

D3.1 List of African personalised medicine needs

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Executive summary

This document describes the “List of African personalised medicine needs” identified by EU-Africa PerMed through consultation of and exchange with diverse African stakeholders. The deliverable considers output of WP2 mapping, the survey launched in preparation and the conclusions of the first stakeholder workshop organised by EU-Africa PerMed (February 2022).

Compared to the majority of European countries, in Africa precision or personalised medicine (PM) as a concept and the potential or benefit it can provide to healthcare systems is still widely unknown and therefore the implementation level is low. The PM adoption and overall maturity level differs between the African countries. There is a common understanding that PM approaches require a set of distinct infrastructures and frameworks as well as education and training (E&T) activities to generate workforces. National strategic setting is needed to allow sustainable and national funding mechanisms that are independent of external resources and priority setting.

Collaboration is the keyword and the solution to allow PM developments and adoption despite the potentially current lack of national prioritisation for this new medical field that is bringing the patient in the very centre of healthcare through targeted prevention, diagnosis and treatment strategies. Through collaboration, the critical mass in terms of human resources, infrastructure, sample sizes but also necessary funding/budget for research and innovation (R&I) can be broad together. Furthermore, and most importantly, the more inclusive PM approaches are for example through integration of databases and knowledge from all over the world, the better approaches are applicable broadly, e.g. for different populations and in the context of different genomic backgrounds. Therefore, and based on the discussions with African stakeholders of different countries, EU-Africa PerMed proposes a regional approach (North, South, East, West and Central Africa regions) for collaboration within the African continent and with Europe, for building and strengthening regulatory frameworks and developing regional strategies for purposes of enhancing collaborations within and between regions. The country level was identified as the platform for the implementation and allocation of resources for PM infrastructure as well as for actioning priorities. There is the urgent need to sensitised policy makers on the benefits of PM, particularly from the point of health economics, for easy development and adoption of PM policies.

This document summarises the PM application and medical fields for that PM approaches would be beneficial for African countries as well as PM thematic area priorities. The efforts needed to enable PM implementation are outlines together with aspects to be developed to ensure socio-economic returns in African countries.

The African stakeholders underlined during the first stakeholder workshop that the identified needs cannot be tackled, fostered or implemented in a linear time scale one after the other but should receive support the very same time and in parallel.

The African stakeholders confirmed the wish to collaborate in the African context but also through joint collaborations with Europe to foster PM development and implementation. They do see a major role of EU-Africa PerMed as driving force, bringing PM knowledge to the continent and fostering PM strategic developments and collaborations.





List of African Personalised Medicine Needs

1. INTRODUCTION

To explore and analyse the potential and advantages of collaboration in Research and Innovation (R&I) in the field of personalised medicine (PM) between Africa and Europe, in the first instance the identification and prioritisation of the PM needs in Africa is needed.

The main challenges in PM were identified through extensive mapping activities in work package 2 (WP2) and via a direct exchange with African PM stakeholders in the first workshop and the related workshop preparatory survey.

This deliverable will feed into the general EU-Africa PerMed objective 2:

To explore and analyse with relevant stakeholder, the potential for and advantages of collaboration in PM between Africa and Europe, identifying areas of mutual interest and added value for both regions and building sustainable links between both regions, as a means to integrate the African continent in the global PM agenda.

It will furthermore contribute to work package 3 (WP3) specific objectives:

- Explore and analyse the potential and advantages of collaboration of Africa and Europe in the field of PM.
- Identify areas of mutual interest and added value for future collaboration.
- Build sustainable links between Africa and Europe in PM research, development, innovation and implementation to better integrate the African continent in the global PM agenda.

The information provided in this document is a first starting point and further African PM needs might be identified through the different activities (stakeholder interviews, webinars, surveys, etc.) organised within WP3 in 2022-2023.

This is the first of in total five, interconnected deliverables within WP3. The first three deliverables (D3.1, D3.2 and D3.3) contribute to the overall topic "Explore and analyse the potential and advantages of collaboration in PM between Africa and Europe", developed in the first half of the EU-Africa PerMed project. In the second half of the project duration, WP3 will concentrate on "Defining and implementing actions for the future" and will develop two deliverables in this context (D3.4 and D3.5). Concretely:

Explore and analyse the potential and advantages of collaboration in PM between Africa and Europe

- D3.1: Outlines the first observations regarding the African needs in the field of PM identified by EU-Africa PerMed through mapping activities in WP2 and collected through direct exchanges with African stakeholders, i.e. the preparatory workshop survey and the 1st Stakeholder Workshop.
- D3.2: will outline the outcome of discussions with African stakeholders regarding areas of mutual interest between Europe and Africa in the field of PM and is therewith going a step further than D3.1 by reflecting not only on the potential of collaboration in the field of PM to tackle the identified needs but more concretely on collaborations between Africa and Europe in this field.
- D3.3: will again concentrate predominately on the African perspective with a gaps-and-needs assessment, setting the African needs (D3.1) in PM in the context of existing frameworks in and the current status of the African PM ecosystem. The regional approach will serve to structure the discussions with the stakeholders and therewith the development of D3.3. EU-Africa PerMed will seek



the validation of results presented in D3.3 through the second stakeholder workshop organised beginning of 2023.

Defining and implementing actions for the future

- D3.4: will be based on the outcome of EU-Africa PerMed and more specifically on D3.1, D3.2 and D3.3 and will further develop an action plan to facilitate, foster and promote PM collaboration of Africa and Europe. This will include a prioritisation of the gaps previously identified and the identification of topics of collaboration in research, research supporting activities and strategic level. EU-Africa PerMed will seek the validation of the action plan presented in D3.4 through the third stakeholder workshop organised in 2024.
- D3.5: will present the results of the third stakeholder workshop and the overall observations collected during the EU-Africa PerMed project in form of a policy brief: “Sustainable European and African collaboration”.



As indicated above, deliverable 3.1 is describing and based on the information collected so far within the project EU-Africa PerMed. Although the content is comprehensive, more exchange with African stakeholders is needed to get sufficient input of all different PM stakeholder communities. Most importantly, the project will further outreach to stakeholders from the different African regions (North, South, East, West and Central Africa) to validate the first regional analysis, for that in some cases only few inputs were received so far, to give a more representative picture.

It is not an objective of D3.1 to provide any solution to the needs identified but simply lists the identified needs. Potential solutions will be developed during the next months of the project and outlined in other deliverables of WP3.

2. BACKGROUND INFORMATION: MAPPING THE SCIENTIFIC AND POLICY LANDSCAPE OF PERSONALISED MEDICINE IN AFRICA

To set the scene for the work of EU-Africa PerMed and the exchange of the project with African stakeholders, it was essential to conduct in a first step an extensive scientific and policy mapping of African competencies, collaboration capacities, capabilities and existing needs in addition to the identification of supporting policies and programmes for PM in Africa. This work was performed in WP2 and presented in two deliverables: D2.1. “Mapping the scientific and policy landscape of PM in Africa” and D2.2. “The EU-AFRICA PerMed stakeholder mapping report”.



Through a scientific mapping process, D2.1 enhanced the understanding of the status, topics and trends of PM in Africa, and identified collaborations capacities, key actors and areas of mutual interest between African countries and European institutions. The policy mapping furthermore aimed to identify policies and programmes in African countries that are supporting and promoting health research and innovation as well as to highlight specific policies, programmes and initiatives that support specifically PM activities including research projects, training, infrastructure, innovation, the industry already existing or operational.

The outcomes of these mapping activities were presented in a comprehensive way in D2.4 “Policy Brief: Opportunities to advance Personalised Medicine in Africa”:

According to the WHO, the African continent is experiencing a comparatively high burden of disease, particularly in infectious diseases such as malaria, HIV/AIDs, and non-communicable diseases like cancer, hypertension, cardiovascular and diabetes. Precision or personalised medicine approaches could be one of the solutions to manage this disease burden. But is there the needed ecosystem in place to implement PM in healthcare systems? The data collected through WP2 shows that African countries are at varying levels of development of PM research and implementation capacity.

A bibliometric study, with PubMed as primary data source (2011-2020), was performed to support answering key questions on the basis, themes and trends of PM in Africa including collaboration capacities, identification of competencies and key actors, and generating insights for mutual areas of interest with European institutions. A significant increase of the number of PM related literature was observed since 2015. The collaboration among African countries or interregional African collaboration (North, South, East, West, Central) is in general low but increasing with around 16% of publications co-authored by at least two African countries.

In terms of research topic, almost 82% of the articles found were related to 13 disease categories, predominantly infectious diseases, followed by cancer, immune and nervous system related diseases (see also EU-Africa PerMed D2.1). The majority of publications were in the field of diagnosis and treatment while prevention as topic was approx. 7 times less present. In general, international cooperation in PM was increasing over time with a peak in 2020 (75%). European collaboration increased significantly in 2013 and reaching its peak in 2019 with more than 350 co-authored publications with African institutions.

The scientific mapping showed a high number of scientific publications for South Africa and Egypt, both having dedicated PM research programs. Furthermore, Egypt showed to have a high number of collaborations with Europe while South Africa showed to have research supported to a high extend through national budget.

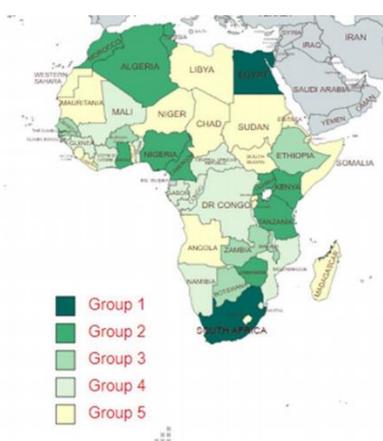


Figure 1: Representation of the PM/genomic capacities in African countries (Source: Sela et al., 2021)

PM research initiatives have been also identified in Algeria, Cameroon, Ethiopia, Ghana, Kenya, Morocco, Nigeria, Tanzania, Tunisia, and Uganda. Other countries had limited PM research. It was noted that a high number of countries were facing limitations such as poor infrastructure, lack of technical capacity, and no funding for genomic/genetic research, all important aspects needed for PM implementation.

WP2 outlined that the status of PM research and implementation divides the African countries into five groups based on their strength defined though six dimensions (Figure 1): Governance of health research, financing of health research, resources for health research, health research outputs, international collaborations in health research, and PM/genomic research. For group 1 countries, PM is a relevant issue for the governments, dedicated PM programmes and infrastructures, respective governance, research funding, capacities and international collaboration are in place. In contrast, group 5 countries only show very low or no activities in the above mentioned 6 dimensions.



Considering the outcome of the mapping exercise, four major PM development areas for African countries are identified:

1. Investing and building on current research efforts

To achieve health goals and targets, matched investment in research and innovation (R&I) to improve access to medical technologies and products is required: Need to invest in locally driven research by empowering local research institutions and establishing innovation hubs, and to allocate at least 1% of the national gross domestic product for R&I (*African Union Commission, 2014*).

Create sustainable core capabilities in 'omics research required for a PM ecosystem: e.g. foster and build on ongoing research on disease surveillance, especially at the genome level, e.g. including pharmacogenomics.

2. Developing skills to allow PM developments and implementation

PM requires multidisciplinary and intersectoral collaboration/approaches. The different stakeholders need to be trained to enable PM development and particularly future implementation into practice, e.g. to understand and efficiently use of the vast amount and different types of health data soon being available for diagnosis, treatment choice and prevention measures. This will result in a new generation of informed, empowered, engaged, and responsible PM stakeholders, particularly focussing on healthcare providers. The development of PM skills and capacity building could be facilitated through the establishment of PM dedicated or efficient use of already existing PM related centres of excellence (e.g. H3Africa, AWI-Gen project, NGS-SA), by focussing on human genomics by leveraging public-private networks and collaborations.

Improved education and training (E&T) will path the way towards a patient-centric approach with medical insurance actuaries that facilitate reimbursement of novel approaches for more accurate and precise diagnosis and treatment.

3. Establishing and implementing PM supporting policy and ethics frameworks

Data related aspects: Needed are frameworks that cover data and sample protection and their use in research, and data sharing protocols and the provision of already available data identities. The capacity of institutional review boards (IRBs) in terms of skills and diversity has to be strengthened, especially for reviewing protocols in genomics and other PM-based research. Install regulatory authorities for medicines, e.g. involved in approving products for the market access, not only at the national but also regional level. Commonly accepted legal and policy frameworks for a health agenda for Africa would promote and facilitate a harmonised PM adoption and implementation on the continental level.

As outcome of the first EU-Africa PerMed stakeholders' meeting, it is proposed to use **regional platforms** to promote PM in Africa. The regional economic blocks are suitable for leading the establishment of policy to govern PM and create more awareness of the PM value to the African people and to enhance resilient healthcare systems.

4. Citizen education

If people and communities understand the PM value, the demand will increase for this form of precision healthcare, adapted regulation, and ethics on data and sample management. Improved literacy enables the establishment of political frameworks to tackle effectiveness, efficiency, equity, and ethical issues and therewith the development and implementation of PM approaches.

Considering the above listed key PM development areas, EU-Africa PerMed outlined in its policy brief D2.4 the following four recommendations:

- 1) **Create awareness:** Creating awareness and communicating the value of PM to the general public, policymakers, and researchers, as well as engaging and empowering all concerned stakeholders. This



will enhance the demand for precision healthcare and lead the way to adapted regulation, and frameworks, e.g. on ethics related to data and sample management.

