

**THE EU-AFRICA PERSONALISED MEDICINE
STAKEHOLDER MAPPING REPORT**

November 2021

ABOUT THIS REPORT

This report is produced within the framework of the [EU-Africa PerMED project](#), an EU funded project with grant agreement no.964333 and entitled "Building links between Europe and Africa in personalized medicine". The aim of the report is to provide key insights on the various stakeholders and their role in supporting personalized medicine in Africa within the scope of EU-Africa PerMED project. In this respect, the report purposes to perform stakeholders mapping including various sets of actors in Africa; Innovation enablers & health research organizations; research and innovation funders; health system policymakers; healthcare providers; industry and private businesses; and civil society organizations. The report is important to establish a framework that values the viewpoints of various stakeholders and stimulate an effective engagement process while focusing on personalized medicine value chain from various dimensions including their nature and scope of activities, areas of interest and focus as well as a potential contribution to making a success of personalized medicine.

ABOUT EU-Africa PerMED PROJECT

The EU-Africa PerMed project aims is to incorporate African countries into major European initiatives especially International Consortium for Personalised Medicine (ICPerMed) activities in order to contribute to a successful implementation of personalized medicine, fostering joint personalized medicine projects and programs between Africa and Europe, as well as strengthening bilateral EU-Africa science and technology relations in the area of health research and innovation. Ultimately, incorporating African countries into the global personalized medicine research agenda can contribute to shortening existing health disparities between developed and developing countries, as well as facilitating access to new tools and technologies that have the potential to improve health care in Africa.

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EXECUTIVE SUMMARY

In this report, we present the results of a stakeholder mapping exercise utilizing the existing networks of the EU-Africa PerMed Consortium. Stakeholders were identified and mapped according to their relevance to Personalised Medicine (PM) in Africa. Even though the contact list is not exhaustive, the list is expansive in showing the different levels of stakeholders working within or may be affiliated with the PM space in Africa.

The team developed a framework and used it to identify and engage individuals, organizations, networks, and initiatives relevant to the EU-Africa PerMed project. As a result, 472 contacts were identified. Contacts were organized into six categories: Innovation enablers/health research organizations; research and innovation funders; health system policymakers; healthcare providers; industry and private businesses; and civil society organizations.

Once the contacts were collected in an Excel Data Base, The team carried out a mapping exercise to: i) Determine each stakeholder's level of control/power versus the influence of each stakeholder within their country context; ii) Based on the outcome of the mapping exercise, define the priority stakeholders for the project and iii) Define which stakeholders will be invited to participate in the upcoming stakeholder workshop of EU-Africa PerMed project.

The report also includes as Annex, the results of the stakeholder survey carried out as part of the activities of both the policy and stakeholder mapping (the relevant reports are available at the project website). This survey had as principal objective to collect qualitative information about the situation of PM in Africa to complement the policy mapping work. As a second objective, the survey helped to start communicating about the project to the stakeholders identified.

1. INTRODUCTION

The most critical aspect of precision medicine is the knowledge needed to understand the relationship between genetic variability, lifestyle, the environment, and health. Since the first human genome was sequenced in the early 2000s, nations with access to this technology have executed extensive scale population studies. These studies have led to the reality of precision or personalized medicine as we know it today. Unfortunately, due to many challenges, limited population genomic studies are conducted on the African population.¹ There is inadequate information on African Populations to understand the relationship between genetic variability and the precise diagnosis, treatment, and risk of developing diseases. Therefore, stimulating genomic science to understand African populations will become a key area in developing Precision Medicine (PM).

Implementation of precision medicine requires several resources such as access to technology infrastructure and population genomic and phenotypic data; extensive research on specific diseases in individual populations; skills in genomic comprehensive data analysis and interpretation. This also requires research and clinical infrastructure for conducting research and routine genetics testing. Even though there are some limitations in the availability and implementation of these resources, there are notable examples of success in the continent. Initiatives by the Wellcome Trust DELTAS program, the GSK Africa OpenLab, the South African Medical Research Council Precision Medicine program, the Human Heredity and Health in Africa (H3Africa) Initiative have led to the development of baseline studies and PM solutions.² These

¹ Wonkam, A. Sequence three million genomes across Africa. Capture the full scope of variation to improve health care, equity, and medical research globally. *Nature* 590, 209-211 (2021). doi: <https://doi.org/10.1038/d41586-021-00313-7>

² The H3Africa Consortium. Enabling African scientists to engage fully in the genomic revolution. *Science* 344(6190), 1346–1348 (2014).

initiatives have developed skills and infrastructure for genomics data generation, analysis, training as well as the development of precise diagnostics.

Research is the foundation to enable PM. There needs to be sufficient African population genomics knowledge generated to inform the development of diagnostics and appropriate therapies to make PM a reality in Africa. Further to the development of genomics and data science on the continent, the tangibility of PM is to administer the proper treatment to the right patient at the right time. Meeting the challenge of building sustainable research and translational enterprise for PM in Africa will require close partnership between African and established sources of support. There are also benefits to collaborating and developing the necessary infrastructure, particularly in resource-limited settings. Countries should pool resources and efforts to ensure efficiency. PM has shown that utilizing data and tools to intervene early in the treatment of patients can considerably reduce the cost of treatment and care. All stakeholders representing scientists, clinicians, policymakers, and patients need to address the gaps between research and applied PM. The patient-centric approach in medical care requires the buy-in from stakeholders across the healthcare spectrum. This includes patients, care providers, clinical laboratories, researchers, and supportive health systems to ensure consideration of each patient's health context.

The EU-Africa PerMed project aims to establish a framework that values various stakeholder viewpoints to identify the main challenges and opportunities of PM in Africa and to engage with key target groups, and invite them to participate in project activities.

2. THE STAKEHOLDER MAPPING PROCESS

The mapping process was informed by the AAS Policy Paper 1 (2020)³ and shown in Figure 1. The paper outlines the different stakeholder groups that constitute the PM ecosystem. Stakeholders in PM fall into three categories depending on their involvement within the ecosystem. They may be involved at different levels as defined below:

- i) **At an individual or micro level-** where the primary stakeholders are patients who directly benefit or anticipate PM healthcare and they may have a **high interest in the** application of PM, as they need to understand the benefits and convey informed consent as well as participate. However, they do not have a high level of influence in uptake of PM within the ecosystem due to their lack of specific knowledge in the field or limited access to healthcare. Researchers who are generating the knowledge to develop PM based solutions in Africa have a high interest and should be seen as pertinent stakeholders. They have dedicated their efforts toward building a foundation that will eventually underpin PM in Africa. Hence they may not have high influence in the funding agenda or the macro healthcare systems but they do have a level of influence on how research is prioritized within their institutions and sometimes through involvement in key national committees they may be able to advocate for PM within their countries.
- ii) **Involvement at the meso level-** the primary stakeholders are the institutional or organizational level who may be involved in the health innovation and health system oversight. The primary stakeholders are those involved in public and private healthcare facilities, technology infrastructure, insurance companies, national think tanks on how to develop and implement PM applications, data infrastructure, and bio banking facilities. These may also include private suppliers such as biotechnology companies and genetic testing service labs. These stakeholders hold a high interest in PM and although they do not set a national mandate, they can actively practice PM approaches and stimulate the critical

³ AESA (2020) A Framework for the Implementation of Genomic Medicine for Public Health in Africa October 2020. Nairobi: Alliance for Accelerating Excellence in Science in Africa.

mass required to establish fully fledged industry development as well as private sector PM healthcare. The industry players have the power to dictate pricing and efficiency in the supply-chain. They are expansive and can operate across borders. Therefore, they can be considered to be highly influential and hold high interest.

iii) **Impactful involvement at a macro level** - the primary stakeholders are mainly government and regional representatives. They hold high influence on national and regional mandates. Even if these stakeholders do not hold a high interest in driving PM they are the most influential in sanctifying a macro context for PM in their respective countries.

