahasha
Tomás López-Peña
Stuart Ali
Christopher Mathew
Abdoulaye Djimde
Jean-Luc Sanne
Elvis Temfack
Janine Scholefield
Paul Tanui
Erika Sela
Amr Radwan
Lynette Kamau
Yosr Hamdi
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Manfred Accrombessi
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Ask to Unmute
Maria Jose Ruiz Alvarez (t-MoH)
Badara Cisse
Ntsama Mataka
Habiba Bouhamed Chaabouni
Michele Ramsay
Zané Lombard
Karabo Kgomo
Michael Joulie
Frank Ndakala
Ulrike Bußhoff
Windingoudi Justin KABORE
Charity Muchoki
Walter Jaoko
Rispah Torrorey
Michelle Mulder
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Carmen Swanepoel
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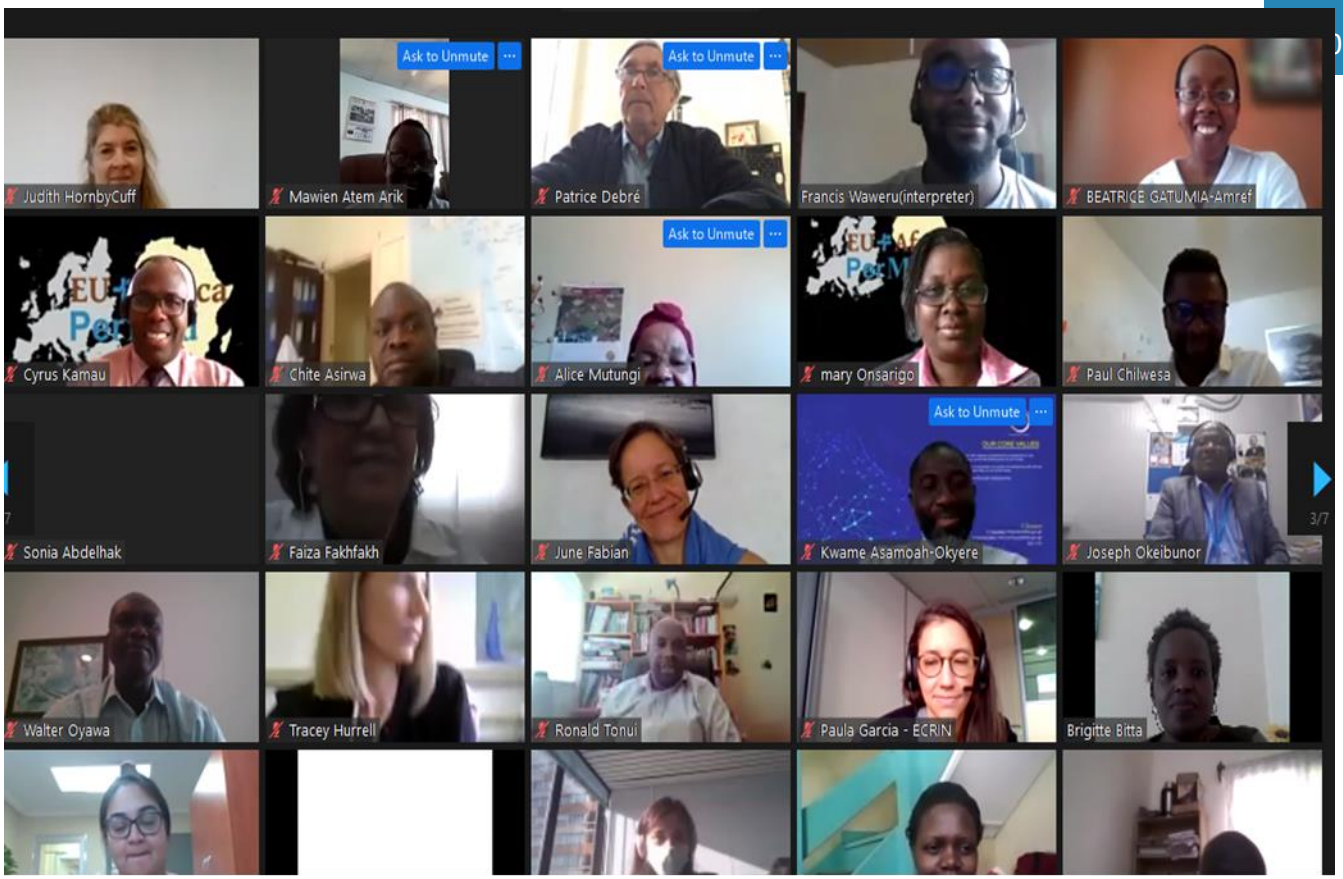