- 2) **Skills and infrastructure development:** Training and education, especially for healthcare professionals to allow PM implementation and integration into practice, leading to a new generation of informed, empowered, engaged, and responsible PM stakeholders. Invest in sequencing and genotyping facilities, biobanks for samples and their associated data, (health) data infrastructures and information management systems (data generation/storage/analysis pipelines), electronic health records, internet connectivity, and facilities for clinical application and research as well as clinical trials.
- 3) **Support research, data generation, mining, and translation into clinical care:** Build and support sustainably infrastructures (e.g. for all kind of lifestyle data, health data and the generation of genetic data from African populations) to development accurate and affordable diagnosis as well as targeted treatment approaches. Clinical translation of generated data to ensure overall data availability, allowing patient-centred care and other benefits that arise with the implementation of PM approaches in healthcare.
- 4) **Ethical and regulatory framework development, strengthening, and harmonisation:** Establishing, strengthening, and harmonising a cohesive legal and regulatory framework. These frameworks will cover data and sample protection and use in research. Further, enhancing the capacity of institutional review boards (IRBs) in terms of skills and diversity, especially for reviewing protocols in genomics and other PM-based research.

This deliverable D3.1 outlines individual needs that together will support the different African countries to achieve the above listed recommendations.

3. DESCRIPTION OF PERSONALISED MEDICINE NEEDS IN AFRICA IDENTIFIED

After the WP2 mapping exercises, WP3 aims to establish sustainable collaboration and foster direct exchanges with African stakeholders to 1) validate and further specify the information collected in WP2, 2) to explore and analyse the potential and advantages of collaboration in PM between Africa and Europe and 3) to define and implement actions for the future. For this purpose, in total three stakeholder workshops are planned, but also other means to exchange with and collect contribution of the different kind of stakeholders, e.g. through individual interviews or surveys.

In preparation of the first stakeholder workshop, EU-Africa PerMed launched a survey to be completed by workshop participants resident in an African country (survey structure outlined in annex 2). The survey questions were selected carefully to provide the needed input for the work of WP3 and the baseline for discussions with African stakeholders. The majority of the survey outcome was presented by EU-Africa PerMed during the workshop and further discussed with the participants, either in plenary sessions or the topic specific breakout rooms.

The survey results are presented in annex 1, showing the overall feedback of the African stakeholders but also region-specific analyses (North, South, East, West and Central Africa). Overall, the feedback of the different regions was comparable with slight differences in the level of PM adoption and implementation but also prioritisation of thematic areas or medical fields. There was a strong wish for collaboration, within Africa but also between African and European stakeholders, particularly on the level of research or research supporting activities compared to the policy and strategic level.



The discussions with the stakeholders during the first stakeholder workshop, organised by EU-Africa PerMed, confirmed and underlined the feedback collected through the survey:

- The PM implementation, adoption and overall maturity level differs between the African countries. Compared to the majority of European countries, the PM implementation level is low.
- PM can be advanced through research and research supporting activities, for example by setting up infrastructures, whether for biological samples, data or clinical practice fostering PM development and implementation.
- There is the wish for collaboration between countries in the African context.
- Regional collaborations in Africa (North, South, East, West and Central Africa regions) are the most preferred mode to start fostering PM in Africa, especially for the development and adoption of a strategic PM agendas. Building/strengthening regulatory frameworks and developing regional strategies for purposes of enhancing collaborations within and between regions.
- The country level would be the platform for implementation and allocating resources for PM infrastructure as well as for actioning priorities.
- Policy makers also need to be sensitised on the benefits of PM, particularly from the point of health economics, for easy development and adoption of PM policies.

The below analysis is only focussing on PM specific reflections and is not treating the highly heterogeneous healthcare systems from one country to another in Africa or regional differences (e.g. concerning lack of health coverage).

Creation of knowledge, awareness and synergies

The most important outcome of the survey, that was also confirmed by the stakeholder workshop, is the persistent and highly important need to improve the understanding of precision or personalised medicine, as a concept and the benefit it could bring to societies and healthcare systems. This “creation of knowledge” concerns all levels and all different stakeholders, starting with the researcher, the clinician, general practitioner, data scientist, biotechnology and industry sector, policy actors as well as the patient and the citizens ensuring the acceptance of PM applications in prevention, diagnosis and treatment, and the collaboration of the society for developing new approaches. The particular need to inform policy-makers was identified. The lack of understanding and knowledge about existing or novel technology may reduce on the policy-level the acceptance and awareness for their importance and benefit for the society and therewith the support for R&D, R&I and implementation. 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.

Within the African context, there is the need to create synergies, a coordinated and continuous interaction, between the different stakeholders on country, regional and continental level. National pilot committees dedicated to PM could be built on the country level as “think tanks” to identify, assemble and strengthen the PM community, to align strategies and activities within one country, to increase the transparency and sustainability but also to get a clear picture on the maturity level of the healthcare system.

The maturity level of the African countries is very diverse. Therefore, there is a need for cross-border collaboration within the African context but also internationally. Within the African context, national pilot committees can exchange with committees from other countries for example through regional PM groups that could support the development of holistic PM approaches and alignment of dissemination and exploitation activities.

Regional PM groups can join on the continental level allowing the pooling of national/regional resources (i.e. experts, workforces, infrastructures, analytical platforms, education and training activities, etc.) to maximise



the impact of investments on national/regional level and to strengthen the integration of the African PM perspective in the global agenda. The organisation on the regional and continental level would also allow all countries to respond in a coordinated way and rapidly on emergency issues, e.g. pandemic situations.

International collaboration on all levels (on the strategic level, e.g. with ICPeMed, or through collaborative research funding, e.g. through the ERA PerMed or EDCTP funding schemes) can support the global PM development and implementation process and therewith allow equitable access to and benefit of novel and targeted diagnostic, prevention and therapeutic approaches to all. Projects like EU-Africa PerMed are needed e.g. to harmonise developments so that PM approaches are broadly applicable and reflect global health priorities, to raise interest in and foster international cooperation (e.g. for pandemics response) or to mutualise knowledge and technologies. For the long-term, sustainable collaboration are needed on all levels (R&I, clinical as well as policy level).

Before starting a time-consuming collaboration developing process from scratch that is dedicated to PM only, already existing networks or initiatives should be deployed and connected (e.g. the Institute Pasteur Network; EDCTP; and others only based in Africa). As personalised medicine is not disease specific and requires multidisciplinary and intersectoral collaboration anyhow, the exploitation of existing collaboration may accelerate the PM advancements.

Following the outcome of the mapping exercise, further African needs in the field of personalised medicine are detailed under the four major PM development areas identified for African countries (see below). Africa is facing an overall lack in almost all components of PM, but this lack could be overcome by a better deployment of resources and instalment of dedicated policies. The African stakeholders underlined during the first stakeholder workshop that the below needs cannot be tackled, fostered or implemented in a linear time scale, one after the other, but should receive support the very same time and in parallel.

1. Investing and building on current research efforts

There is need for more advocacy for funding in PM. To allow PM adoption and implementation in the African context, there is the need to provide adequate budgets for and sustainable funding/investment in PM research and innovation (R&I) on the local level for example through dedicated PM programmes. These investments should be supported and provided e.g. by the government, based on national priority setting and not depend on priorities and funding of external entities. This includes both, the public and private sector.

Personalised medicine is based on the overall understanding of disease mechanisms and trajectories but most importantly integrates also the individual characteristics of each person, including e.g. the genome, metabolome, diverse 'omics levels but also lifestyle data or the microbiome. To develop PM approaches that are broadly applicable, it is essential to integrate data from diverse populations. The African population is highly diverse between the regions, the countries and even within a country. There is the need to collect potentially missing information/data through dedicated (research) programmes (e.g. genomic programmes or by introducing EHR) and to develop collaboration for (research and health) data sharing and collaborative data mining. For the development of PM approaches that are applicable in the African context, research still has to provide the baseline e.g. genomics data still lacking (e.g. increased research is needed on polymorphism in Africa).

Medical fields for that PM approaches would be the most needed were identified and confirmed during the stakeholder workshop:

1. Cancer
2. Cardiovascular disease (including hypertension)
3. Diabetes (and other metabolic diseases)
4. Infectious diseases



5. Rare genetic diseases
6. Immune disease (incl. transplantation, autoimmune diseases)
7. Neurological diseases
8. Mental health disorders

Despite the fact, African PM stakeholders indicated cancer as priority within the medical field, it was discussed during the workshop that knowledge obtained and evidence for PM approaches already existing in the field of infectious diseases could be used as starting point for PM implementation in Africa.

Precise diagnostics was ranked as most important and promising PM application field, followed by efficient treatment choice, medical decision support tools, prevention strategies, understanding of disease risk, prediction of disease trajectories and rehabilitation/follow-up. But the **current need** on that the regions/countries should first concentrate on were prioritised in the following order:

1. Targeted treatment strategies
2. Improved precise diagnostics
3. Targeted prevention
4. Clinical decision support
5. Ethical, legal social frameworks
6. Disease risk analysis

Finding solutions for the above-mentioned medical and PM application needs can be realised through the development of novel and the efficient use of already existing infrastructures of different kind that are supported through sustainable funding mechanisms:

- **Research facilities**, e.g. to increase knowledge on genomics in African populations; to get a better understanding of disease mechanisms, allowing the identification and validation of biomarkers or of therapeutic targets, etc.;
- **Clinical facilities**, e.g. for patient counselling, screening (for example genetic testing services, prevention diagnostics), treatment and monitoring; sample collection and storage in biobanks; biological sample processing and data generation facilities;
- **Data infrastructures**, e.g. data storage, curation, mining, analysis, interpretation and sharing; data harmonisation; knowledge bases with up to date information on genotype-phenotype link and actionability; different kind of datasets: biological, clinical, omics and imagine as well as lifestyle; integration of existing and new data; patient registries.

In general, there seems to be a lack of materials and equipment to perform both research and care. Platforms or infrastructures might be expensive to be developed or maintained but cross-border collaboration might be the key to obtain the required resources on the one hand and to allow equal access to all to the most adapted technology.

Digital solutions may seem of interest, both for engaging citizens in their health and for healthcare organisations to develop information systems (e.g. EMR).

There is the need to harness and employ already existing or novel technologies to bridge gaps in access to health services. Implementation of PM at regional level and collaboration will increase the market access.

For PM R&I as well as implementation, there is the need to link academia and industry through collaborations and private-public partnerships (including health economic research and evaluations already at early stages of R&D). It was discussed during the workshop that fostering of public-private partnerships should take place on the country level to cope with the diverse policies in place.



There is the need to develop and deploy sustainable and scalable models to invest in health, business models for bringing innovations and solutions to the market and technology-driven payment models for healthcare.

2. Developing skills to allow PM developments and implementation

Revise and adapt current curricula: Dedicated PM education and training (E&T) activities already at the university and medical school level for researchers and healthcare professionals. E&T could also integrate training in leadership, healthcare management and governance to foster better implementation of novel PM approaches.

Develop new models for health workers education and training to develop specialised PM workforces: There is the need to set up centres of excellence to continuously train and upskill healthcare workforces for application of PM in healthcare pathways starting with diagnostics (e.g. knowledge on diagnostic methods, tools and technology), targeted treatment approaches (considering and combining different kind of data for patient stratification) up to prevention (considering and combining different kind of data, health data, genomic and medical but also lifestyle data). One specific topic might be genomic medicine training programmes for healthcare professionals. To improve education and literacy in a long-term perspective, E&T activities need dedicated and sustainable budgets allocated.

The E&T could be centralised on the continental level, could take place through external collaborations outside of Africa or could be revolutionised, facilitated (better access) and scaled up by the use of eLearning and mLearning approaches. This would allow E&T activities also in countries with few resources and independent on the national PM maturity level.

Efforts and strategies are furthermore needed to bring back skilled people to Africa or to engage them after specialised trainings on a long-term basis, to capitalise of their knowhow for the further development and implementation of PM approaches. This can be realised and encouraged for example by creating opportunities and favourable conditions such as adequate remuneration, national or regional dedicated programmes (e.g. genomics or personalised medicine programmes) and infrastructure, research/clinical facilities and platforms allowing them to exercise their specialisation.

3. Establishing and implementing PM supporting policy and ethics frameworks

To develop PM applications and foster their implementation, policy frameworks have to set in place that allow and even require the establishment of PM supportive ecosystems for example through regulatory, data governance and ethics consent processes governing all the above-mentioned activities. PM ecosystems can support and provide the baseline for innovative health services and solutions: improve access, provide facility and community-based health services.

Policy-level collaborations should be promoted, e.g. high-level policy dialogue, research ethics/bioethics frameworks, forums of discussion between regulatory agencies and adoption of common standards.

The stakeholder workshop participants indicated through the preparatory survey the research-supporting **areas in that effort is needed to make PM possible in the different countries/regions**. All below listed areas received high number of votes, showing that support is needed on all levels:

81% indicated that coordinated support is needed for the scientific and technological level, i.e.

- development of national strategic plans, programmes, actions supporting PM-related basic, translational and clinical research;
- support for PM research infrastructures, i.e. biobanks, large-scale genomic databases, DNA sequencing facilities, etc.;



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- development and implementation of undergraduate and post graduate training focused on PM, including genomic science, bioinformatics and data science;
- coordinated support to improve data sharing and data harmonisation of existing databases;
- fostering academia-industry research collaboration.

For better integrating PM into healthcare and clinical practice, 84% indicated that coordinated support is needed on the operational level, i.e.

- training and education of healthcare providers;
- access to genetic testing infrastructure in hospitals;
- increase access to novel drugs;
- transfer of research to the market;
- readiness of clinical trial sites to participate in developing prevention care personalised medicine strategies.

73% indicated the further needs for the governance, regulatory side and ethics, i.e.

- existence of ethical, social, legal (regulatory) frameworks for genetic data (data ownership, privacy, security/protection, sharing);
- level of awareness and knowledge about PM of policy makers;
- trust amongst citizens and patient;
- payment strategies.