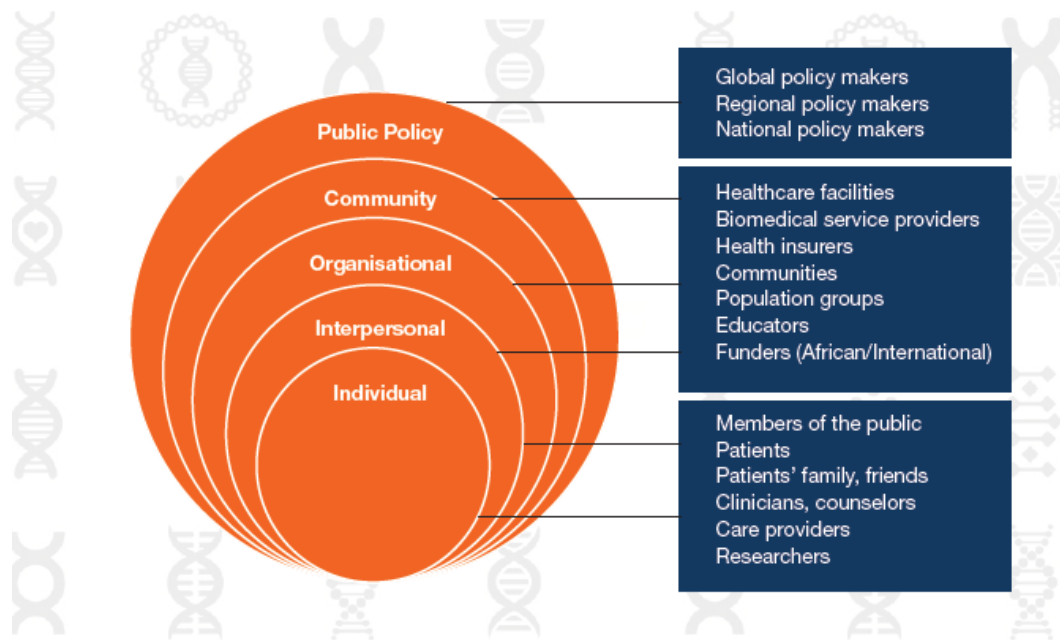


Figure 1: A socio-ecological framework for stakeholders in precision medicine

As shown in figure 1, these stakeholder categories were simplified according to relevance for the EU- Africa PerMed project. TABLE 1, shows the various stakeholder categories that were deemed necessary for this project. Work package 2 (WP2) has identified and mapped some of the main stakeholders relevant to PM in Africa. Even though the contact list is not exhaustive, the list is expansive in showing the different levels of stakeholders working within or who may be affiliated to the PM ecosystem in Africa.

A framework was developed and used to guide the identification and engagement of individuals, organizations, networks and initiatives relevant to the EU-Africa PerMed project. As a result, **472 contacts were identified**. These contacts were organized according to six categories: Innovation enablers/health research organizations; research and innovation funders; health system policy makers; healthcare providers; industry and private businesses; and civil society organizations. TABLE 1, outlines the stakeholder groups and indicates their relevance to the respective work packages within the project.

TABLE 1 – Stakeholder groups and Work Package involvement

GROUP	STAKEHOLDERS	Necessity of involvement for Work Package objectives
INNOVATION ENABLERS/ HEALTH RESEARCH ORGANIZATIONS GROUP 1	1.1 Universities Research groups -health sciences (Doctors, including experts from Life sciences in biostatistics, bioinformatics and genomics) from non-medical experts in Big Data and AI) 1.2 Research centers/institutions including science councils and private institutions 1.3 Private-public partnerships 1.4 Regulators (important to think about customs) 1.5 Biobanks (public and Private) 1.6 Ethics Councils and committees 1.7 Research consortium and networks	All stakeholders relevant for WP2 and WP6 Groups 1.1, 1.2, 1.3, 1.4, 1.6, 1.7 relevant for WP3 Groups 1.1, 1.2, 1.5, 1.6, 1.7 relevant for WP5
RESEARCH AND INNOVATION POLICY AND FUNDERS GROUP 2	2.1 Science granting councils 2.2 Research funding agencies, 2.3 Science & Technology ministries 2.4 Private foundations 2.5 Multilateral funding agencies	All groups relevant for WP2, WP3 (?), WP5, WP4, WP6
HEALTH SYSTEM POLICY MAKERS GROUP 3	3.1 Health ministries 3.2 International organizations (WHO, Multilateral organizations) 3.3 Regional Agencies (include Parastatals those in policy research and form the advisory capacity to government) and other players involved in policy and health system research. 3.4 Regulators	All groups relevant for WP2, WP3, WP4 and WP6
HEALTHCARE PROVIDERS Group 4	4.1 Hospitals 4.2 Laboratory facilities/ infrastructure	Relevant for WP2 and WP3
INDUSTRY AND PRIVATE BUSINESSES GROUP 5	5.1 Pharmaceutical companies 5.2 Biotech companies 5.3 Genomic testing companies 5.4 Diagnostic Laboratories 5.5 Technology suppliers 5.6 Medical insurers 5.7 Health Data companies	Relevant for WP2 and WP3

	5.8 Health incubators (organizations promoting start-ups in health)	
CIVIL SOCIETY ORGANIZATIONS GROUP 6	6.1 Patient groups 6.2 Advocacy groups	Relevant for WP2

3. METHODOLOGY

Activity 1: Identifying stakeholders

All consortium members and institutions were assigned regions and countries and they all provided contact details of people and organizations involved in PM or initiatives relevant to the area. An Excel template was developed to collate contact information. Sub-categories were used to assist to delineate stakeholders such as the contact person’s organization, their designation, and email address among other important details. Each contact was categorized within their regions and the six categories: health research organizations; research and innovation funders; health system policymakers; healthcare providers; industry and private businesses; and civil society organizations (Figure 2).

The distribution of each category is delineated further (Figures 3 to 8). Figures 3, 4, 5, 6, 7, 8 shows the country representation of the stakeholder groups. There is an uneven distribution of the total number of contacts within the stakeholder database per region. It is apparent that the largest volume of stakeholders emanate from Southern Africa and the least number of contacts were collated from the Central African region. In all regions, the greatest number of stakeholders constituted the ‘health research organizations’ category. Whilst the ‘health system policy makers’ category dominated the Central African region contact list.