Figure 17: *A section of group photo during the workshop*

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6.0 ANNEXES

6.1. Workshop Agenda

DAY 1 – 9TH FEBRUARY 2022 ***General Moderators of the Day:*** *Teresia Nyawira, National Commission for Science, Technology and Innovation, and Lynette Kamau, African Population and Health Research Center, Kenya*	
TIME	**ITEM**
08:45-09:00	**DIAL IN AND SOUND CHECK**
09:00-09:30	**WELCOME AND OPENING OF THE WORKSHOP** *Moderator of Session: Boniface Wanyama, National Commission for Science, Technology and Innovation, Kenya* ***Prof. Walter Oyawa*** *– Director General, National Commission for Science, Technology and Innovation, Kenya* ***Irene Norstedt*** *- Director of the "People" Directorate within DG Research and Innovation, European Commission* ***Dr. Patrick Amoth*** *– Director General, Ministry of Health, Kenya*
09:30-09:45	**BRIEF INTRODUCTION TO THE EU-AFRICA PerMed PROJECT AND THE OBJECTIVES OF THE WORKSHOP** ***Teresia Nyawira,*** *National Commission for Science, Technology and Innovation, Kenya* ***Joaquín Guinea / Erika Sela,*** *Innovatec, Spain*
09:45-09:55	**BENEFITS OF EU-AU COLLABORATION IN PERSONALISED MEDICINE: THE VISION FROM THE EUROPEAN COMMISSION** ***Jean-Luc Sanne****, Policy Officer, Directorate-General for Research and Innovation, European Commission*
09:55-10:15	**KEYNOTE PRESENTATION: A VISION OF PERSONALISED MEDICINE IN AFRICA** ***Prof. Michèle Ramsay****, Sydney Brenner Institute for Molecular Bioscience, University of the Witwatersrand, South Africa*
10:15 – 10:30	**PRESENTATION OF THE INTERNATIONAL CONSORTIUM FOR PERSONALISED MEDICINE** ***Monika Frenzel****, Agence Nationale de la Recherche (ANR), France*
10:30-10:45	**QUESTIONS AND ANSWERS**
10:45-11:00	**COFFEE BREAK**
AN OVERLOOK OF PERSONALISED MEDICINE IN AFRICA	
11:00-13:15	**8 MINUTES PRESENTATIONS FOLLOWED BY A ROUNDTABLE DISCUSSION** *Moderator:* ***Rizwana Mia****, South African Medical Research Council* • **The vision from WHO**- ***Dr. Joseph Okeibunor****, World Health Organization / Regional Office for Africa* • **The vision from the African Union** – ***Mr. Paul Tanui****, African Union Development Agency -NEPAD* • **North African - *Dr. Yosr Hamdi****, Institute Pasteur, Tunisia* • **Southern Africa - *Prof. Collet Dandara****, Africa Pharmacogenomics Network, South Africa* • **East Africa** - ***Dr. Joseph Sitienei****, Ministry of Health, Kenya* • **West Africa** - ***Dr. Badara Cisse****,* Institut de Recherche en Santé, de Surveillance Epidémiologique et de Formation, *Senegal* • **Central Africa** - ***Dr. Peggy Raymonde Conjugo-Batoma****,* Communauté Economique des Etats d'Afrique Centrale
	QUESTIONS AND OPEN DISCUSSION ON CHALLENGES AND OPPORTUNITIES OF PERSONALISED MEDICINE IN AFRICA
13:15-13:30	**Wrap Up and Closing of the Day** ***Erika Sela****, Innovatec, Spain and* ***Boniface Wanyama****, National Commission for Science Technology and Innovation, Kenya*