For further discussions with the African stakeholders and to develop collaboration strategies, it is essential for EU-Africa PerMed to get an understanding of the efforts still needed and steps to be taken towards PM implementation in the African context. The **most important research and implementation supporting needs that could overall help to improve healthcare in the countries/regions** were ranked below:

1. Efficiency in management of healthcare, e.g. electronic medical records and other data driven systems;
2. Creation of infrastructure, e.g. genomic platforms;
3. Maximisation of healthcare investments;
4. Citizen and patient education;
5. Health insurance, such as private or universal health insurance;
6. Ethics committees for patients and citizens.

The listed topics are not only related to personalised medicine but are essential aspects for PM development and implementation.

Navigating through different, country-specific regulations in cross-border collaboration is challenging, for joint actions in Africa but also with international partners. Harmonised regulations or coordinated support for the understanding of the current frameworks are needed to support cross-border collaboration in research but also clinical settings (e.g. for clinical trials, access to novel or generic drugs). Standardisation of health technology assessment (HTA) and the regulation for the approval of new drugs is needed and harmonisation across regions would result in a high number of patients getting access to drugs. National regulatory authorities for medicines, who are involved in approving products before they come to the market, should be integrated at the regional level.

Ethical and legal frameworks exist in African countries but they need to be strengthened while social frameworks need still to be further developed. Institutional Review Boards need to be strengthened in terms of skills and diversity, especially for reviewing PM related protocols concerning for example genomics approaches. Harmonisation of practices and expectations along the entire PM pipeline, can facilitate the collaboration.



4. Citizen education

To create trust in diagnostics and treatment approaches and to increase the participation in research and prevention strategies, the general population needs to understand the concept of PM. Furthermore, citizens need access to information related to their health. Continuous activities need to be set in place to package and disseminate health and technology information to the general public. This will also increase the trust of the general population in research, research organisations and scientists as well as in healthcare providers.

African countries suffer from mistrust (internally and externally), as resources (e.g. samples and human work forces) were drawn off for a long-time to other countries without providing any benefit to the local/concerned society. There is a need for awareness campaigns to enhance trust in Africa, by increased and adapted communication about PM initiatives, biobanking, databases or publications existing, and on the importance and benefits of these initiatives, e.g. by putting databases into the public domains. This will result in an increased citizen participation in R&I.

E&T of citizens is also needed to improve the adherence to medication, treatment procedures, follow-up and prevention strategies and therewith the success of the implementation of PM healthcare pathways and healthier lifetime.

Besides the importance of citizen education on the one hand, the social environment should be considered in PM research and clinical application on the other hand.

4. COMPREHENSIVE LIST OF PERSONALISED MEDICINE NEEDS IN AFRICA

This section is listing, for a better visibility, the precision or personalised medicine needs in Africa in a table format:

PM need	Description
Create awareness and understanding of PM as a concept	Concerns all levels and all different kind of stakeholders, starting with the researcher, the clinician, general practitioner, data scientist, biotechnology and industry sector, policy actors as well as the patients and the citizens ensuring the acceptance of PM applications in prevention, diagnosis and treatment, and the collaboration of the society for developing new approaches.
Create evidence for the utility of PM approaches	Use the vast knowledge of African countries, e.g. in the field of infectious diseases to create evidence for the utility of PM approaches. This may include sharing of good practices and communication of concrete examples.
Co-creation: develop collaboration in Africa:	National PM pilot committees: “think tanks” to identify, assemble and strengthen on national level the PM community, to align strategies and activities, to increase the transparency and sustainability but also to determine the maturity level of the national healthcare system.
<ul style="list-style-type: none"> • National pilot committees • Regional collaboration • Continental perspective 	Regional collaboration: National pilot committees join through regional PM groups to support the development of holistic PM approaches and alignment of dissemination and exploitation activities.



	Continental collaboration: Regional PM groups can join on the continental level allowing the pooling of national/regional resources (i.e. experts, workforces, infrastructures, analytical platforms, education and training activities, etc.) to maximise the impact of investments on national/regional level and to strengthen the integration of the African PM perspective in the global agenda.
Co-creation: International PM collaboration.	Development of long-term and sustainable collaborations on all levels, i.e. R&I, clinical as well as policy level. Strengthen the integration of the African PM perspective in the global agenda. Integrate the PM perspective in already existing collaborations.
Sustainable, adequate and national PM budget/funding	A sustainable budget allocation for PM research, development and innovation, coming from national resources, allows the implementation of national priorities and needs as well as the creation of a PM ecosystem. One starting point could be the development of dedicated PM programmes on the national level.
Foster public-private partnerships/collaboration	There is the need to link academia and industry through collaborations and partnerships to foster PM R&I, market access of new innovations and therewith PM implementation.
Sustainable and scalable business and payment models in healthcare	Development and deployment of sustainable and scalable models to invest in health, business models for bringing PM innovations and solutions to the market and technology-driven payment models for healthcare.
Identification and prioritisation of medical application fields for that PM approaches could provide solutions	<p>Precise diagnostics was ranked by African stakeholders as most important and promising PM application field, followed by efficient treatment choice, medical decision support tools, prevention strategies, understanding of disease risk, prediction of disease trajectories and rehabilitation/follow-up. The current need on that the regions/countries should first concentrate on were prioritised in the following order (considering the outcome of the stakeholder survey):</p> <ol style="list-style-type: none"> 1. Targeted treatment strategies 2. Improved precise diagnostics 3. Targeted prevention 4. Clinical decision support 5. Ethical, legal social frameworks 6. Disease risk analysis
Identification and prioritisation of medical needs for that PM approaches could provide solutions and funding or translational research	<p>Medical fields for that PM approaches would be the most needed were identified and confirmed during the stakeholder workshop:</p> <ol style="list-style-type: none"> 1. Cancer 2. Cardiovascular disease (including hypertension) 3. Diabetes (and other metabolic diseases) 4. Infectious diseases 5. Rare genetic diseases 6. Immune disease (incl. transplantation, autoimmune diseases) 7. Neurological diseases



	<p>8. Mental health disorders Support translational research and therewith the integration of PM approaches in medical care</p>
<p>Development of novel and efficient use of already existing infrastructures of different kind, supported by sustainable funding</p>	<p>PM can be advanced through research and research supporting activities, for example by setting up infrastructures, whether for research facilities, clinical facilities or data infrastructures fostering PM development and implementation.</p> <p>A diverse set of infrastructures already exist and need to be efficiently used, while others, mostly related to data (particularly genomic data; health data, e.g. collected through electronic health records) or clinical practice, still need to be developed. All kind of infrastructures and platforms need sustainable funding mechanisms.</p>
<p>Development or adaption of curricular for the research and medical sector</p>	<p>Dedicated PM courses in universities, medical schools and others will result in trained and skilled researchers and healthcare forces that can support the development and implementation of PM.</p>
<p>Develop new models for health workers education and training</p>	<p>Set-up of centres of excellence to upskill healthcare workforces in PM: Need to upskill the healthcare workforce in the field of PM e.g. on precise diagnostics, targeted treatment and prevention.</p>
<p>E&T activities for IRB</p>	<p>Institutional Review Boards need to be strengthened in terms of skills and diversity, especially for reviewing PM related protocols concerning for example genomics approaches.</p>
<p>Efforts and strategies are needed to bring back skilled people to Africa</p>	<p>Create opportunities and favourable conditions for skilled people (e.g. considering salaries, infrastructures, opportunities to deploy and further develop their knowledge) to encourage them to return/stay in Africa.</p>
<p>Ethical, legal and regulatory framework development, strengthening and harmonisation</p>	<p>Need to develop a cohesive legal and regulatory framework. Dedicated policy frameworks allow and even require the establishment of PM supportive ecosystems, e.g. through regulatory, data governance and ethics consent processes governing all activities related to PM development, implementation and use in clinical settings and healthcare pathways.</p> <p>Dedicated policy collaborations are needed to advance the</p> <ul style="list-style-type: none"> • scientific and technological level, • operational level, • governance, regulatory side and ethics, <p>The most important research and implementation supporting needs that could overall help to improve healthcare in the countries/regions were ranked as followed:</p> <ol style="list-style-type: none"> 1. Efficiency in management of healthcare, e.g. electronic medical records and other data driven systems; 2. Creation of infrastructure, e.g. genomic platforms; 3. Maximisation of healthcare investments;



	<ol style="list-style-type: none">4. Citizen and patient education;5. Health insurance, such as private or universal health insurance;6. Ethics committees for patients and citizens.
Harmonised regulations	To support cross-border collaboration in research and clinical settings (e.g. for clinical trials).
Standardisation and harmonisation across regions: HTA and the regulation for drug approval.	Standardisation of health technology assessment (HTA) and the regulation for the approval of new drugs is needed and harmonisation across regions would result in a high number of patients getting access to drugs.
Need to understand the social environment	The social environment and citizens' needs have to be considered when PM approaches are developed.
Need to involve patients on all levels	In PM, the patient is in the very centre of healthcare and should be involved in all processes (planning, deployment, analysis and communication): research, clinical trial as well as implementation.
E&T of citizens and patients	Continuous activities to package and disseminate health and technology information to the general public, to increase the trust of the general population in research, research organisations and scientists as well as in healthcare providers. It will also increase the citizen participation in R&I.



ANNEX 1: ANALYSIS OF THE PREPARATORY SURVEY

This annex shows the detailed outcome of the preparatory survey launched in advance of the first stakeholder workshop and completed by workshop participants before the event. The survey results were presented partially during the workshop and discussed together with the participants in breakout rooms and plenary sessions.

In this deliverable, the answers are presented in a continental view (all answers assembled) and the regional perspectives. Thereby, the survey answers are presented for each African region (following the definition of the UNESCO): North, South, East, West and Central Africa (see also EU-Africa PerMeds D2.1. Report: "Mapping the Scientific and Policy Landscape of Personalized Medicine in Africa", Fig. 17, page 36).

The results are presented in the following order:

1. All answers together: "the continental perspective"
2. The regional perspective: North Africa
3. The regional perspective: South Africa
4. The regional perspective: East Africa
5. The regional perspective: West Africa
6. The regional perspective: Central Africa

Considering the number of answers received through this survey and especially for certain regions, the survey outcome has to be seen as "snapshot", taking into account that the African continent is very large, the personalised medicine stakeholder community broad and multidisciplinary as well as intersectoral. For obtaining a more detailed analysis a higher number of answers has to be collected including all concerned stakeholder communities. The regional analyses are showing an approximation of the current situation, as for some countries/regions only few stakeholders participated in the survey. Furthermore, the overall analysis is showing an approximative situation for the African context, the continental view, as some countries/regions are more represented than others. EU-Africa PerMed will validate the survey outcome and the information provided in this deliverable with the stakeholders during the regional meetings planned in WP3 but also during the annual stakeholder meetings to that representatives of all regions are invited.

Despite the above described limitation of the survey, for EU-Africa PerMed, this survey outcome represents an important baseline to continue the exchanges and collaboration with African stakeholders and to further develop the input received.

For the analysis of the survey, four overall sections were developed:

1. **The current status of PM** – overall knowledge about and current interest in PM as well as level of adoption and implementation of PM in healthcare systems,
2. **The potential of PM** – medical and application fields, PM priorities and potential socio-economic benefits
3. **Aspects needed to make PM a reality** – efforts needed and aspects supporting improved healthcare
4. **African perspective and collaboration in PM** – African contribution to the global agenda, collaboration (on which level and role of EU-Africa PerMed) and areas of mutual benefit between Africa and Europe

As for Central Africa very few answers were received, the analysis is concentrating mainly on the other four regions.



The current status of PM

It is essential to have an overview on the general understanding of and the knowledge about PM in Africa. This understanding will allow EU-Africa PerMed to launch general discussions about PM as topic, to further develop reflections towards PM implementation in Africa and to path the way for collaborations between Africa and Europe in this field.

Strong regional differences were observed for the question: *'Is "personalised medicine" or "precision medicine" as a concept known in your region/ country?'*. While overall 65% agreed in this assumption, the PM concept seems to be better known in North (78%) and South (86%) Africa than in East (37%), West (40%) and Central (33%) Africa.

It was overall agreed that **PM is an issue of interest in the country** for all concerned stakeholder and in the following order:

1. For the research and academic system,
2. For the healthcare providers (doctors, nurses, hospital managers, health insurance),
3. For the private healthcare sector (pharma, biotech, hospitals),
4. For the government, research and innovation policy and funding,
5. For the government and the public healthcare system,
6. For the patients and the general public.

Interestingly, in East Africa, all stakeholder groups seem to be concerned to the same extent, while in the North and the West, there is a clear focus on the research, academic and clinical sector with a low involvement of the patient and citizen. In South Africa, there seems to be a high interest of PM for all stakeholders and interestingly higher for the private sector compared to the clinical ones.

Considered **level of adoption and implementation of PM in the country's healthcare system**, including both public and private healthcare, the responders gave diverse feedbacks for each region. The choices "high" and "very high" were rarely used, leaving to the assumption that PM is not a priority in the African countries. Overall the following order could be identified for Africa as a continent:

1. Genetic and molecular testing services available in hospitals
2. National/regional legislation for genetic data
3. PM-related programs provided by the healthcare system such as targeted oncology therapies, pharmacogenomics testing, prenatal diagnosis, genetic cancer risk assessment and counselling
4. Biobanks and patient registries with genetic/genomic data
5. Existing national PM strategies
6. Education and training on PM for health workforce

On the regional perspective, the level of adoption and implementation of PM differs, e.g.

- South Africa follows the above listing.
- East and West Africa have a focus on biobanks and patient registries with genetic/genomic data and East Africa also on education and training on PM for health workforce,
- North Africa seems to concentrate on PM-related programs,



The potential of PM

For the establishment of an African PM agenda, continental and international collaboration in PM and the integration of the African perspective in the global agenda, it is essential to understand the needs and the potential application opportunities for PM in the different countries, e.g. concerning the medical and PM application (prevention, diagnosis, treatment/therapy, etc.) fields, PM priorities and potential socio-economic benefits.