Region	Stakeholder groups	No.
Central Africa	1. Health research organizations	8
	2. Research and innovation funders	5
	3. Health system policy makers	18
Eastern Africa	1. Health research organizations	46
	2. Research and innovation funders	20
	3. Health system policy makers	34
	4. Healthcare providers	4
	5. Industry and private businesses	4
	6. Civil society organizations	2
Northern Africa	1. Health research organizations	16
	2. Research and innovation funders	8
	3. Health system policy makers	7
	4. Healthcare providers	2
	5. Industry and private businesses	2
Southern Africa	1. Health research organizations	96
	2. Research and innovation funders	31
	3. Health system policy makers	33
	4. Healthcare providers	3
	5. Industry and private businesses	10
	6. Civil society organizations	2
Western Africa	1. Health research organizations	46
	2. Research and innovation funders	16
	3. Health system policy makers	57
	5. Industry and private businesses	2
Grand Total		472

Figure 2: Regional representation of stakeholders within the African Continent

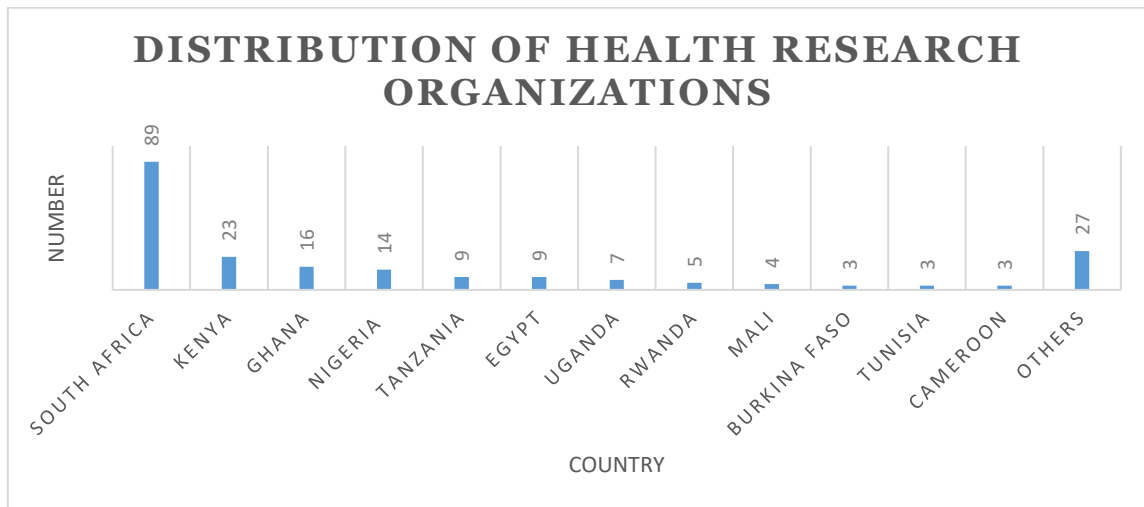


Figure 3: Distribution of health research organizations

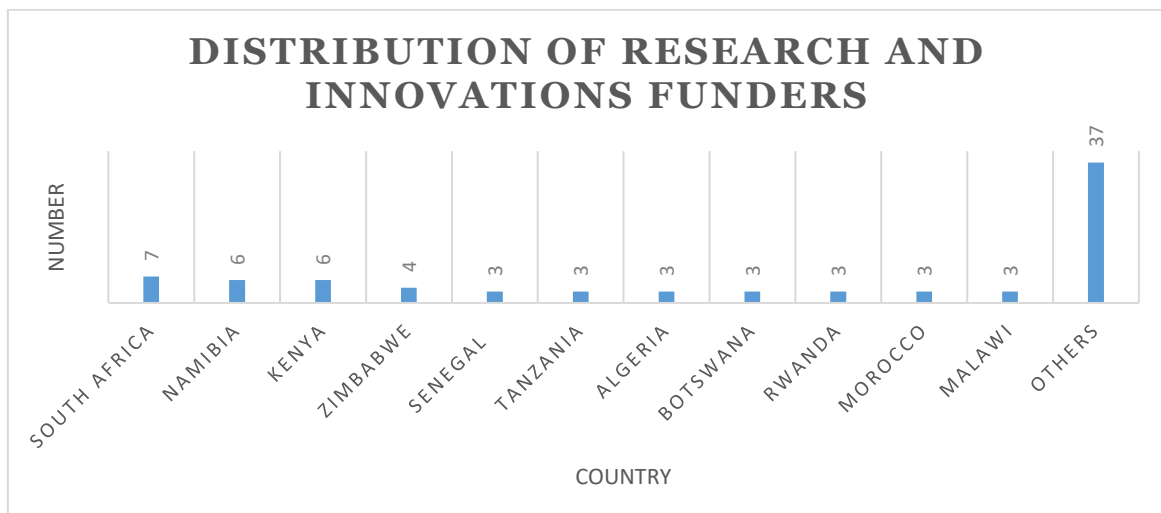


Figure 4: Distribution of research and innovation funders

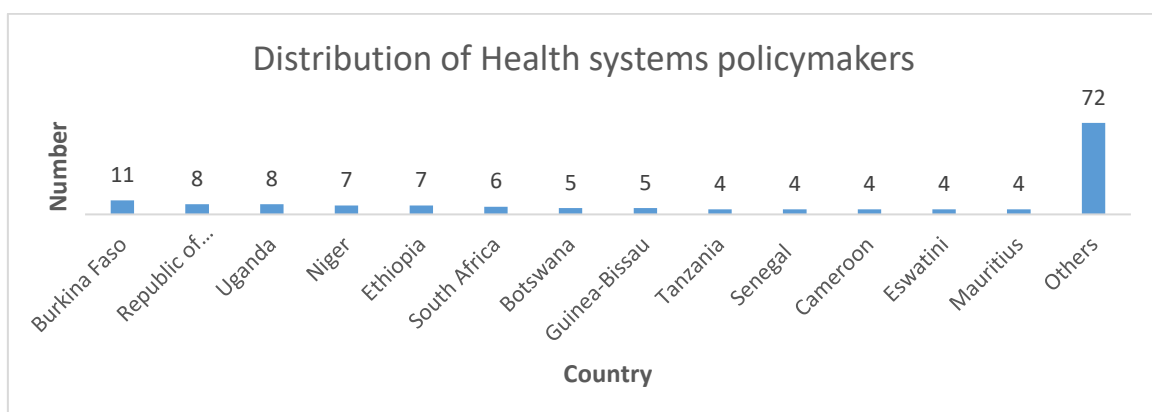


Figure 5: Distribution of health systems policymakers

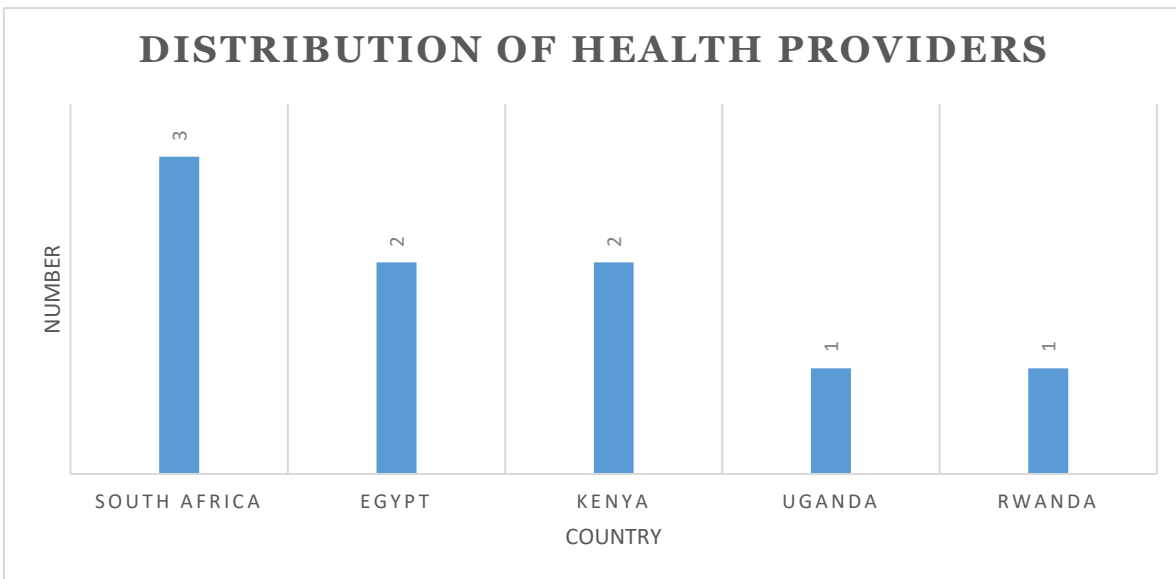


Figure 6: Distribution of health providers

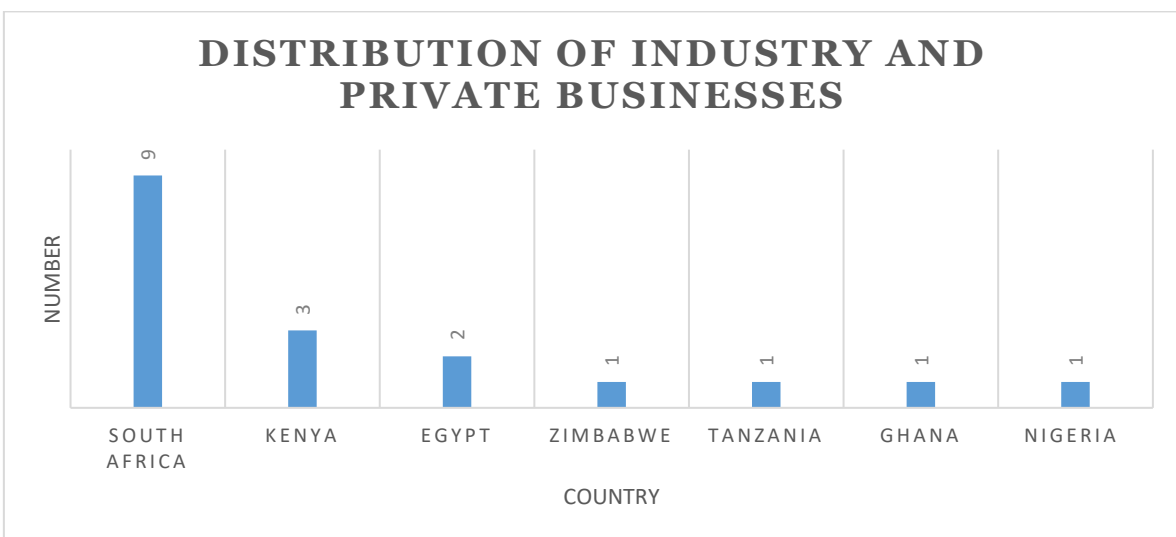


Figure 7: Distribution of industry and private businesses



Figure 8: Distribution of civil society organizations

Activity 2: Stakeholder mapping by level of influence and interest

Stakeholder mapping is the visual process of laying out all the stakeholders of the PM ecosystem on one map. The main benefit of a stakeholder map is **to get a visual representation of all the people who can influence PM, specifically related to the outcomes of this project and how they are connected**. Utilizing the stakeholder database developed in Activity 1, a workshop took place on November 6, 2021 to discuss the process taken to map the contacts. The purpose of the exercise was to:

- Determine each stakeholder’s level of control/power versus the influence of each stakeholder within their country context.
- Based on the outcome of the mapping exercise, define the priority stakeholders for the project
- Define which stakeholders will be invited to participate in the upcoming stakeholder workshop

The mapping was guided by the following approach. **The stakeholder** database included a mapping section with four descriptions to define the level of **influence and interest** of each stakeholder.