DAY 2 – 10 FEBRUARY 2022 ***General Moderators of the Day: Teresia Nyawira**, National Commission for Science, Technology and Innovation, Kenya and **Monika Frenzel**, Agence Nationale de la Recherche, France*	
HOUR	**ITEM**
08:45-09:00	**DIAL IN AND SOUND CHECK**
09:00-09:10	**WELCOME AND OPENING OF THE SECOND DAY OF THE WORKSHOP** • ***David Njubi**, National Commission for Science, Technology and Innovation, Kenya* • ***Monika Frenzel**, Agence Nationale de la Recherche, France*
IDENTIFYING AND PRIORITISING PERSONALISED MEDICINE NEEDS IN AFRICA	
09:10-09:20	**PRESENTATIONS OF THE RESULTS OF THE PRE-WORKSHOP SURVEY ON PERSONALISED MEDICINE HEALTH NEEDS AND PRIORITIES IN AFRICA** ***Lynette Kamau**, African Population and Health Research Center, Kenya*
09:20-09:35	**EXAMPLE FROM THE VIEW OF AN AFRICAIN COUNTRY – SOUTH AFRICA** ***Rizwana Mia**, South African Medical Research Council, South Africa*
09:35-10:30	**IDENTIFYING AND PRIORITISING PERSONALISED MEDICINE NEEDS IN AFRICA** **DISCUSSION IN SMALL WORKING GROUPS** General moderator: ***Monika Frenzel**, Agence Nationale de la Recherche, France* *Group 1:* Scientific and Technological Needs *Group 2:* Scientific and Technological Application Fields *Group 3:* Operational Needs for Better Integrating PM into Healthcare and Clinical Practice *Group 4:* Governance/Regulatory/Ethics Needs to Make PM a Reality *Group 5: What is/are the Need/s to Improve Healthcare*
10:30-10:50	**COFFEE BREAK**
10:50-11:20	**PLENARY SESSION: PRESENTATION OF THE RESULTS OF THE GROUP DISCUSSIONS BY THE MODERATORS** Moderator: ***Monika Frenzel**, Agence Nationale de la Recherche, France*
POTENTIAL AND ADVANTAGES OF COLLABORATION IN THE FIELD OF PERSONALIZED MEDICINE BETWEEN AFRICA AND EUROPE	
11:20-11:30	**INTRODUCTION INTO THE SESSION** ***Monika Frenzel**, Agence Nationale de la Recherche, France*
11:30-12:45	**IMPULSE TALKS *(10 Minutes Talk for Each Presenter)*** Moderator: ***Patrice Debre**, The Institut National de la Santé et de la Recherche Médicale, INSERM, France.* • **LESSONS LEARNT – HOW TO CREATE COLLABORATION (Africa/Europe)** ***Prof. Moses Bockarie**, Director of International Cooperation (Africa) and Head of Africa Office, European & Developing Countries Clinical Trials Partnership* • **PERSONALIZED MEDICINE RESEARCH, INFRASTUCTURES/PLATFORMS** ***Prof. Yazdan Yazdanpanah**, Director of National Agency for Research on AIDS and Viral Hepatitis and I3M Thematic Institute* • **PATIENT VIEW – HOW TO ENGAGE THE PATIENTS AND SOCIETY** ***Angela Nguku**, Deputy Chief Executive Officer, White Ribbon Alliance Global* • **EDUCATION – CAPACITY BUIDING** ***Prof. Abdoulaye Djimdé**, Pathogens Genomic Diversity Network Africa*

European Commission

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6.2. Biographies for Key Speakers

Prof. MOSES BOCKAIRE

Prof. Bockarie, a Fellow of the Royal College of Physicians of Edinburgh, is a specialist in the field of neglected infectious diseases and an internationally experienced researcher. He has worked in many countries in Africa, Europe and the Pacific region, and in the United States of America.

He is the 2016 recipient of the Royal Society of Tropical Medicine and Hygiene Mackay Medal for outstanding work in tropical health. Professor Bockarie is also Chair of the WHO/TDR Scientific Working Group for Vectors, Environment and Society and a member of the WHO Regional Programme Review Group for Neglected Tropical Diseases in the African Region. He is now the Director of International Cooperation (Africa) and Head of Africa Office of European & Developing Countries Clinical Trials Partnership (EDCTP).

Dr. BADARA CISSE

MD, MSc, PhD, Senior Scientist, IRESSEF. He holds a degree in Medicine (1991, Senegal), a master's degree in Epidemiology in 2002 from the London School of Hygiene & Tropical Medicine (LSHTM, University of London) and PhD in Public Health in 2005. From 2007 to 2014, he was an LSHTM lecturer in malaria prevention and control. On secondment in Senegal at his own University (UCAD), he initiated and managed a large and complex research program on malaria control and elimination worth US$12.1 million. He joined IRESSEF in December 2016 to lead the Epidemiology Unit. Basically, with responsibilities that include 1) strategic and scientific leadership to facilitate IRESSEF development as a new hub of excellence in West Africa ; 2) detection of talents, training and mentoring junior scientists; 3) protocols development, fundraising and project coordination.