Considering the overall feedback but also the ones of the individual regions, **the PM application fields the most needed** have been ranked predominantly in the following order:

1. Offer precise diagnostics
2. Efficient treatment choice
3. Medical decision support tools
4. Prevention strategies
5. Define disease risk
6. Predict disease trajectories
7. Rehabilitation and follow-up

This feedback was confirmed by the selected **PM thematic area on that the regions/countries should first concentrate on:**

1. Targeted treatment strategies
2. Improved precise diagnostics
3. Targeted prevention
4. Clinical decision support
5. Ethical, legal social frameworks
6. Disease risk analysis

Some positions changed compared to the previous question on the needs: Treatment identified as more important than diagnostics, and targeted prevention more than clinical decision support.

On the regional perspective the focus differs slightly. While the feedback of South and East Africa is corresponding overall to the above order, West Africa might focus first on disease risk analysis and less on treatment and support tools. North Africa is prioritising targeted prevention and ELSI frameworks and less diagnosis. This outcome of this question is essential to support EU-Africa PerMed in identifying and prioritising precision/personalised medicine needs in the different regions/countries.

In terms of **disease fields for that PM approaches would be the most needed**, the following order was obtained (with diabetes and infectious diseases on the same position):

1. Cancer
2. Cardiovascular disease (including hypertension)
3. Diabetes (and other metabolic diseases)
4. Infectious diseases
5. Rare genetic diseases
6. Immune disease (incl. transplantation, autoimmune diseases)
7. Neurological diseases
8. Mental health disorders

The order of the disease field priorities differs slightly between the regions. Particularly for the North, PM approaches are less needed prioritised for infectious diseases compared to rare diseases.



To answer the question **“What do you think is the most important aspects that will ensure socio-economic returns within your country/region?”**, the survey participants were asked to score four proposed answers. The overall feedback is comparable to the ones of the individual regions:

1. Improved cost-effectiveness (ratio of the cost of an intervention to the effect for the patient/citizen, e.g. cure, reduction of side effects, prevention of disease occurrence etc.)
2. Reduction of poverty through equitable access to healthcare – “No one left behind”
3. More relevant healthcare considering patient's individual needs
4. Job creation

Aspects needed to make PM a reality – efforts needed and aspects supporting improved healthcare

EU-Africa PerMed aims to understand the efforts still needed and steps to be taken towards PM implementation in the African context to allow the access of citizens and patients to PM approaches in healthcare.

Precision or personalised medicine is shown to offer great value in healthcare. A first question aimed to obtain an understanding on the **most important aspects that could help to improve healthcare in the countries/regions**. The following order was developed considering all responders and reflecting the situation in South Africa:

1. Efficiency in management of healthcare (e.g. electronic medical records, and other data driven systems)
2. Creation of infrastructure (e.g. genomic platforms)
3. Maximisation of healthcare investments
4. Citizen/patient education
5. Health insurance (such as private or universal health insurance)
6. Ethics committees for patients and citizens

The feedback of the participants of North and West Africa shows the need for the maximisation of healthcare investments, for the eastern and western countries the citizen and patient education were found to be important.

Regarding the **areas in that more effort is needed to make PM possible in the different countries/regions**, all below listed areas received high number of votes, with slightly different priorities amongst the regions:

1. **Operational needs for better integrating PM into healthcare and clinical practice** (i.e. training and education of healthcare providers; access to genetic testing infrastructure in hospitals; increase access to novel drugs; transfer of research to the market; readiness of clinical trial sites to participate in developing prevention care personalised medicine strategies)
2. **Scientific and technological needs** [i.e. existence of national strategic plans, programmes, actions supporting PM-related basic, translational and clinical research; infrastructures for PM research (i.e. biobanks, large-scale genomic databases, DNA sequencing facilities, etc.); undergraduate and post graduate training focused on PM, including genomic science, bioinformatics and data science; efforts to improve data sharing and data harmonisation of existing databases; academia-industry collaborations in research]
3. **Governance / regulatory / ethics needs** [i.e. existence of ethical, social, legal (regulatory) frameworks for genetic data (data ownership, privacy, security/protection, sharing); level of awareness and knowledge about PM of policy makers; trust amongst citizens and patient; payment strategies]



Particularly, in East Africa more efforts are needed for the governance, regulation and ethics while the operational side was on the third position. West Africa seems to focus first on scientific and technological needs.

African perspective and collaboration in PM – African contribution to the global agenda, collaboration (on which level and role of EU-Africa PerMed) and areas of mutual benefit between Africa and Europe

Precision or personalised medicine is a very broad field, e.g. in terms of disease fields, but also requires truly multidisciplinary and intersectoral approaches involving a diverse set of contributors for the development but also and particularly for the implementation of approaches in healthcare pathways, bringing into the focus the end-users: healthcare providers, patients and citizens. Furthermore, to implement PM approaches, a dedicated ecosystem needs to be set in place, including infrastructures of different kinds: biobanks with biological samples, technology platforms (e.g. imagine, omics technologies, etc.), data centres (collection, storage, mining, etc.) supporting research efforts but also clinical networks. Collaboration on the national, regional, continental and international level allows the efficient use of resources, knowhow (e.g. through collaborative projects, expert exchange, knowledge transfer, etc.) but also of resources (avoid duplication of efforts and common investment in the same research question, etc.).

The pre-requirement for developing collaborations is the understanding of the needs, priorities and interests of the different parties. Based on this knowledge, common strategies can be developed and collaborations established on different levels, e.g. research, research supporting (for example infrastructures), clinical and strategic/policy level.

Through the survey, EU-Africa PerMed aimed to collect the opinion of stakeholders on the African contribution to the global agenda, the most efficient collaboration approaches in the African context but also between Africa and Europe and areas of mutual benefit between Africa and Europe.

The clear majority of survey participants agree that the **contribution African countries can bring into global PM reflections and developments** are to 98% the diversity of populations, i.e. diverse genetic backgrounds to develop broadly applicable PM approaches and efficacious drugs, vaccines and biologics and to 91% a strong understanding in a dedicated disease field, such as understanding prognosis of disease, including host pathogenesis of infectious diseases within African populations.

The majority of overall responders and those of East Africa thinks that **PM development within Africa could be fostered the best on the regional level**, followed by the country and thereafter the continental level. For the North African stakeholders, a slight majority would prefer first country specific developments, followed directly by regional collaborations. For South African stakeholders, the regional level has also priority but followed clearly by the wish of collaborations on the continental level and not on the country level. For West Africa, there is a slight priority on the regional approach but all three levels received nearly similar positive support.

Efforts to strengthen collaboration should most importantly being increased on the scientific level and to a lesser extend also on the policy level. Overall, the clear majority (95%) of the African stakeholders thinks that EU-Africa PerMed can be a driving force towards the development of PM in Africa.

The participants overall highly agree (average score 8.8 out of 10) that there is a **need for strengthening EU-AU collaboration in PM**. As areas in which collaboration between Africa and Europe could be of mutual benefit the participants ranked as followed:

1. Sharing of knowledge
2. Sharing of infrastructure for research
3. Common training and education activities



4. Common funding activities
5. Technology developments
6. Alignment of strategies
7. Development of ethical frameworks and regulation
8. Common policy development

The separation in the regions confirmed that the same prioritisation exists for the individual regions. In North Africa, the wish/need to develop common funding activities is lower compared to the other regions. In general, the feedback confirmed that collaboration priorities are currently predominately on the research or research supporting level than on the policy and strategic level. A potential explanation might be the type of survey participants, mainly coming from research and clinics.

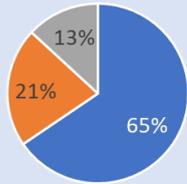


All answers together: "the continental perspective"

Outcome "the continental perspective": 84 answers, stakeholders of all African regions

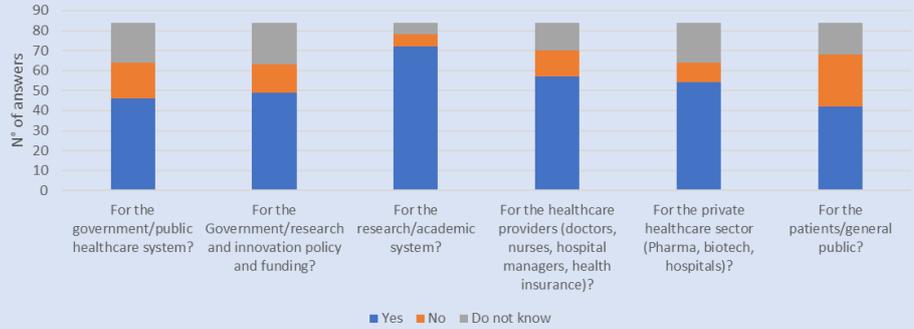
The current status...

Is "personalised medicine" or "precision medicine" as a concept known in your region/ country?

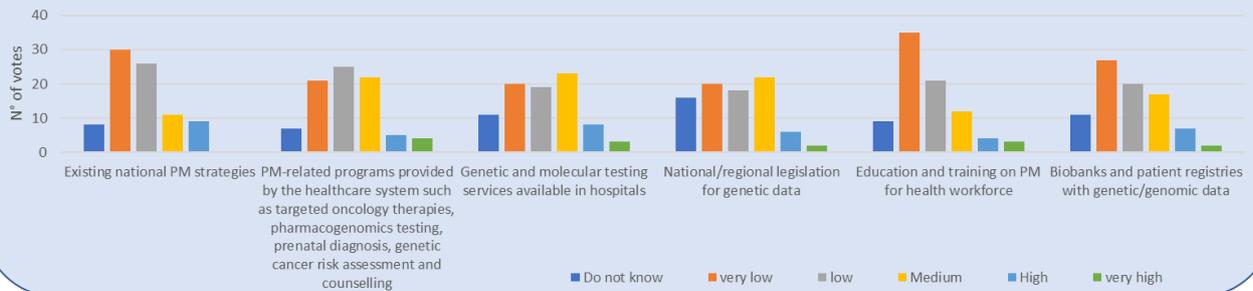


■ Yes ■ No ■ I don't know

Is personalised medicine an issue of interest in your country?

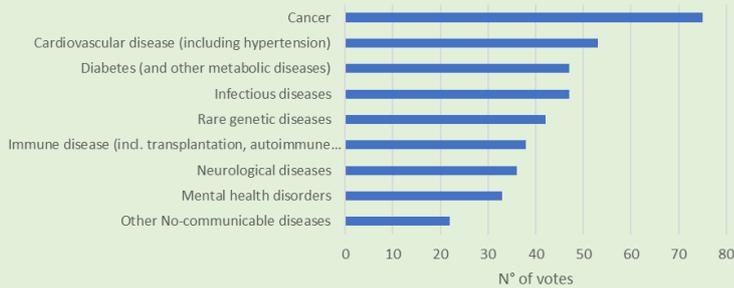


Level of adoption and implementation of personalised medicine (PM) in your country's healthcare system

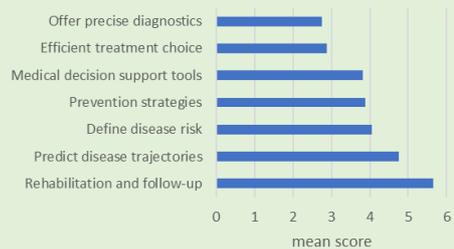


The potential....

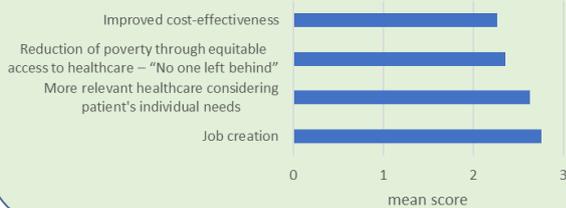
Medical fields where personalised medicine approaches would be the most needed in your region/country?



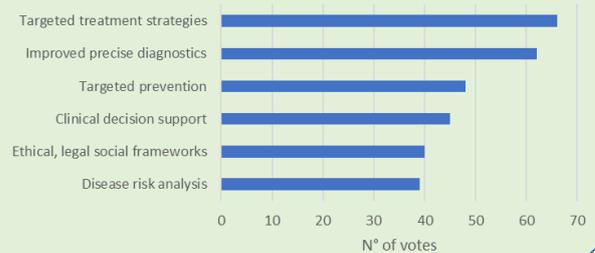
The most promising/important application personalised medicine could offer in your region/country?



Most important aspects that will ensure socio-economic returns within your country/region



Personalised medicine thematic area priority

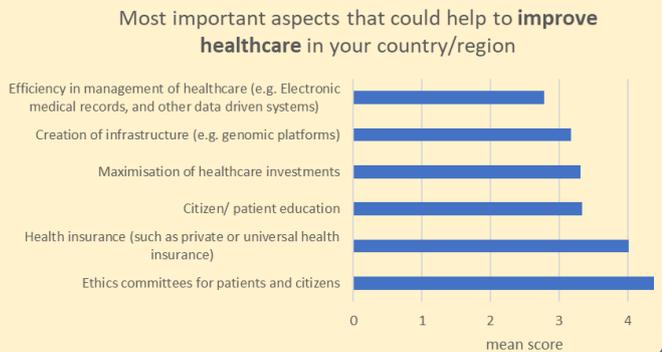




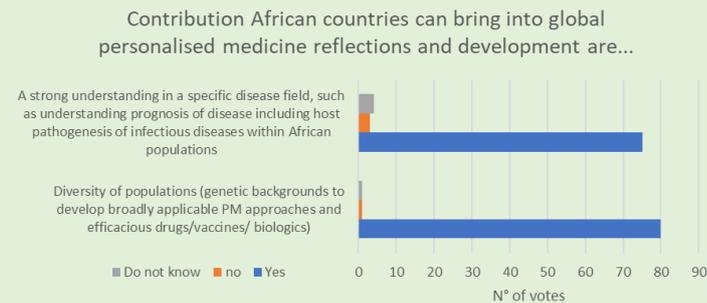
All answers together: "the continental perspective"

Outcome "the continental perspective": 84 answers, stakeholders of all African regions

Make personalised medicine a reality...