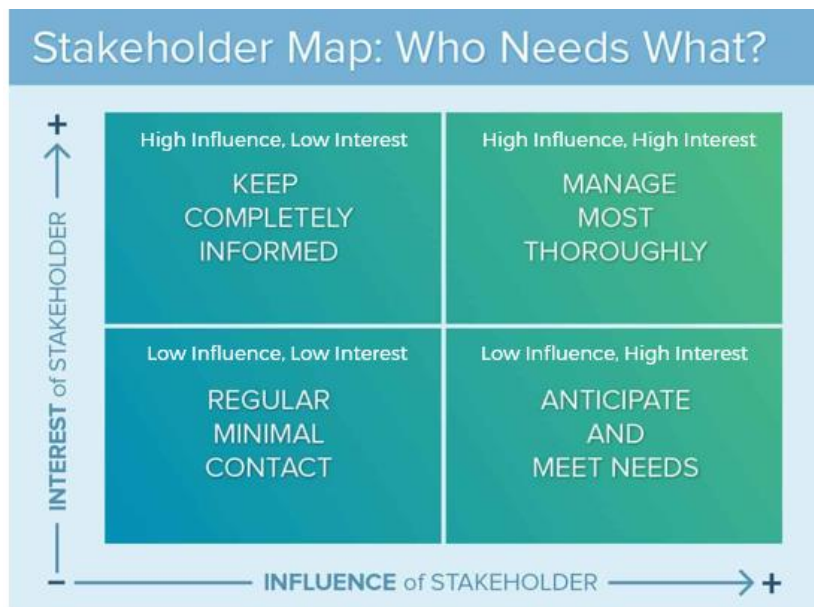


Figure 9: Stakeholder matrix of influence and interest

A set of criteria were developed to guide where each contact would be categorized as indicated below:

Criteria for Influence

- A person’s position and ability to influence change (policy/legislation) these constituted – legislators, Ministers of Health etc.
- Provider of grant/research funding
- Who has great networks and will assist the project connect with key stakeholders?
- Industry players who can influence the supply chain within the PM ecosystem, these include healthcare providers; insurance companies (payers) etc.
- Those responsible for available infrastructure that will enable PM activities.

Criteria for Interest

- Who will assist in achieving project objectives?
- Recipient of grant funding and researchers who are developing new knowledge and have published on PM.
- Involved in PM from a policy, programme or training perspective.
- Research organizations.

Activity 3: Defining the relevance of each stakeholder to the project

Utilizing the criterion set out in Activity 2, each contact was further categorized indicating which quadrant they belong to, and further defined their relevance to the project. While at this point relevance to the project may be subjective, it is believed that the number of stakeholders to engage and the role they will play in the future will be understood as the implementation of the project continues. However, it is anticipated that more informative feedback will be derived from the first stakeholders meeting, to take place in February 2022 (Task 2.4).

The mapping exercise highlighted the level of influence and interest of PM stakeholders within Africa. Figures 10 to 13 show the distribution of relevance these stakeholders have within their respective countries. South Africa was shown to illustrate the highest level of interest and Ghana showing the least level of interest. However, it should be noted that this data is skewed as this is largely dependent on the number of contacts listed per country. South Africa has the most number of stakeholders listed. Therefore, the level of interest of stakeholders listed within each country, may be deemed more feasible for this analysis Figures 10- 13 highlight the distribution of stakeholders based on the level of relevance to the project by country. The most significant distribution of the level of relevance to the project was seen in the top 11 countries. The remaining countries showed insignificant or no stakeholders to map and report on.