Before joining the LSHTM, Badara had the privilege to lead the field activities of the Institut Pasteur "Dielmo Project", a longitudinal prospective study to monitor and analyse the causes of fever in rural Senegal. More recently, as senior technical advisor at MACEPA PATH, he got involved in development of protocols, training manuals and field implementation guides. Among personal achievements, he designed and led to WHO recommendation an innovative tool for malaria prevention, namely seasonal malaria chemoprevention or SMC. In 2007, Badara secured an EDCTP Senior Fellowship grant to determine the best antimalarial combination therapy for SMC. All these studies led to publications in The Lancet and in other top-ranked peer-reviewed journals.

Dr. PEGGY R. CONJUGO-BATOMA

Peggy R. Conjugo-Batoma, Doctor of Medicine, and with over 20 years' experience in public health. She started her medical careen in her country of origin, the Central African Republic first as a field doctor in the hospitals of Bangui. She then joined the vast humanitarian support movement established in the country for about three decades by giving support through the following positions: (i) Assistant to the Coordinator of MSF Spain, (ii) National Coordinator of GIP-ESTHER (Groupe Inter Profession – Ensemble pour une Solidarité Thérapeutique Hospitalière en Réseau) (iii) National Consultant, then (iv) Assistant to the Head of the Humanitarian Emergencies and Epidemiological Surveillance Program at WHO (National Office in Bangui as National Professional Officer/ NOC). During these years in international NGOs, she developed skills in emergency management, drug management as well as in the management of health projects and programs.

Since April 2018 she works as Head of Health Service at ECCAS (The Economic Community of Central African States). At this position, she has been in charge of supporting the Project to Strengthen National and Regional Systems for the Surveillance of Diseases with Potential epidemic in Central Africa, fourth phase of the Program (REDISSE IV) financed by the World Bank. She has also participated in the validation of the Regional Strategic Response Plan against Covid-19 and the implementation of the Strategic Plan through the support of ECCAS Health Focal Points or Contact Points for the activities of cross-border management issues in collaboration with the EU Project on the Border Program which has granted funds for Health (Covid-19 in particular).

Prof. COLLET DANDARA

Collet Dandara is a Professor of Human Genetics, Principal Investigator of the Pharmacogenomics and Drug Metabolism Research Group at the University of Cape Town. From the early days of his career, Professor Dandara's research and publications focused on foundational studies in pharmacogenetics, and later pharmacogenomics, characterising genomes of African populations to identify genomic clues on differential drug responses observed in patients. His work has laid a firm basis on understanding the profile of genetic variants of pharmacogenomics importance in African populations, leading to novel discoveries as well as providing mechanistic understanding of the functional significance of such genetic variants and the networks they are involved in. The work by the Pharmacogenomics & Drug Metabolism Group has contributed to the understanding of the diversity of the genomes of African populations. Lately, cognisant of the wide use of traditional medicine, the group has started research on the pharmacogenomics of herbal medicines. Through his research, professor Dandara was nominated the Vice-Chair of the African Consortium of Pharmacogenomics (APC) in 2018; is a member of the African Society of Human Genetics (AfSHG); serves as a committee member of International Scientific Advisory Committee (ISAC) for the Human the Human Variome Project (HVP); is a member of the Global Genomic Medicine Collaboration (G2MC) Initiative and is on the working group of the Global Pharmacogenomics Network. Professor Dandara has authored more 140 publications in international journals and an H-index of 26 and an i10-index of 60. Professor Dandara serves on Editorial Boards of several international journals.

Dr. PATRICE DEBRÉ

Patrice Debré, received his degrees in medicine from Paris University in 1971. He subsequently became specialist in hematology. His research career includes a research fellowship at the Harvard Medical School, USA, in the department of the Nobel Prize winner Baruj Benacerraf, head of clinics at the department of hematology at the Paris University Pitié-Salpêtrière Hospital, Professor of Immunology at the Pierre and Marie Curie Paris University and the first chairman of the clinical department of immunology at the Pitié-Salpêtrière Hospital (1981). He was (1983-2013) director of several CNRS and INSERM units, then of a Federative Institute of Immunology, Cancer and Infection. He contributed to more than 450 peer reviewed articles concerning various aspects of clinical and translational research in immunology and Immunopathology.