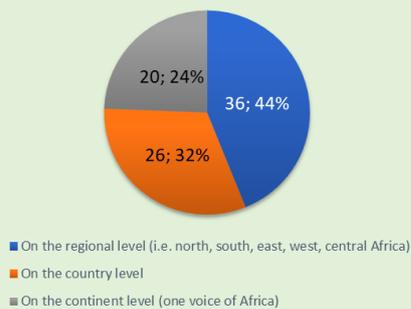


The African perspective and collaboration in personalised medicine...

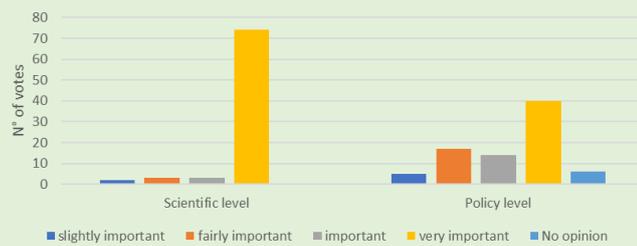


95% think that the EU-Africa PerMed initiative can be a driving force towards the development of personalised medicine in Africa

Fostering PM development in Africa



Strengthen collaboration, at what level do you think it is more important to increase efforts?



Areas in which collaboration between Africa and Europe could be of mutual benefit



The need for strengthening EU-AU collaboration in PM: Scored 8,8 out of 10

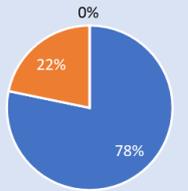


The regional perspective: North Africa

Outcome "the regional perspective": 23 answers, North Africa

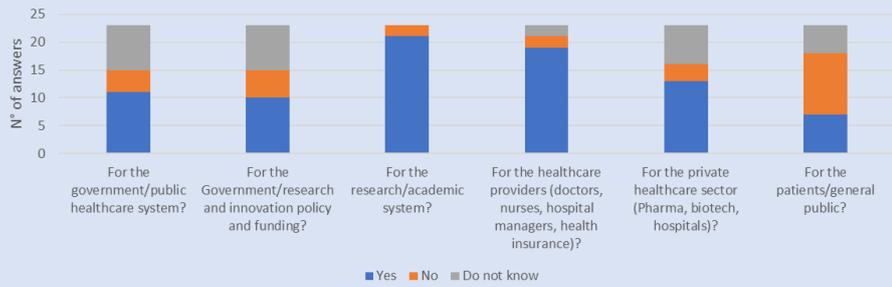
The current status...

Is "personalised medicine" or "precision medicine" as a concept known in your region/ country?



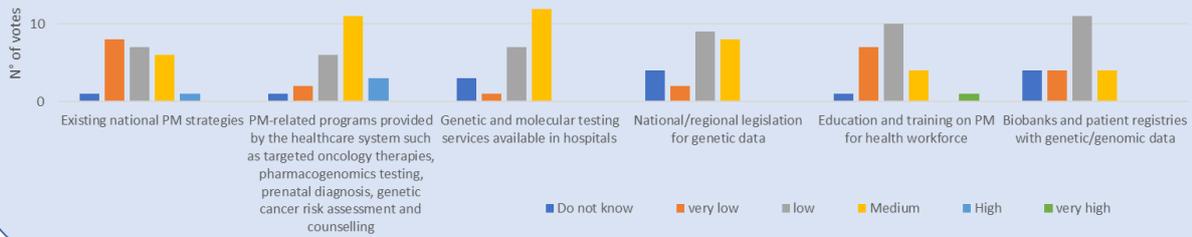
■ Yes ■ No ■ I don't know

Is personalised medicine an issue of interest in your country?



■ Yes ■ No ■ Do not know

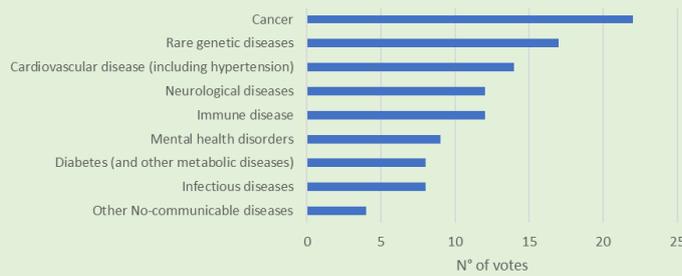
Level of adoption and implementation of personalised medicine (PM) in your country's healthcare system



■ Do not know ■ very low ■ low ■ Medium ■ High ■ very high

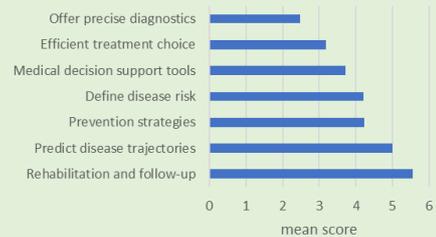
The potential....

Medical fields where personalised medicine approaches would be the most needed in your region/country?



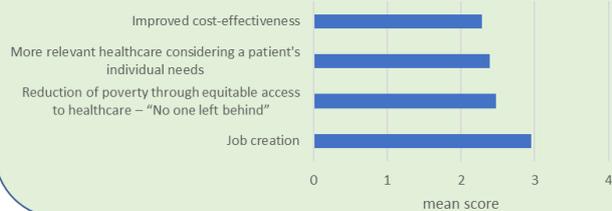
N° of votes

The most promising/important application personalised medicine could offer in your region/country?



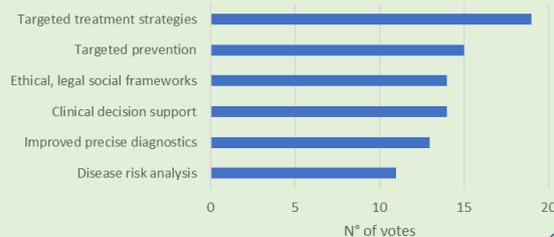
mean score

Most important aspects that will ensure socio-economic returns within your country/region



mean score

Personalised medicine thematic area priority



N° of votes



The regional perspective: North Africa

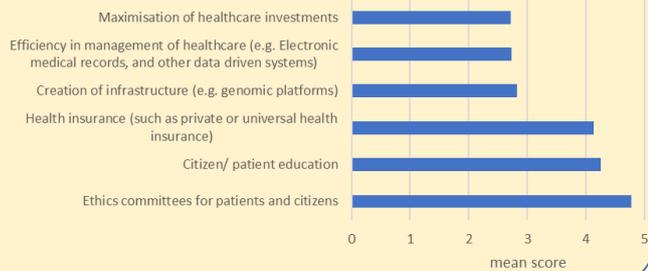
Outcome "the regional perspective": 23 answers, North Africa

Make personalised medicine a reality...

Efforts needed to enable personalised medicine

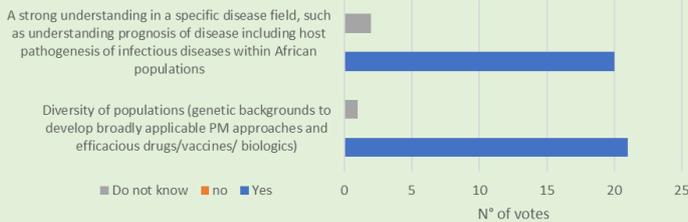


Most important aspects that could help to improve healthcare in your country/region



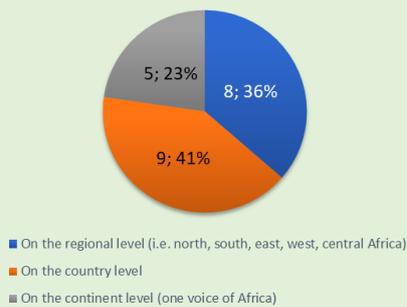
The African perspective and collaboration in personalised medicine...

Contribution African countries can bring into global personalised medicine reflections and development are...

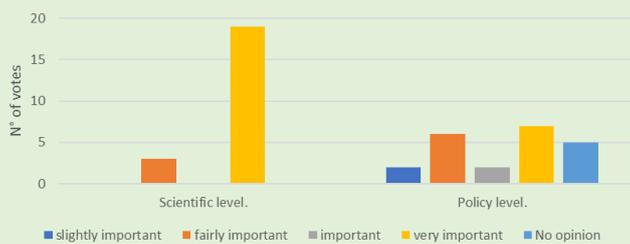


95% think that the EU-Africa PerMed initiative can be a driving force towards the development of personalised medicine in Africa

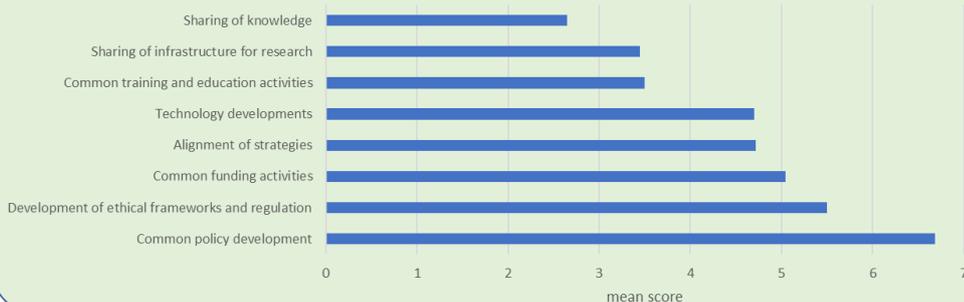
Fostering PM development in Africa



Strengthen collaboration, at what level do you think it is more important to increase efforts?



Areas in which collaboration between Africa and Europe could be of mutual benefit



The need for strengthening EU-AU collaboration in PM: Scored 8,7 out of 10

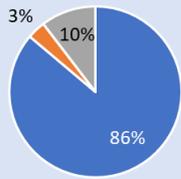


The regional perspective: South Africa

Outcome "the regional perspective": 29 answers, South Africa

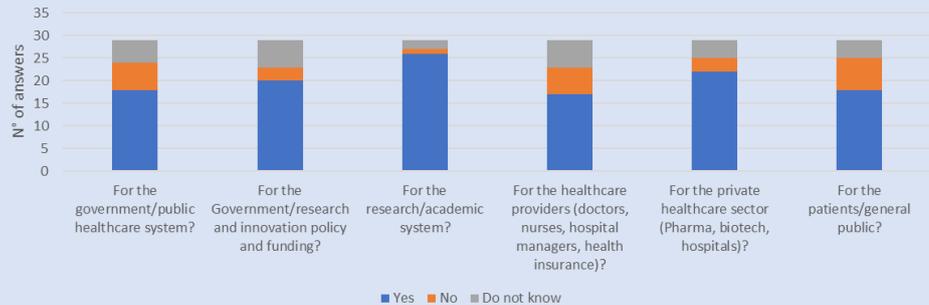
The current status...

Is "personalised medicine" or "precision medicine" as a concept known in your region/ country?

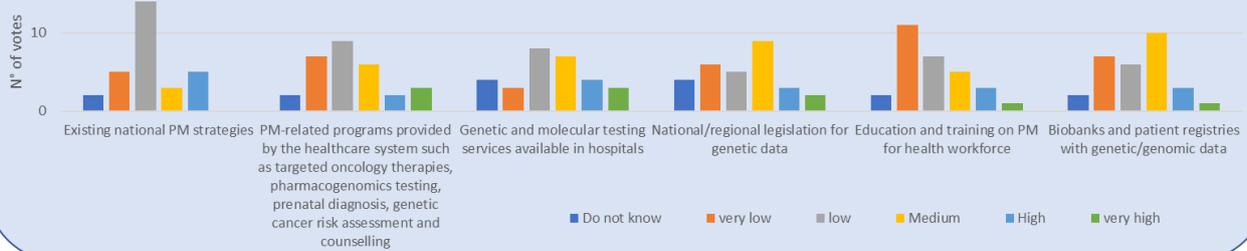


■ Yes ■ No ■ I don't know

Is personalised medicine an issue of interest in your country?

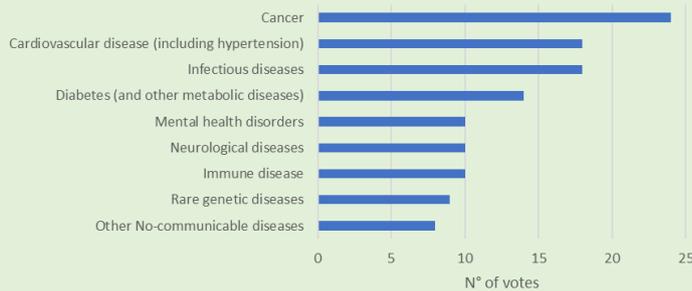


Level of adoption and implementation of personalised medicine (PM) in your country's healthcare system

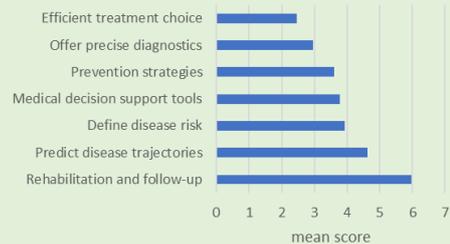


The potential....

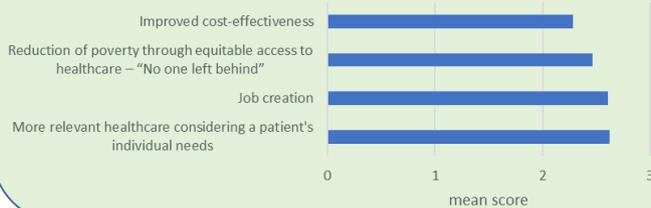
Medical fields where personalised medicine approaches would be the most needed in your region/country?