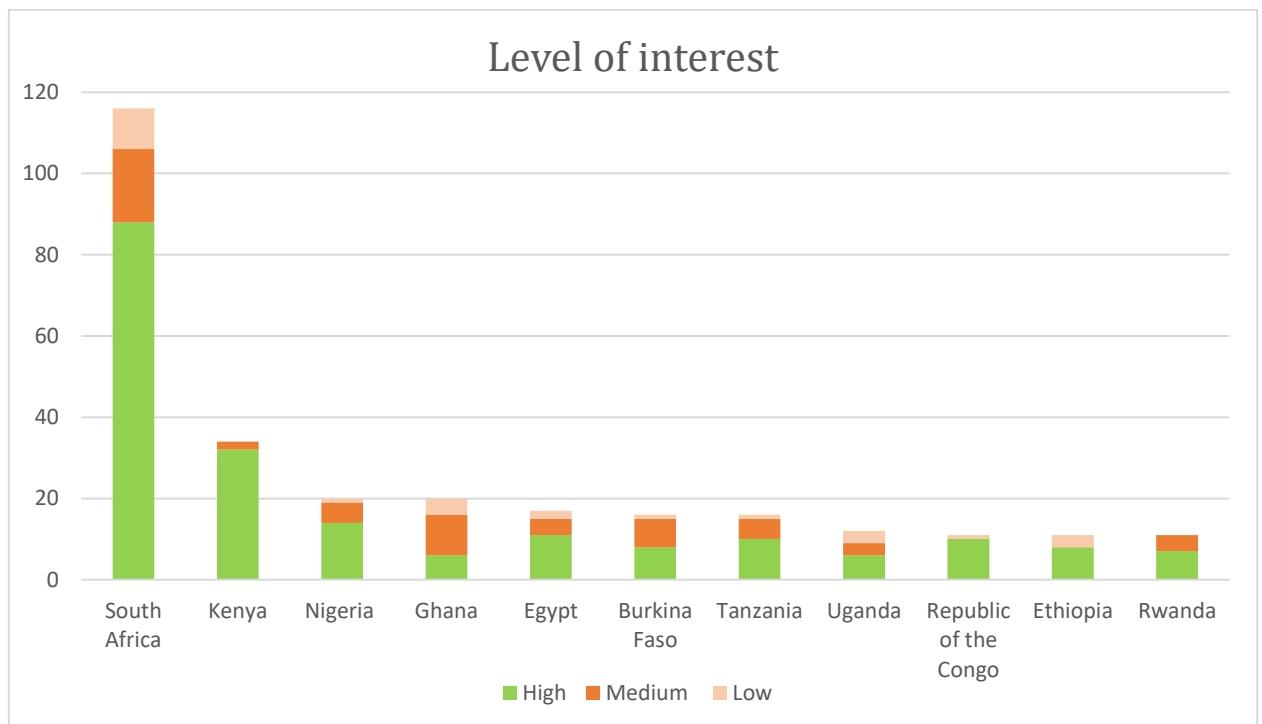


Figure 10: Distribution of the level of interest to the project for the top 11 countries

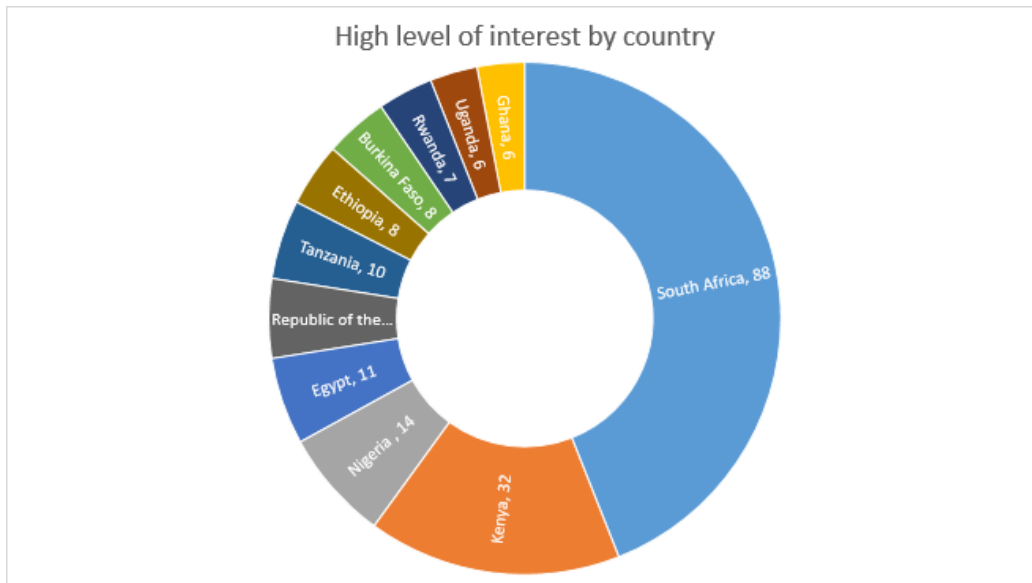


Figure 11: Distribution of high level of interest to the project by top 11 countries

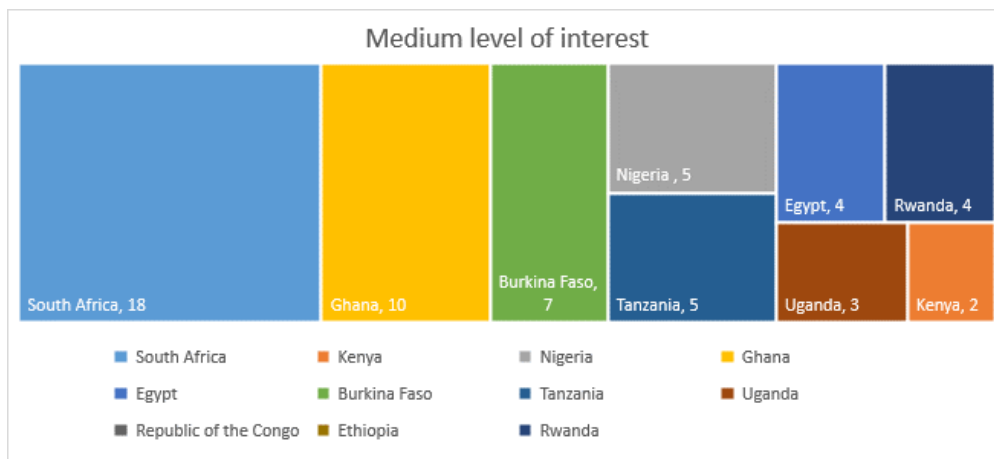


Figure 12: Distribution of medium level of interest to the project for the top 11 countries