Professor Patrice Debré actively worked internationally and became the French ministry of Foreign Affairs (2009-2011) and French ambassador for the fight against HIV / AIDS and communicable diseases. He was the French representative at the board of most multilateral organizations fighting against pandemics, including the Global Fund, UNITAID, RBM, UNAIDS (2008-2011) and EDCTP (2003-2012). In addition to these international activities related to medicine, he became chair of the board of CIRAD, the major French institution dedicated to international research in agriculture, including zoonosis and food security (2004-2010). In parallel, Professor Patrice Debré was appointed at major positions in French administration of science and education.

Prof. ABDOULAYE DJIMDÉ

Abdoulaye Djimde received a PharmD degree from Ecole Nationale de Medecine et de Pharmacie of Bamako, Mali in 1988, a PhD in Microbiology and Immunology from University of Maryland, Baltimore, Maryland, USA in 2001 and is a Professor of Parasitology-Mycology. He is currently Head of the Molecular Epidemiology and Drug Resistance Unit of the Malaria Research and Training Center, University of Science, Techniques and Technologies of Bamako, Mali. The primary goal of his research is to understand how the malaria parasite becomes resistant to antimalarial drugs and how that resistance spreads over time and space. With his team and collaborators he conduct field and laboratory based analyses to explore how genetic events in the malaria parasite, the human host and the mosquito vector's genomes relate to treatment outcome and the spread of drug resistance.

In addition to his own research, he was instrumental in the formation of the Worldwide Antimalarial Drug Resistance Network and served on its Scientific Advisory Board for several years. He was appointed as Chair of the Multilateral Initiative on Malaria Task Force within WHO-TDR. In 2009, he was appointed as one of two International Fellows at the Wellcome

Trust Sanger Institute. He currently serves as coordinator of the West African Network for Clinical Trials of Antimalarial Drugs (WANECAM) and Leader of the Plasmodium Diversity Network-Africa (PDNA). He is the Founding President of the African Association for research and control of AntiMicrobial Resistance (AAAMR, www.africaamr.org). He has co-authored over 135 peer reviewed scientific publications.

Dr. MONIKA FRENZEL

Dr. Monika Frenzel, Senior Scientific Officer for transnational collaborations in the Biology and Health department of The French National Funding Agency (L'Agence Nationale de la Recherche), represents ANR in several transnational collaborations and international funding programmes. As such, she is part of the coordination and support action (CSA) ICPerMed Secretariat and ICPerMed itself. She represents ANR within the ERA Net on Personalised Medicine ERA PerMed and was appointed chair for the respective programme.

Monika Frenzel completed her PhD in Physical Biochemistry and Radiation Biology and worked as researcher in the field of cytogenetics and cohort studies.

PAULA GARCIA

Paula Garcia is a project manager at ECRIN. She is focused on infrastructure development projects in Europe and beyond, helping ECRIN to liaise and cooperate with other existing and upcoming research infrastructures and networks. Paula has previous experience in international scientific cooperation and in the field of development aid. She previously worked as a project manager for the French research agency on HIV/AIDS and viral hepatitis (ANRS) managing projects in developing countries. She has also worked for a public health consulting firm and for the pharmaceutical industry.

Paula received a Bachelors degree in Chemistry Pharmacy and Biology from the Universidad Autonoma de Guadalajara (Mexico) and an International Masters of Public Health from the Ecole des Hautes Etudes en Santé Publique (France).

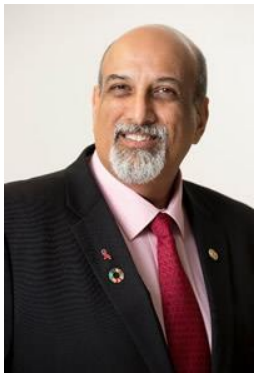
Dr. JOAQUIN GUINEA

Dr. Joaquín Guinea is the director and founder of Innovatec. He is an Engineer with MSc (1981, Tokyo) and PhD. (1989, Madrid). Since 1995 he has been expert evaluator (including chairman positions) for EU R&D projects in the areas of International Collaboration, Regional Development, Technology Transfer, Biotechnology, Health, Future and Emerging Technologies (FET) and Science with and for the Society (SwaftS). He has been the coordinator of the FP7 project EVAL-HEALTH: Developing and Testing of New Methodologies to Monitor and Evaluate Health Related EU-Funded Interventions in Cooperation Partner Countries (2011-2014) and he has been also evaluator of International Research Agendas promoted by the Foundation for Polish Science and for R&I projects funded by the Flanders Innovation and Entrepreneurship agency (VLAIO, Belgium).