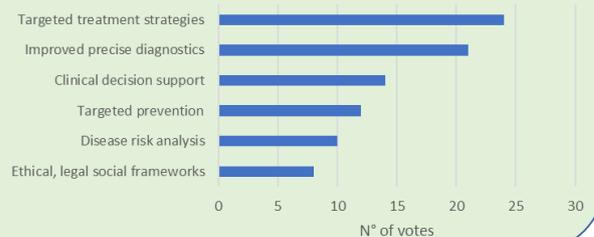
The most promising/important application personalised medicine could offer in your region/country?



Most important aspects that will ensure socio-economic returns within your country/region



Personalised medicine thematic area priority

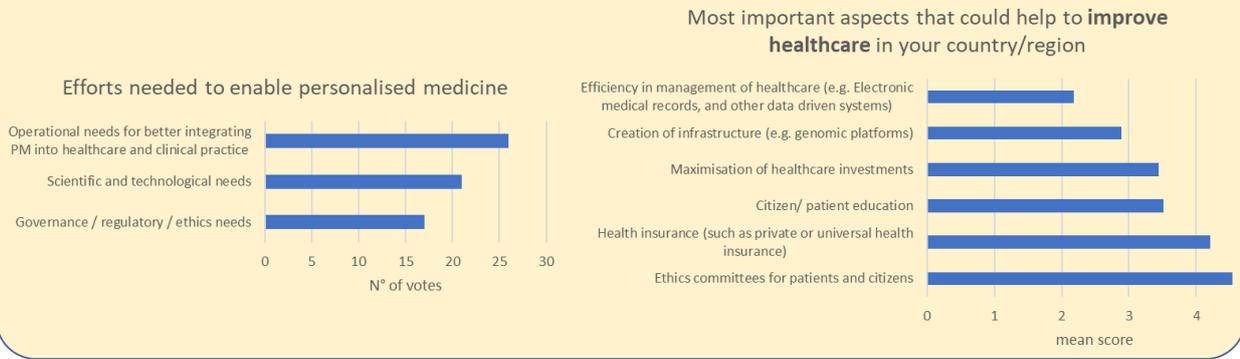




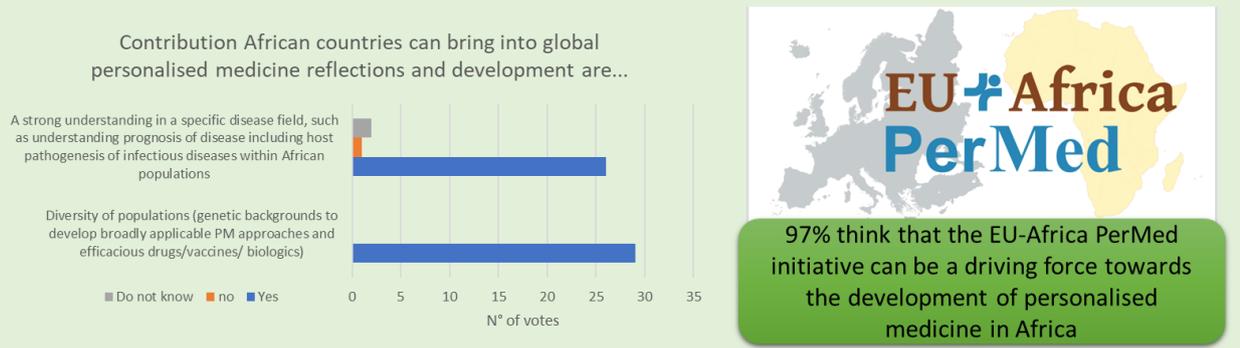
The regional perspective: South Africa

Outcome "the regional perspective": 29 answers, South Africa

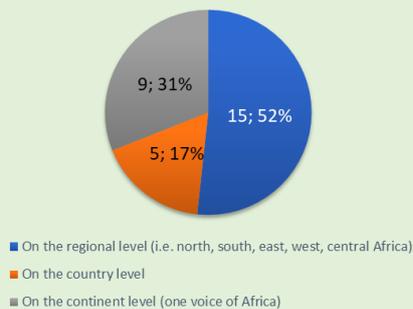
Make personalised medicine a reality....



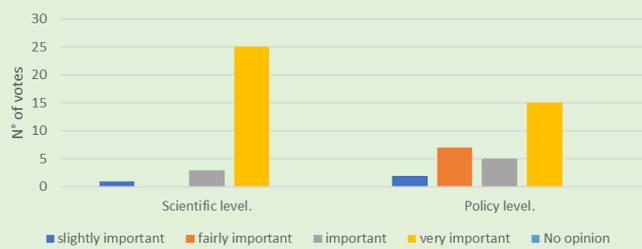
The African perspective and collaboration in personalised medicine...



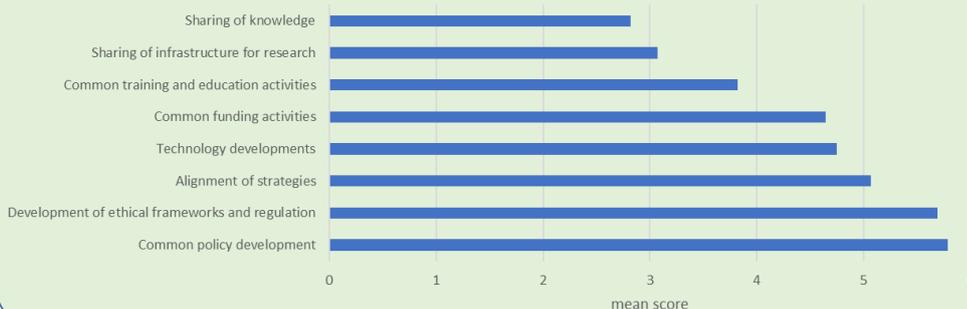
Fostering PM development in Africa



Strengthen collaboration, at what level do you think it is more important to increase efforts?



Areas in which collaboration between Africa and Europe could be of mutual benefit



The need for strengthening EU-AU collaboration in PM: Scored 8,9 out of 10

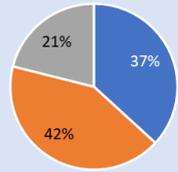


The regional perspective: East Africa

Outcome "the regional perspective": 19 answers, East Africa

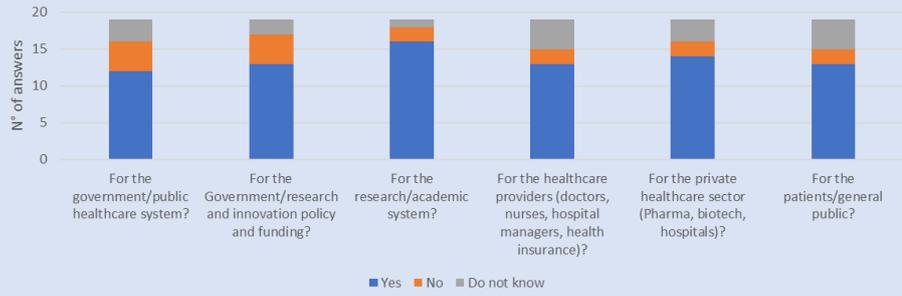
The current status...

Is "personalised medicine" or "precision medicine" as a concept known in your region/ country?



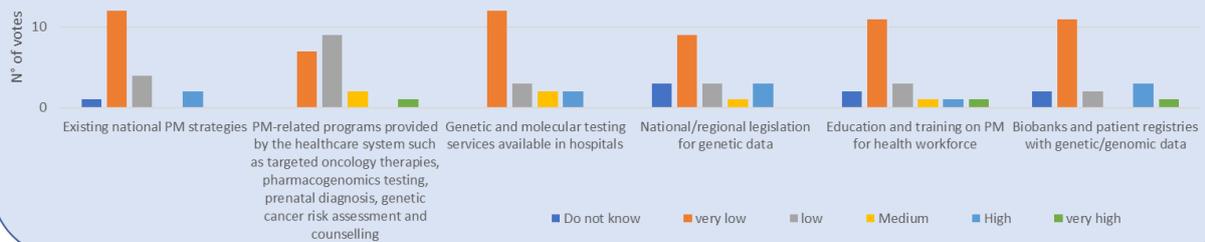
■ Yes ■ No ■ I don't know

Is personalised medicine an issue of interest in your country?



■ Yes ■ No ■ Do not know

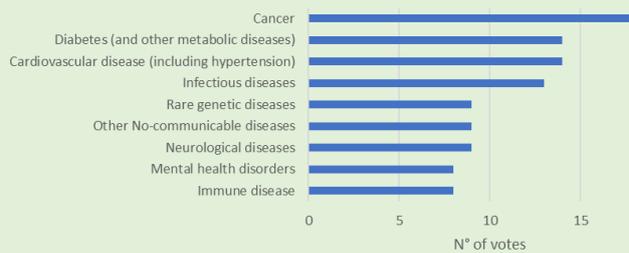
Level of adoption and implementation of personalised medicine (PM) in your country's healthcare system



■ Do not know ■ very low ■ low ■ Medium ■ High ■ very high

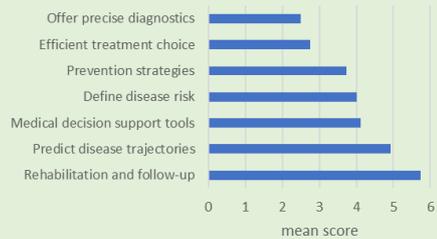
The potential....

Medical fields where personalised medicine approaches would be the most needed in your region/country?



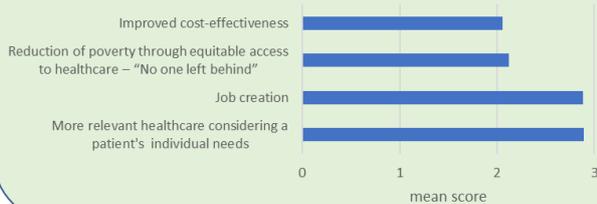
N° of votes

The most promising/important application personalised medicine could offer in your region/country?



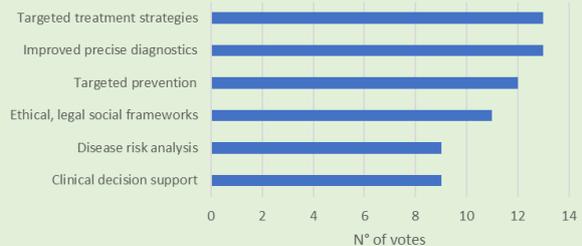
mean score

Most important aspects that will ensure socio-economic returns within your country/region



mean score

Personalised medicine thematic area priority



N° of votes



The regional perspective: East Africa

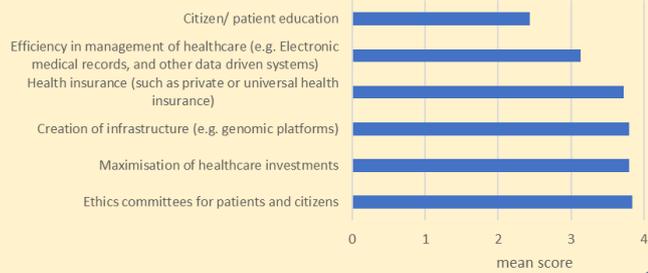
Outcome "the regional perspective": 19 answers, East Africa

Make personalised medicine a reality...

Efforts needed to enable personalised medicine

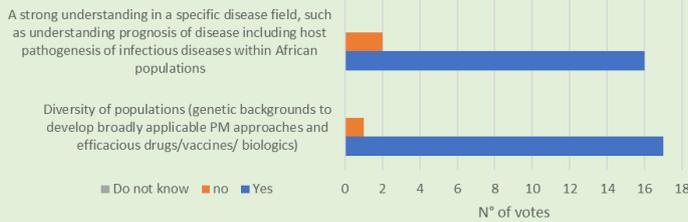


Most important aspects that could help to improve healthcare in your country/region



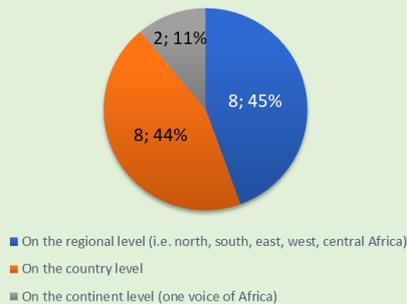
The African perspective and collaboration in personalised medicine...

Contribution African countries can bring into global personalised medicine reflections and development are...

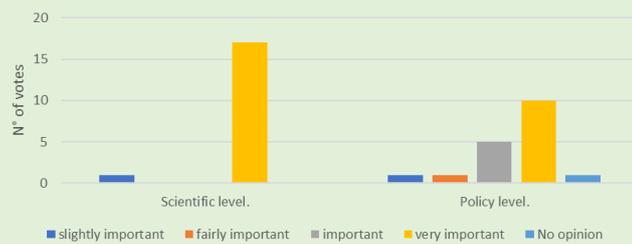


89% think that the EU-Africa PerMed initiative can be a driving force towards the development of personalised medicine in Africa

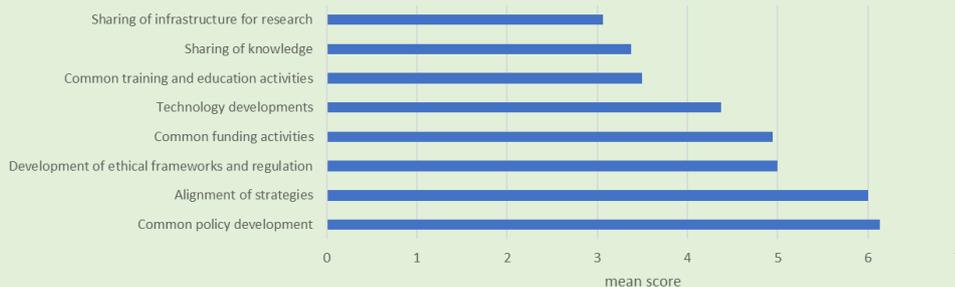
Fostering PM development in Africa



Strengthen collaboration, at what level do you think it is more important to increase efforts?