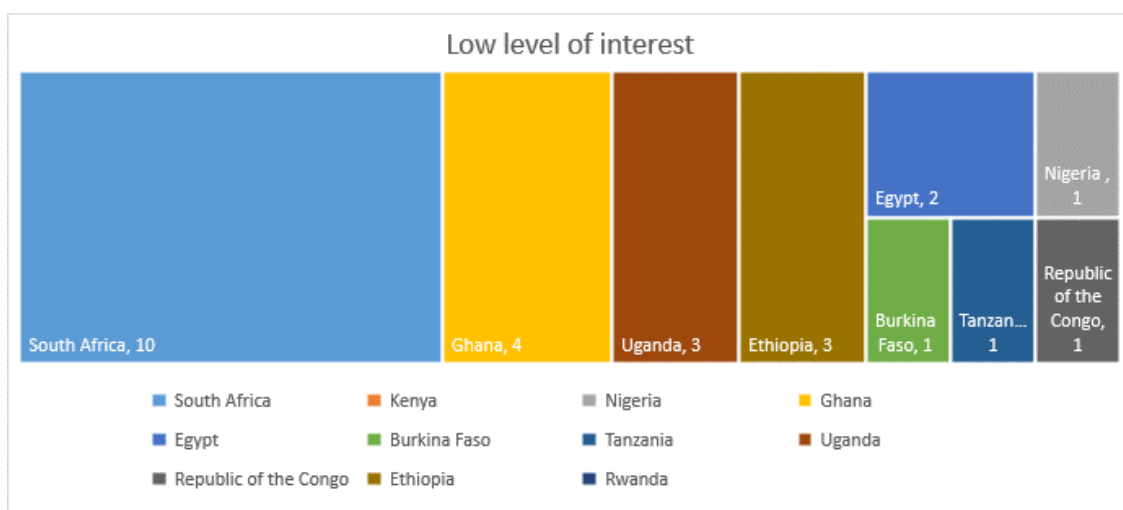


Figure 10: Distribution of low level of interest to the project for the top 11 countries

4. CONCLUSION

The stakeholder mapping work has provided an initial database of contacts belonging to the stakeholder groups selected for the project, classified by relevance for the project, based on a set of criteria for influence and interest, as outlined in this report. This database will be refined, and an increase in the number of contacts from countries is expected as the project advances. Personal engagement with stakeholders for the different activities planned in WP2 (1st stakeholder workshop) and the rest of the work packages will contribute toward a more robust stakeholder database. The database is a valuable starting point to create the project Communication and Dissemination list (WP6).

In the following Annexes (1 and 2), a set of tables is included, showing the distribution of contacts within each stakeholder group by country. It is essential to mention that there is a much higher number of contacts for countries such as South Africa and Kenya in many cases. This is because relevant organizations from those countries are partners of the project and have been able to identify more contacts. It is also a fact that the number of organizations identified for each of the five African regions is not well balanced (high numbers for Southern Africa and low for Central Africa). While it has been difficult to identify actors for all the six stakeholder groups selected in some areas, the project team will work on solving this issue in the coming years as planned activities are implemented in WP3, WP4, and WP5. The deliverable report 2.1 highlighted the potential of leading scientific researchers on the African continent, and these contacts will be added to the stakeholder database.

Annex 3 includes the stakeholder survey results carried out by WP2 and excluded in the previous deliverable (D2.1) as it was incomplete at the time of submission. This survey aimed to understand PM in African countries to commence engagement with potentially relevant stakeholders.

ANNEX 1: A list showing the distribution of contacts in each of the stakeholder groups by country

STAKEHOLDER GROUPS	COUNTRY	NO.
1. HEALTH RESEARCH ORGANIZATIONS	South Africa	89
	Kenya	23
	Ghana	16
	Nigeria	14
	Tanzania	9
	Egypt	9
	Uganda	7
	Rwanda	5
	Mali	4
	Burkina Faso	3
	Tunisia	3
	Cameroon	3
	Côte d'Ivoire	2
	Ethiopia	2
	Senegal	2
	Malawi	2
	Gabon	2
	Republic of the Congo	2
	Morocco	2
	Zimbabwe	2
	Algeria	2
	Liberia	1
	Eswatini	1
	Mauritius	1
	DR Congo	1
	Niger	1
Benin	1	
Cabo Verde	1	
Seychelles	1	
Madagascar	1	
2. RESEARCH AND INNOVATION FUNDERS	South Africa	7
	Namibia	6
	Kenya	6
	Zimbabwe	4
	Senegal	3
	Tanzania	3
	Algeria	3
	Botswana	3
	Rwanda	3
	Morocco	3
	Malawi	3
	Nigeria	2
	Burkina Faso	2
	Seychelles	2

	Ethiopia	2
	Zambia	2
	Ghana	2
	Côte d'Ivoire	2
	Lesotho	2
	Djibouti	2
	Angola	2
	Mozambique	2
	Gambia	1
	Liberia	1
	DR Congo	1
	(blank)	1
	Mali	1
	Benin	1
	Uganda	1
	Republic of Chad	1
	Tunisia	1
	Republic of the Congo	1
	Cameroon	1
	Egypt	1
	Burundi	1
	Eswatini	1
	Niger	1
	Burkina Faso	11
	Republic of the Congo	8
	Uganda	8
	Niger	7
	Ethiopia	7
	South Africa	6
	Botswana	5
	Guinea-Bissau	5
	Tanzania	4
	Senegal	4
	Cameroon	4
	Eswatini	4
	Mauritius	4
	Somalia	3
	Nigeria	3
	Djibouti	3
	Zambia	3
	Sierra Leone	3
	Egypt	3
	Togo	3
	Côte d'Ivoire	3
	Rwanda	2
	Cabo Verde	2
	Kenya	2
	Gambia	2
	Burundi	2
3. HEALTH SYSTEM POLICY MAKERS		

	Ghana	2
	DR Congo	2
	Guinea	2
	Mali	2
	Zimbabwe	2
	Angola	2
	Republic of Chad	2
	Eritrea	2
	Mozambique	2
	Benin	2
	Morocco	2
	Liberia	2
	Sudan	1
	Algeria	1
	Lesotho	1
	Mauritania	1
	Malawi	1
	Seychelles	1
	Namibia	1
	Equatorial Guinea	1
	Tunisia	1
	Gabon	1
	Madagascar	1
	Central African Republic	1
	Comoros	1
	South Sudan	1
4. HEALTHCARE PROVIDERS	South Africa	3
	Egypt	2
	Kenya	2
	Uganda	1
	Rwanda	1
5. INDUSTRY AND PRIVATE BUSINESSES	South Africa	9
	Kenya	3
	Egypt	2
	Zimbabwe	1
	Tanzania	1
	Ghana	1
	Nigeria	1
6. CIVIL SOCIETY ORGANIZATIONS	South Africa	2
	Eritrea	1
	Kenya	1
GRAND TOTAL		473

ANNEX 2: A list showing the distribution of contacts in each of the stakeholder groups by level of relevance to the project

COUNTRY	HIGH	LOW	MEDIUM	TOTAL
South Africa	88	10	18	116
Kenya	32	0	2	34
Nigeria	14	1	5	20
Ghana	6	4	10	20
Egypt	11	2	4	17
Burkina Faso	8	1	7	16
Tanzania	10	1	5	16
Uganda	6	3	3	12
Republic of the Congo	10	1	0	11
Ethiopia	8	3	0	11
Rwanda	7	0	4	11
Niger	5	2	2	9
Senegal	7	2	0	9
Zimbabwe	9	0	0	9
Cameroon	6	0	2	8
Botswana	6	0	2	8
Morocco	5	1	1	7
Mali	4	1	2	7
Côte d'Ivoire	4	1	2	7
Malawi	4	1	1	6
Eswatini	5	0	1	6
Algeria	6	0	0	6
Guinea-Bissau	0	4	1	5
Zambia	5	0	0	5
Djibouti	0	0	5	5
Mauritius	0	1	4	5
Angola	4	0	0	4
Mozambique	4	0	0	4
Benin	2	0	2	4
DR Congo	3	0	1	4
Seychelles	3	1	0	4
Liberia	0	2	2	4
Togo	0	3	0	3
Cabo Verde	1	0	2	3
Gabon	0	2	1	3
Republic of Chad	1	2	0	3
Burundi	2	0	1	3
Lesotho	2	1	0	3
Tunisia	2	0	1	3
Eritrea	0	0	3	3
Gambia	1	0	2	3

Somalia	0	0	3	3
Sierra Leone	0	1	2	3
Namibia	0	1	1	2
Madagascar	1	0	1	2
Guinea	0	1	1	2
Mauritania	0	1	0	1
South Sudan	0	0	1	1
Central African Republic	0	0	1	1
Equatorial Guinea	0	1	0	1
Sudan	0	0	1	1
Comoros	0	1	0	1
Grand Total	292	56	107	455

**ANNEX 3.
RESULTS OF THE EU-AFRICA STAKEHOLDER SURVEY**

1) INTRODUCTION

As part of the policy and stakeholder mapping exercise carried out in the context of the EU-Africa PerMed project work package 2 (WP2), a survey was launched to collect information about PM in African countries. At the same time, the survey served the purpose of introducing the EU-Africa PerMed project to stakeholders and anticipate forthcoming activities such as training and the stakeholder workshop.