Dr. YOSR HAMDI

Dr. Yosr Hamdi is a Research Assistant at Institut Pasteur of Tunis, Tunisia. She is a specialist in cancer genomics and precision oncology. Dr. Hamdi is also a member of the H3Africa Consortium and recently joined the COVID-19 Host Genetics Initiative Consortium. She serves on the advisory boards of several pharmaceutical and biotechnology companies related to genomics and cancer targeted therapies. She started in the field of human genetics with Pr. Alan Anderson who led her graduation project on the Human Genome Project. at Laval University, Quebec, Canada. Then, she had a Master degree in Cellular & Molecular Biology at the Faculty of Medicine, Laval University where she did bioinformatics studies on genes involved in oxidative stress and their association with breast cancer. In 2009, she joined the Genomics center of CRCHUL-Quebec, where she obtained her PhD in Molecular Medicine. By combining genomics, molecular biology and bioinformatics, Dr. Hamdi continues the genomic and molecular investigations of cancer in African populations by implementing Genomics Medicine and Precision Oncology.

Prof SALIM ABDOOL KARIM



Salim S. Abdool Karim is a South African clinical infectious diseases epidemiologist who is widely recognised for his research contributions in HIV prevention and treatment. He is Director of the Centre for the AIDS Program of Research in South Africa (CAPRISA) and CAPRISA Professor of Global Health at Columbia University. He is also Pro Vice-Chancellor (Research) at the University of KwaZulu-Natal, South Africa and Adjunct Professor of Medicine at Cornell University, New York. He is also an Associate Member of The Ragon Institute of Massachusetts General Hospital (MGH), Massachusetts Institute of Technology (MIT) and Harvard University.

His clinical research on TB-HIV treatment has shaped international guidelines on the clinical management of co-infected patients. He was co-leader of the CAPRISA 004 tenofovir gel trial that provided proof-of-concept that antiretrovirals can prevent sexually transmitted HIV infection and herpes simplex virus type 2 in women. He is co-inventor on patents which have been used in several HIV vaccine candidates and in passive immunisation strategies with broadly neutralising antibodies.

Dr Abdool Karim is Chair of the UNAIDS Scientific Expert Panel, WHO's HIV Strategic and Technical Advisory Committee. as well as the WHO TB-HIV Task Force. He serves on the Boards of several journals, including the New England Journal of Medicine, Lancet Global Health, Lancet HIV and mBio. He is a member of the Royal Society of South Africa, Academy of Science of South Africa, African Academy of Sciences and The World Academy of Sciences (TWAS). He is a member of the US National Academy of Medicine, the American Academy of Microbiology and the Association of American Physicians.

LYNETTE KAMAU

Lynette Kamau is Senior Policy and Communications Officer Senior Policy and Communications Officer at the African Population and Health Research Center (APHRC). Lynette has over eight years' experience in policy engagement, communications, and project management in the research and humanitarian sectors. Before joining APHRC, she worked with the International Committee of the Red Cross (ICRC) regional delegation in Nairobi where she was the Media Officer where she led the coverage of humanitarian responses by the ICRC in three countries, Djibouti, Kenya, and Tanzania. She also worked with media houses and journalism bodies in the three countries to enhance their skills in reporting on conflict and situations of violence. During her time at the ICRC, Lynette initiated a roundtable forum with journalism lecturers from Kenyan universities to discuss the challenges in the coverage of conflict and situations of violence by national media and how they can be addressed at curriculum level. Through her work, she also enhanced a better understanding of legal terminologies stipulated in International Humanitarian Law that inform conflict reporting. Lynette has a Master's in International Studies and a Bachelor's degree in Development Communication, both from the University of Nairobi.

Lynette has a keen interest in global health policy, reproductive, maternal and child health, and gender issues. She believes that evidence in decision making will facilitate the development of local solutions to address Africa's challenges and unearth new frontiers.