Areas in which collaboration between Africa and Europe could be of mutual benefit

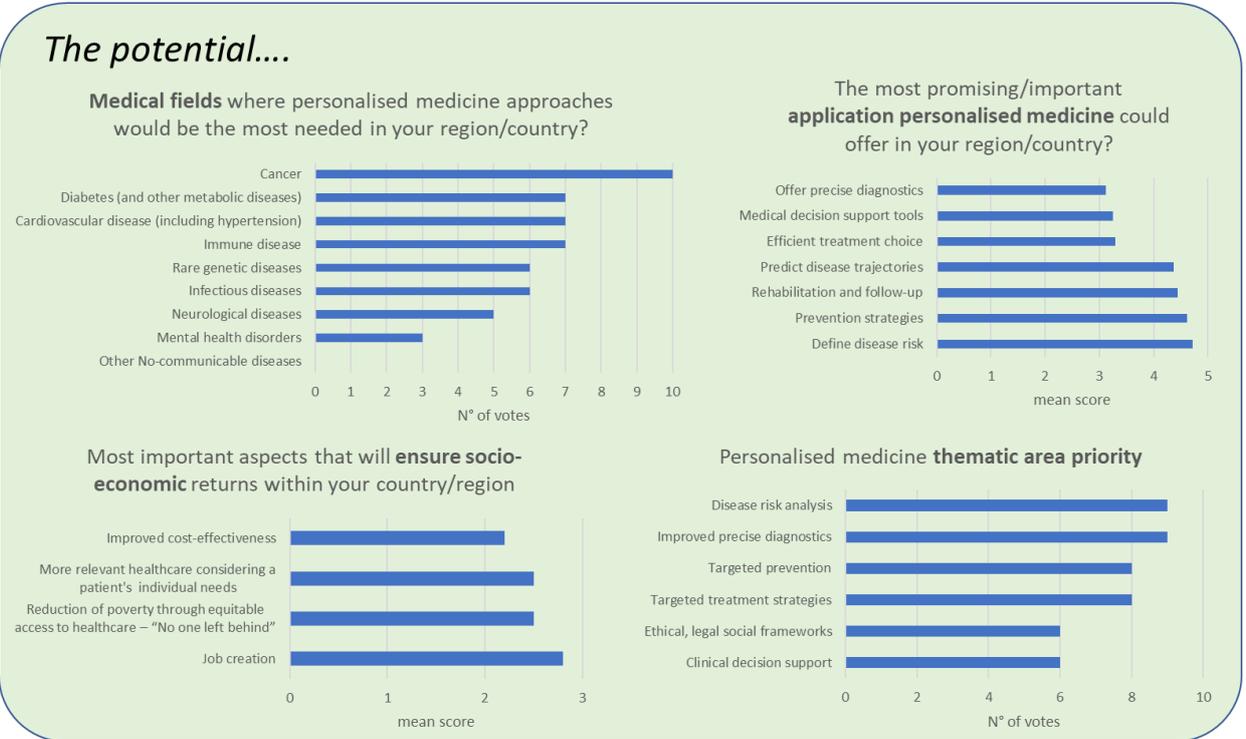
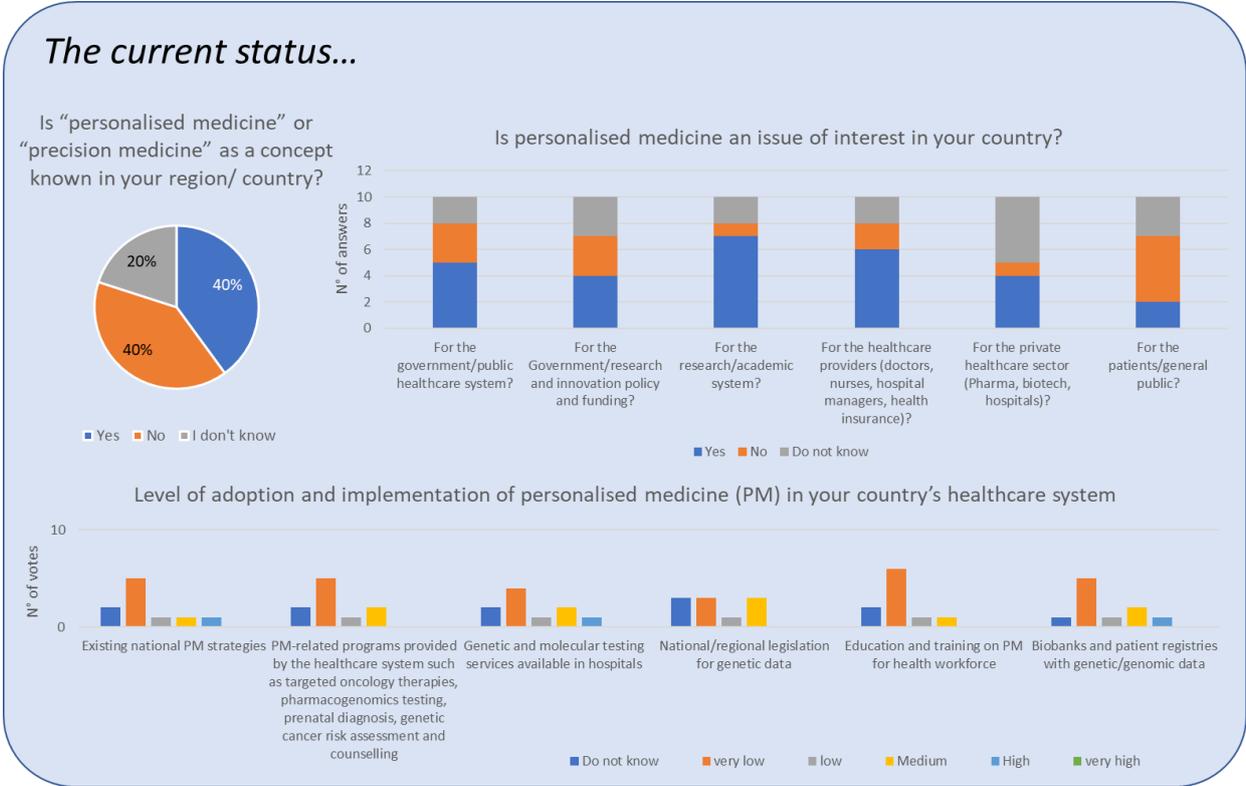


The need for strengthening EU-AU collaboration in PM: Scored 8,6 out of 10



The regional perspective: West Africa

Outcome "the regional perspective": 10 answers, West Africa





The regional perspective: West Africa

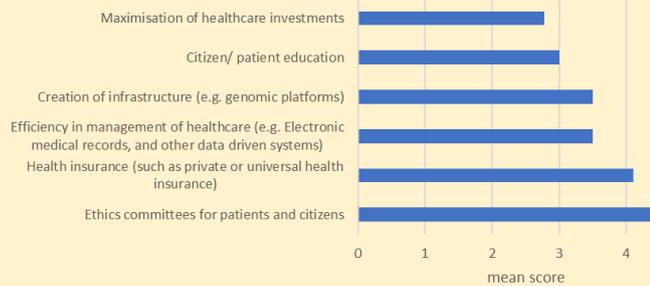
Outcome "the regional perspective": 10 answers, West Africa

Make personalised medicine a reality....

Efforts needed to enable personalised medicine

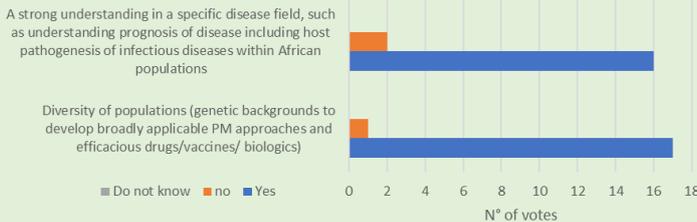


Most important aspects that could help to improve healthcare in your country/region



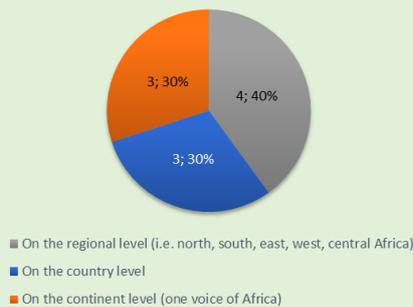
The African perspective and collaboration in personalised medicine...

Contribution African countries can bring into global personalised medicine reflections and development are...

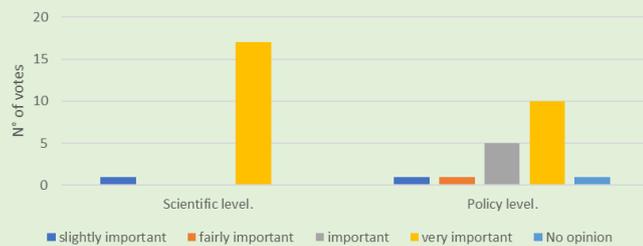


89% think that the EU-Africa PerMed initiative can be a driving force towards the development of personalised medicine in Africa

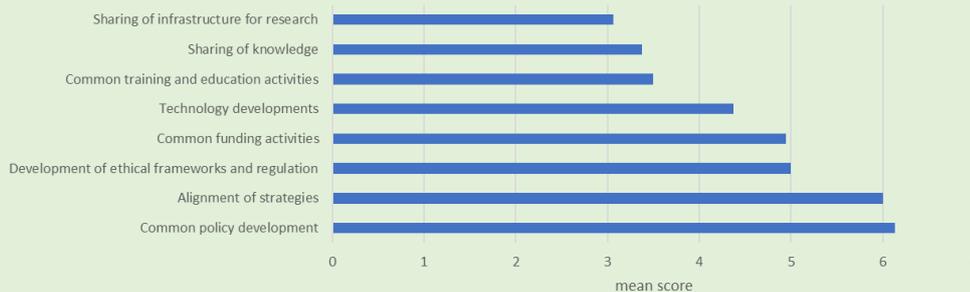
Fostering PM development in Africa



Strengthen collaboration, at what level do you think it is more important to increase efforts?



Areas in which collaboration between Africa and Europe could be of mutual benefit



The need for strengthening EU-AU collaboration in PM: Scored 8,6 out of 10

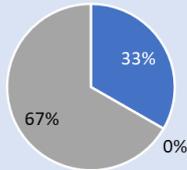


The regional perspective: Central Africa

Outcome "the regional perspective": 3 answers, Central Africa

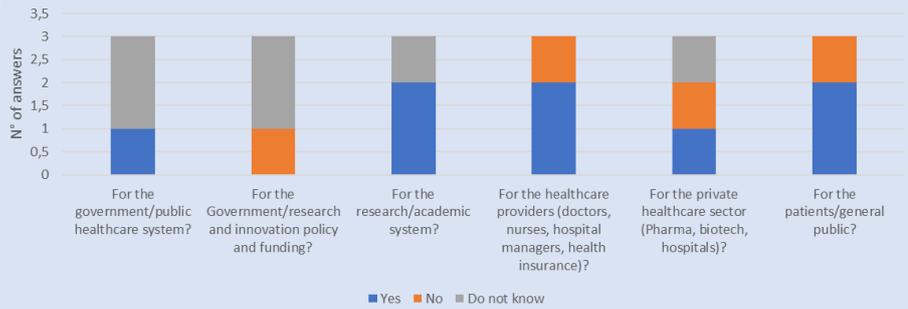
The current status...

Is "personalised medicine" or "precision medicine" as a concept known in your region/ country?



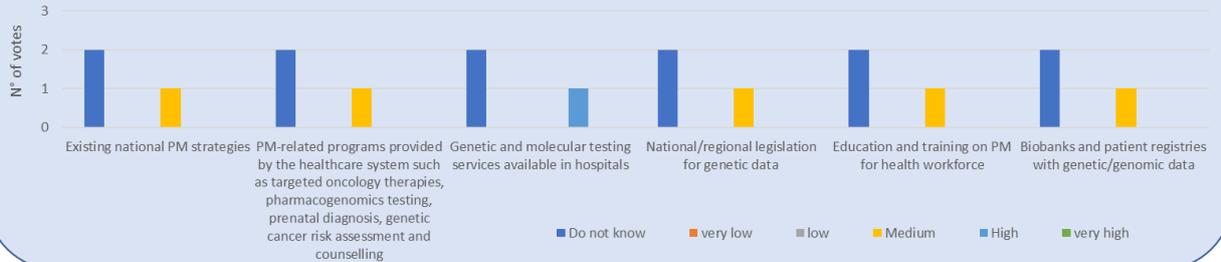
■ Yes ■ No ■ I don't know

Is personalised medicine an issue of interest in your country?



■ Yes ■ No ■ Do not know

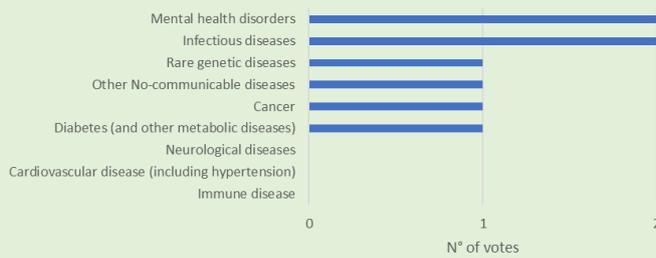
Level of adoption and implementation of personalised medicine (PM) in your country's healthcare system



■ Do not know ■ very low ■ low ■ Medium ■ High ■ very high

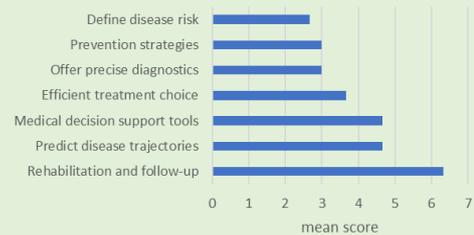
The potential...