2) METHODOLOGY

Emails were sent to a total of 475 contacts, from all types of stakeholder groups and countries, collected as part of the stakeholder mapping work (task 2.3). The distribution of stakeholders per stakeholder group and region are presented in the figures below.

Distribution of contacts by stakeholder group

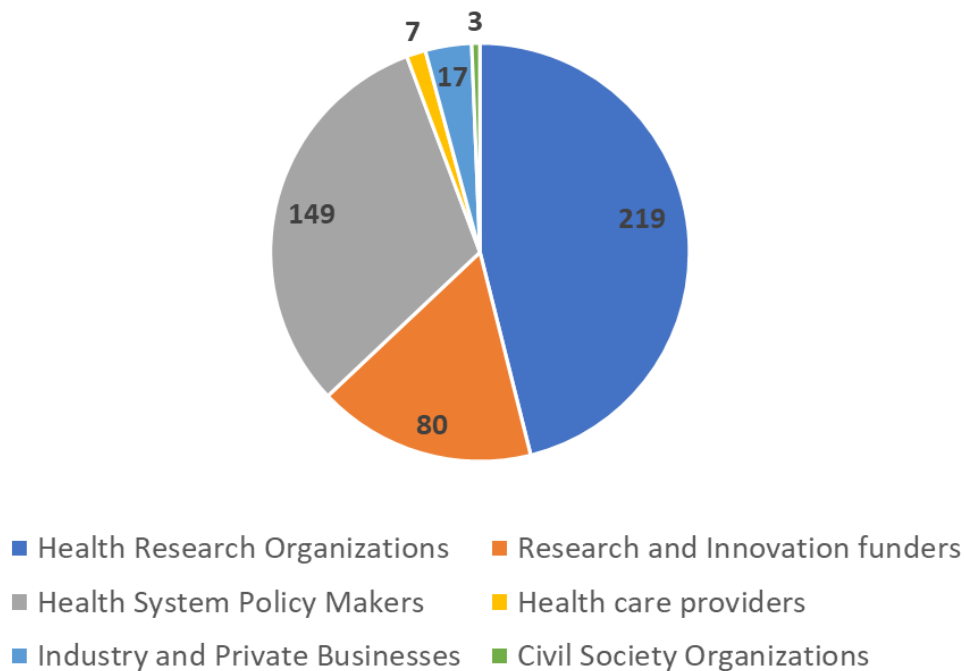


Figure 1: Distribution of contacts by type main stakeholder group category

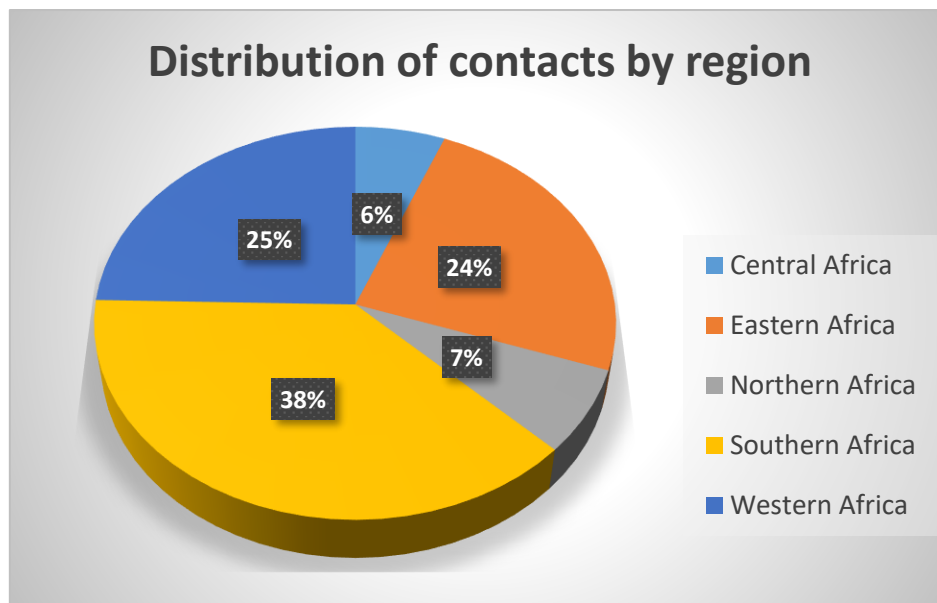


Figure 2. Distribution of the contacts by African Region.

A short questionnaire was prepared in English and French. See Appendix2 for a copy of the questionnaire. Emails were sent by project partner NACOSTI during the months of July-August 2021 and reminders sent to try to increase the rate of response.

Privacy policy

In order to comply with personal privacy policy and ethical standards, a request to read and agree on the privacy statement for this survey was mandatory before completing the survey.

3) RESULTS and DISCUSSION

The stakeholder database had a differing number of contacts listed per country, with South Africa representing the majority of stakeholders. The survey was disseminated to 399 stakeholders. In total, we received 47 responses to the survey, which is a very low response rate (11.8%). Also, not all countries/regions are represented, and some countries had a higher number of responses (i.e., South Africa). Due to these disparities, it is not possible to extract conclusions on PM in Africa, as the current stakeholder list cannot be considered as a representative sample. However, it has provided valuable qualitative information for some countries, and may be used to complement the policy mapping work, included in the mapping report (see deliverable D2.1).

Information collected from the survey related to training activities was compiled and passed on to the partners responsible for WP5 (Capacity building in PM), so that it can be used to understand the African training needs in PM.

The low response rate has served as an indicator that more work must be done to increase the awareness of the project in Africa. Utilizing the policy and scientific bibliometric report (deliverable 2.1), more effort is being channeled to actively disseminate to all stakeholder groups, using different tools for each of the groups and focusing on those countries/stakeholder subgroups where the level of representation is lower. The responses received for the English and French surveys have been merged and were analyzed together.