RIZWANA MIA

Rizwana Mia joined the SAMRC in February 2015. She is responsible for developing the South African Precision Medicine program and incorporating the South African Precision Medicine Think Tank. She has spearheaded strategic partnerships in creating programmatic research as well as core infrastructure to enable and position South Africa in the area of precision medicine. She conceptualized the business plan, secured funding, designed and established the SAMRC Genomics Centre which launched on the 29 July 2019. She currently serves as an advisory board member to the KwaZulu-Natal Research and Innovation Sequencing Platform (KRISP). Rizwana has a strong genetics and product development background having trained as a geneticist. Her prior experience culminates a decade spent building her career at the Technology Innovation Agency (TIA).

Rizwana continues to strive toward enabling new initiatives in South Africa and is currently focused on further development of the South African Precision Medicine Program, as she participates as a co-investigator in the EU-Africa Personalized Medicine (EU-Africa PerMed) Consortium to drive the ecosystem development of the Precision Medicine Agenda for South Africa.

ANGELA NGUKU

Angela Nguku is the Deputy CEO for the Kenya Hub of White Ribbon Alliance Global. She has 14 years of dedicated experience working toward ending preventable maternal and newborn deaths and adolescent health in Kenya, throughout Africa, and around the world.
Angela has worked for AAHI, AMREF, a Christian Aid-led global consortium, and as an Independent Technical and Advocacy Consultant in the RMNCAH program development and management field, as well as an international trainer, mentor and coach.
A passionate midwife, Angela advocates for accountability for the health of mothers, newborns, adolescents and youth, and for midwives' voices to be heard. She is an advisory member of the People's Voice Advisory Board of the Lancet Global Health Commission on High Quality Health Systems in the SDGs Era, the Advisory Group for the Global Action Plan, and the Deliver for Good Campaign in Kenya. In addition, she is a task force member of the CSO Coordination Group of the Global Financing Facility in Kenya, as well as the Kenya SDGs Forum.

Dr. JOSEPH OKEIBUNOR

Dr. Joseph Okeibunor is a Scientist in the Emergency Preparedness and Response programme and coordinator of the research sub-pillar for the WHO AFRO Incident Management and Response Support for COVID-19 response. He holds a PhD in Sociology/Anthropology, specializing in Population and Health Studies, from the University of Nigeria, Nsukka. He is also a Fellow in Global/Public Health from Harvard School of Public Health, Harvard University, Boston Massachusetts, USA. As the team lead for Research Development and Innovation programme in the Assistant Regional Director's cluster in WHO Regional Office for Africa, he acts to strengthen collaboration with partners and other knowledge-based institutions in the region and beyond, on employing evidence to impact on health of the people. He is a public health expert with over 25 years experience. He has held many research positions with WHO. Prior to joining the World Health Organization as staff, he had a distinctive research career as an academic staff of the University of Nigeria, where he rose to the rank of a Professor and Dean. As an academic he conducted many researches and support the evidence led fight against neglected tropical diseases, reproductive health hazards, HIV/AIDS, Tuberculosis and Malaria, among others in Africa. He coordinated the extensive study of community directed interventions into health problems in African, sponsored by WHO/TDR and Bill and Melinda Gates foundation, among other studies. He has an extensive publication record in high impact peer review journal, of international repute.

Prof. TULIO DE OLIVEIRA

Prof. Tulio de Oliveira received his BSc Honours at the University of Natal, South Africa and MSc/PhD at the Nelson R Mandela School of Medicine, UKZN, South Africa. He has been awarded two prestigious fellowships, a European Commission Marie Curie Research Fellow at the University of Oxford, U.K. from 2004-2006 and a U.K. Royal Society Newton Advanced Fellowship at the Wellcome Trust Sanger Institute and University of Edinburgh from 2015-2019. He was the Director of the Genomics Program at the Wellcome Trust Africa Centre for Health and Population Studies and an Affiliate Senior Lecturer at the Division of Infection and Immunity at the University College London (UCL) from 2009 to 2016. In 2015, he was promoted to Professor at UKZN and in 2017, founded KRISP at the Nelson R Mandela School of Medicine, UKZN, South Africa. KRISP aims to create a scientific environment in Africa that delivers high level science, creates innovations and reverses the brain drain. KRISP researchers have published 13 manuscripts in Science, Nature and Lancet journals in the first two years of operation! He have also trained > 2000 individuals in scientific skills in Africa.