Medical fields where personalised medicine approaches would be the most needed in your region/country?



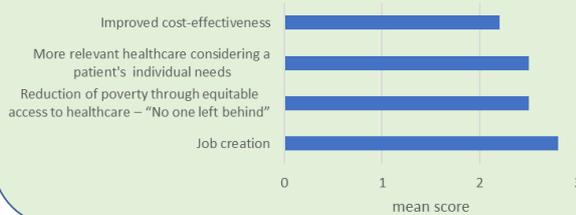
N° of votes

The most promising/important application personalised medicine could offer in your region/country?



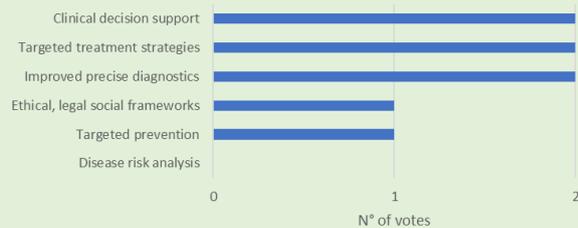
mean score

Most important aspects that will ensure socio-economic returns within your country/region



mean score

Personalised medicine thematic area priority



N° of votes



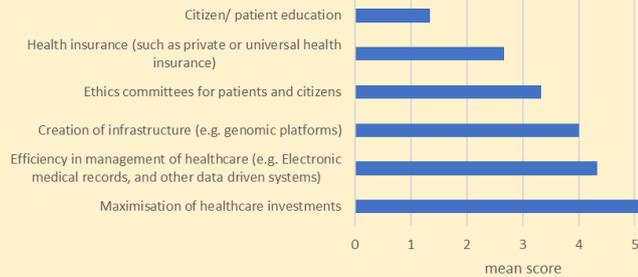
The regional perspective: Central Africa

Outcome "the regional perspective": 3 answers, Central Africa

Make personalised medicine a reality...

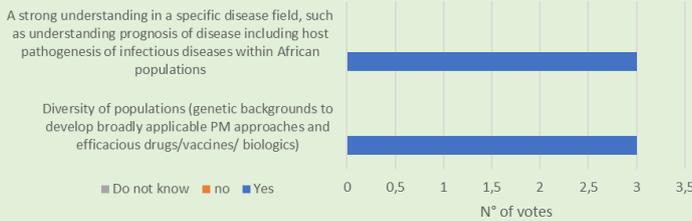


Most important aspects that will ensure socio-economic returns within your country/region



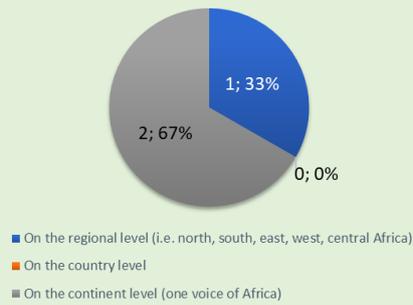
The African perspective and collaboration in personalised medicine...

Contribution African countries can bring into global personalised medicine reflections and development are...

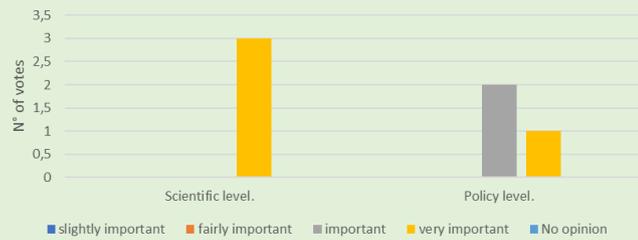


100% think that the EU-Africa PerMed initiative can be a driving force towards the development of personalised medicine in Africa

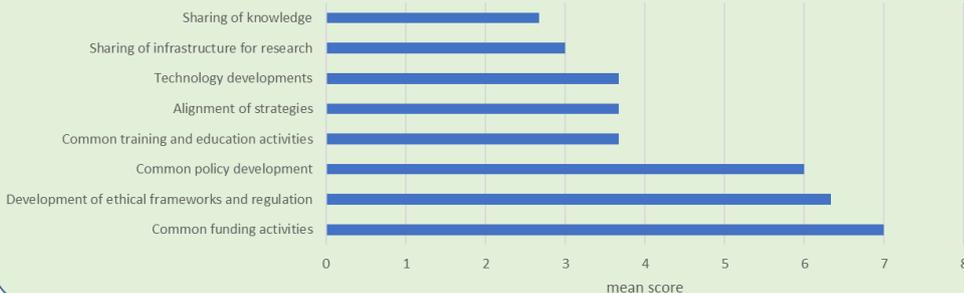
Fostering PM development in Africa



Strengthen collaboration, at what level do you think it is more important to increase efforts?



Areas in which collaboration between Africa and Europe could be of mutual benefit



The need for strengthening EU-AU collaboration in PM: Scored 8,7 out of 10



ANNEX 2: PREPARATORY SURVEY – structure

This section presents the preparator survey. The online survey was available in French and English language. Below is only provided the English version.

1st EU-Africa PerMed Stakeholder Workshop preparatory survey

In preparation of the first stakeholder workshop organised on 9th and 10th of February 2022, EU-Africa PerMed is launching this survey. It will take you only around 10-15 minutes to complete the survey.

Your input is important for focusing the workshop discussions and for allocating you to small discussion groups during the workshop. Furthermore, your responses will help the project to advance in the identification of areas of mutual interest for the collaboration between Africa and Europe in Personalised Medicine.

The survey contains different sections. You are kindly requested to complete all the sections. Thank you very much in advance for your collaboration.

1st EU-Africa PerMed Stakeholder Workshop preparatory survey

GENERAL SECTION

This section allows you to present yourself and your background. Based on your indications, you will be allocated to small discussion groups during the workshop.

* INFORMATION OF THE PERSON COMPLETING THE SURVEY

NAME	<input type="text"/>
FIRST NAME	<input type="text"/>
AFFILIATION	<input type="text"/>
COUNTRY	<input type="text"/>

* **PRIVATE POLICY.** Please note that Personal Data disclosed in this survey will only be utilized to support the preparation and follow-up of the workshop. Contact details will be archived securely and only used with your informed consent. Please reach out to us should you require additional information about the project (info@euafrica-permed.eu)

Link to privacy statement: [privace policy statement](#)



I Have read and agree on the privacy statement for this survey



* 1.1) Please specify the type of organisation you work at?

- Research organisation
- Research and Innovation funder
- Health system policy maker
- Healthcare provider
- Industry and private business
- Civil society organisation
- Other (please specify)

* 1.2) What is your job/position in the organisation you indicated in Question 2? Please stipulate your position below:

- CEO/ General manager
- Clinician
- Funding programme manager
- Research director
- Research project manager
- Researcher
- Policy officer
- Other (please specify)

* 1.3) To understand your expertise please state your expertise from the following options. *More than one option is possible*

- Natural sciences
- Clinics/medical field
- Data sciences
- Social sciences
- Education
- Regulation
- Legislation
- Diplomatic services/collaborations
- Other (please specify)



1st EU-Africa PerMed Stakeholder Workshop preparatory survey

SECTION 2 - SITUATION OF PERSONALISED MEDICINE IN YOUR REGION/COUNTRY

Your feedback in this section will directly feed into the workshop preparations and discussions. Based on your indications, you will be allocated to small discussion groups during the workshop.

* 2.1) Please provide the name of the organisation(s) that is/are contributing to the development of the research agenda/to define research priorities in your region/country.

* 2.2) Is "personalised medicine" or "precision medicine" as a concept known in your region/country?

- Yes
- No
- I don't know

* 2.3) More concretely, based on your own experience and knowledge, is personalised medicine an issue of interest in your country? Please respond in terms of the region/geographical area for which your organisation works. (Please answer all items)

	Yes	No	Do not know
For the government/public healthcare system?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
For the Government/research and innovation policy and funding?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
For the research/academic system?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
For the healthcare providers (doctors, nurses, hospital managers, health insurance)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
For the private healthcare sector (Pharma, biotech, hospitals)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
For the patients/general public?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2.4) On a personal note, in your region/country, what do you think is the most promising/important application personalised medicine could offer? Please rank your choices from 1: most important to 7: least important

	<input type="text"/>	Define disease risk
	<input type="text"/>	Predict disease trajectories
	<input type="text"/>	Offer precise diagnostics
	<input type="text"/>	Efficient treatment choice (e.g. pharmacogenetic, multi-medication)
	<input type="text"/>	Prevention strategies
	<input type="text"/>	Medical decision support tools
	<input type="text"/>	Rehabilitation and follow-up



* 2.5) Following question 2.4: In your region/country, select the medical fields where personalised medicine approaches would be the most needed? *More than one option is possible*

- Infectious diseases
- Immune disease (Including transplantation, autoimmune diseases)
- Cardiovascular disease (Including hypertension)
- Diabetes (and other metabolic diseases)
- Cancer
- Neurological diseases
- Mental health disorders
- Other non-communicable diseases
- Rare genetic diseases
- Other (please specify)

* 2.6) What do you consider is the level of adoption and implementation of personalised medicine (PM) in your country's healthcare system? [This includes both public and private healthcare]

	Very high	High	Medium	low	very low	Do not know
Existing national PM strategies	<input type="radio"/>					
PM-related programs provided by the healthcare system such as targeted oncology therapies, pharmacogenomics testing, prenatal diagnosis, genetic cancer risk assessment and counselling	<input type="radio"/>					
Genetic and molecular testing services available in hospitals	<input type="radio"/>					
National/regional legislation for genetic data	<input type="radio"/>					
Education and training on PM for health workforce	<input type="radio"/>					
Biobanks and patient registries with genetic/genomic data	<input type="radio"/>					

2.7) Precision/personalised medicine is shown to offer great value in healthcare. In your opinion, what do you think are the most important aspects that could help to improve healthcare in your country/region. Please rank the following, 1 for the most important, 5 for the least important.

- Citizen/ patient education
- Maximisation of healthcare investments
- Efficiency in management of healthcare (e.g. Electronic medical records, and other data driven systems)
- Creation of infrastructure (e.g. genomic platforms)
- Health insurance (such as private or universal health insurance)
- Ethics committees for patients and citizens



2.8) In your opinion, what do you think is the most important aspects that will ensure socio-economic returns within your country/region? Please rank the following, 1 for the most important, 4 for the least important.

		Reduction of poverty through equitable access to healthcare – “No one left behind”
		Job creation
		Improved cost-effectiveness (ratio of the cost of an intervention to the effect for the patient/citizen, e.g. cure, reduction of side effects, prevention of disease occurrence etc.)
		More relevant healthcare considering a patient's Individual needs

* 2.9) To help us identifying and prioritising precision/personalised medicine needs in your region/country, which personalised medicine thematic area should your region/country first concentrate on? More than one option is possible

- Improved precise diagnostics
- Targeted treatment strategies
- Clinical decision support
- Targeted prevention
- Disease risk analysis
- Ethical, legal social frameworks
- Other (please specify)

* 2.10) In your opinion, in which of the following areas more effort is needed to make personalised medicine possible in your country? Multiple answers are possible

- Scientific and technological needs** [i.e. existence of national strategic plans, programmes, actions supporting PM-related basic, translational and clinical research; infrastructures for PM research (i.e. biobanks, large-scale genomic databases, DNA sequencing facilities, etc.); undergraduate and post graduate training focused on PM, including genomic science, bioinformatics and data science; efforts to improve data sharing and data harmonisation of existing databases; academia-industry collaborations in research]
- Operational needs for better integrating PM into healthcare and clinical practice** (i.e. training and education of healthcare providers; access to genetic testing infrastructure in hospitals; increase access to novel drugs; transfer of research to the market; readiness of clinical trial sites to participate in developing prevention care personalised medicine strategies)
- Governance / regulatory / ethics needs** [i.e. existence of ethical, social, legal (regulatory) frameworks for genetic data (data ownership, privacy, security/protection, sharing); level of awareness and knowledge about PM of policy makers; trust amongst citizens and patient; payment strategies]



SECTION 3- INTERNATIONAL COLLABORATIONS IN PERSONALISED MEDICINE RESEARCH

* 3.1) The African continent is vast. To foster the development of personalised medicine in Africa, on which level should developments take place?

- On the continent level (one voice of Africa)
- On the regional level (i.e. north, south, east, west, central Africa)
- On the country level

* 3.2) in your opinion, do you agree that the contribution African countries can bring into global personalised medicine reflections and developments are:

	Yes	No	I dont know
Diversity of populations (genetic backgrounds to develop broadly applicable PM approaches and efficacious drugs/vaccines/biologics)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A strong understanding in a specific disease field, such as understanding prognosis of disease including host pathogenesis of infectious diseases within African populations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<div style="border: 1px solid black; height: 40px; width: 100%;"></div>		

3.3) In your opinion, what are the areas in which collaboration between Africa and Europe could be of mutual benefit? Please rank the options, assigning 1: most important and 8: least important

<input type="checkbox"/>	Sharing of knowledge
<input type="checkbox"/>	Sharing of infrastructure for research
<input type="checkbox"/>	Common training and education activities (any focus, e.g. healthcare providers, patients, citizens, researchers)
<input type="checkbox"/>	Alignment of strategies
<input type="checkbox"/>	Common policy development
<input type="checkbox"/>	Common funding activities
<input type="checkbox"/>	Technology developments
<input type="checkbox"/>	Development of ethical frameworks and regulation