Prof. MICHÈLE RAMSAY

Prof. Michele Ramsay is the director of the Sydney Brenner Institute for Molecular Bioscience (SBIMB) at the University of the Witwatersrand, Johannesburg (S. Africa). Professor in Human Genetics and South African Research Chair in Genomics and Bioinformatics of African Populations. Dr. Ramsay obtained her PhD in Human Molecular Genetics from the University of the Witwatersrand. She is a member of the Human Heredity and Health in Africa Consortium (H3Africa) where she leads the AWI-Gen study on the genetic and environmental contributions to obesity and cardiometabolic disease risk in six centres across four African countries. She is a member of the external Advisory Board of EU-Africa PerMed.

ERIKA SELA

Erika Sela is Senior Consultant and co-founder of Innovatec, a Spanish consultancy firm with a broad and long-term expertise in R&I activities. She has a bachelor's degree in Biology. She is now project manager and co-coordinator of the H2020 project EU-Africa PerMed. She has over 20 years' experience in in R&D management in different positions and organizations. In the last years, her main activity has been dedicated to European projects, participating as both partner and coordinator. She is member of EU-LAC PerMed project and participated in the FP7 research project EVAL-HEALTH, developing new methodologies to monitor the impact of international research projects in Public Health.

Dr. JEAN-LUC SANNE

Jean-Luc SANNE received the PhD degree in neurosciences at the University Claude Bernard of Lyon (France). He has been a research fellow in the United States at the University of Georges Town in Washington DC and then at the National Institutes of Health. After an experience in the private sector, in 2000 he jointed the European Commission as a Scientific Officer. He is there devoted to the definition and to the implementation of health research programmes and policies of the European Union. He is in charge of the in vitro diagnostics at the Health directorate of Directorate-General for Research & Innovation since 2002. He currently contributes to the orientation and to the development of European initiatives in the emerging field of personalised medicine, as senior expert in Directorate-General for Research and Innovation – People

PAUL TANUI

Mr Paul Kiptum Tanui is currently Senior Programme Officer – Technical Support for African Medicines Regulatory Harmonisation (AMRH) Programme – a programme coordinated by the African Union African Union Development Agency (AUDA) - NEPAD. He has held this position in for over seven years. Paul is a pharmacist by profession and holds postgraduate qualifications in Healthcare and Business Management. He has over 18 years of experience mainly in pharmaceutical manufacturing, regulatory affairs, medicines regulatory systems strengthening and quality assurance. Before taking up his current position AUDA-NEPAD, he worked for the USAID funded Strengthening Pharmaceutical Systems (SPS) Project/Management Sciences for Health (MSH) supporting medicines regulatory activities at Namibia's Ministry of Health and Social Services (MOHSS)/Namibia Medicines Regulatory Council (NMRC). He has also held other positions as Head Quality Control and Quality Assurance at the Universal Corporation Limited (Kenya) as well as Management positions at health supply chain company Howse & McGeorge Laborex-Eurapharma. He has also served for a period of 3 years as a board member of the Pharmacy and Poisons Board (PPB) - the Kenya National Medicines Regulatory Authority (NMRA).

Prof. YAZDAN YAZDANPANAH

Yazdan Yazdanpanah is currently the head of an Inserm team on decision analysis in Infectious Diseases, the Head of Infectious Disease department at Bichat Claude Bernard Hospital, and Professor of Medicine at Paris Diderot University, France. Yazdan Yazdanpanah became an MD from the Lille School of Medicine, France in 1996. He qualified from the same institution first as a hepatogastro-enterologist in 1996 and next an infectious disease specialist in 2002. He obtained a Master of Science degree in epidemiology from the Harvard School of Public Health, Boston, US in 2000, and a Ph.D degree in public health from the Bordeaux School of Public Health in 2002. In 2006, he became Professor of Infectious Disease.

His research interests include the clinical epidemiology of HIV and viral hepatitis, and the pharmacoeconomics of antimicrobial agents. He is one of the coordinators of Inserm "REACTing », a network under the umbrella of Aviesan (REsearch and ACTion targeting emerging infectious disease) the goal of which is to optimize and coordinate the existing research capacities during emerging and reemerging infection threats. He was recently appointed Director of Aviesan Institute of Immunology, Inflammation, Infectiology, and Microbiology. Prof Yazdanpanah has published extensively in peerreviewed journals and makes frequent presentations at numerous national and international meetings.