Responses were received from stakeholders in the following countries (shown in brackets are the number of responses received from each country): Algeria (1), Botswana (1), Burkina Faso

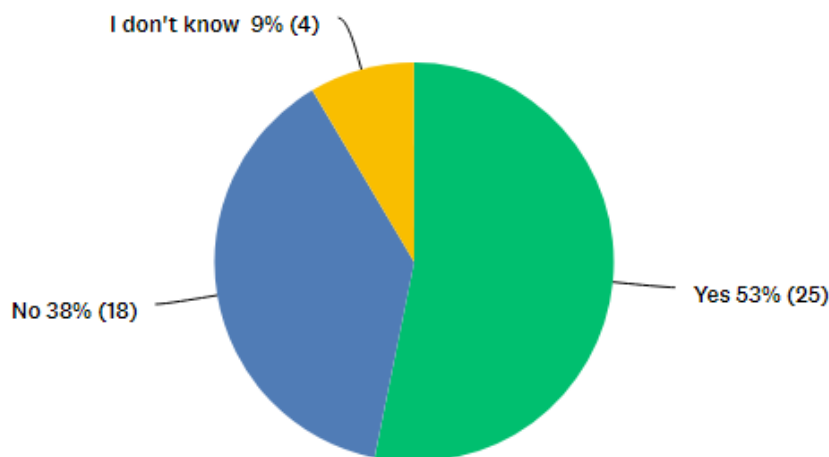
(3), Cabo Verde (1), Egypt (1), Ethiopia (1), Gabon (1), Gambia (1), Ghana (1), Kenya (4), Mali (1), Namibia (1), Niger (1), Nigeria (3), Somalia (1), South Africa (18) Tanzania (2), Togo, Tunisia (2), Zimbabwe (1).

CONCLUSION

The stakeholder mapping exercise provides the consortium with a database of 475 stakeholders within the PM field and representing the most active regions in Africa. The uneven distribution of stakeholders is attributed to the limitation of only relying on project member networks. Therefore, there is no correlation between the number of contacts in association to the bibliometric analysis conducted on the continent. The dissemination of the initial survey and low engagement highlighted the need to create an awareness campaign of the EU-Africa PerMed Project within the African continent. There is a concerted effort to broaden the database through social media and information webinars on the project, using WP6 working group to assist.

Appendix 1: provides the results obtained for the different questions included in the survey.

- 1) **TO YOUR KNOWLEDGE, IS IT A STRATEGIC OBJECTIVE/PRIORITY FOR YOUR GOVERNMENT TO DEVELOP AND IMPLEMENT PERSONALISED MEDICINE (PM) IN YOUR REGION/COUNTRY? (N=47)**



IN CASE YOU HAVE ANSWERED YES, TO QUESTION 1, PLEASE ELABORATE ON YOUR RESPONSE BY CONVEYING YOUR PERSPECTIVE ON: HOW IS PM PERCEIVED IN YOUR COUNTRY? IS PM IN THE NATIONAL HEALTH SYSTEM AGENDA? IS PM REFERRED TO OR HAS AN ALTERNATIVE NAME? IS THERE AN INTEREST TO CONDUCT RESEARCH IN THIS AREA? DOES YOUR GOVERNMENT CONSIDER IT AS A MEANS TO IMPROVE THE HEALTH OF THE POPULATION?

- *The Health Sector is one of the eight (08) of the Commission in charge of the Department of Gender Promotion, Human and Social Development (DPGDHS). The vision of the ECCAS Commission is that this Department constitutes the central objective of the whole of the regional integration process in Central Africa and that the four (04) other Departments are to support this. The DPGDHS aims to generate a citizen with a high human development index (HDI), well equipped technically and scientifically, with a stable social condition capable of contributing to the development of humanity. The Commission has included among the activities of the Strategic*

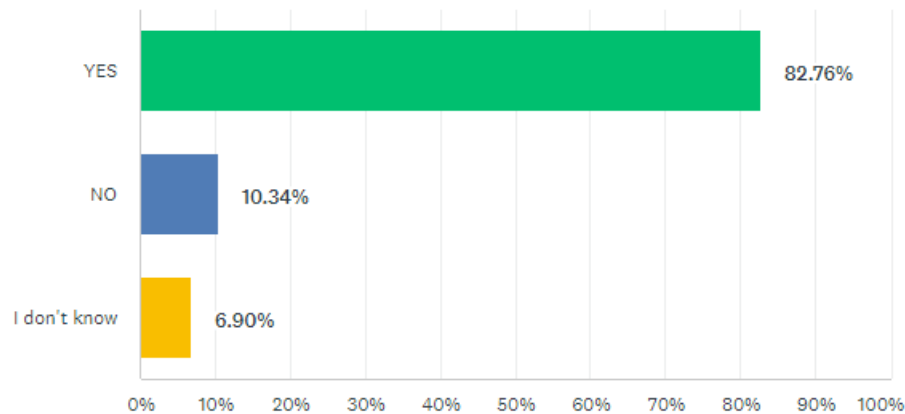
Indicative Plan 2021-2025 the realization of a Study of the Health regional System in order to propose an innovative policy for the satisfaction of the final recipients of health care: the population. The institution makes several pleas with Technical and Financial Partners in order to carry out this important activity which could lead to the adoption of the concept of 'personalized medicine. (GABON, Central Africa Community)

- *The Department of Science and Innovation has provided some funds for precision medicine research. However, these are basic research funds and not focused on population level validation studies and healthcare implementation/integration. So while there seems to be a national agenda it does not seem to be well thought out. (SOUTH AFRICA)*
- *There is significant interest to conduct research in these areas for the benefit of improving health. (TANZANIA)*
- *The importance of PM is definitely appreciated as a means to improve human health of our populations - by organizations such as the South African MRC and Department of Science and Innovation. There is an interest in PM research. Personalized medicine or precision medicine - terms mostly used (as far as I am aware). (SOUTH AFRICA)*
- *It's referred to as Genomic Medicine. The Ministry of Higher and Tertiary Education has listed Genomics as a strategic area of research to improve human health and has made significant investment in technology platforms to do so. It has also partnered with my institute, the African Institute of Biomedical Science and Technology to implement this program. (ZIMBABWE)*
- *There is great effort and interest in health research that is targeting personalized medicine in Kenya (KENYA)*
- *The Department of Science and Innovation (DSI) has identified Precision Medicine as one of the drivers for tailor-made, population based health care solutions. A number of initiatives have been supported to advance R&D in this area, the Southern African Human Genome Programme (SAHGP), Precision medicine initiative of the Strategic Health Innovation Partnership (SHIP), Bioinformatics and Functional Genomics programme offered research grants and student bursaries, Center for High Performance Computing, Center for Proteomic and Genomic Research, SAMRC Genomics Center, DIPLOMICS Platform, KwaZulu-Natal Research Innovation and Sequencing Platform. The SAHGP in particular established that there is enormous genetic diversity in the sub-Saharan region and a lack of an African population reference genome. Plans are underway to create a large population genetics study that will contribute towards the development of precision diagnostics, treatments and data driven prevention healthcare. The objective is to create a South African reference study, a local genome phenome archive and an associated biobanking initiative. (SOUTH AFRICA)*
- *This is considered as a means to improve regional and National health systems. (KENYA)*
- *The SA Medical Research Council has a program to support research in the area of PM and the National Department of Science and Innovation has had several workshops on PM. Several institutions are doing PM research and some MP-related diagnostic tests are offered through the National Health Laboratory Services (NHLS)(A parastatal organisation) and through the private sector. We have run a course on PM at the SBIMB for several years. There is a general view that we need more relevant data on African populations for PM to be implemented in South Africa (and Africa). (SOUTH AFRICA)*
- *PM is being talked about but not proper implementation is currently available. Also, much research still needs to be done to understand PM in an African context. (SOUTH AFRICA)*

- *Personalised Medicine (PM) is yet to gain ground as it should in the country although indirectly this have been considered eg use of Sulphur based drugs but not at genomics level and it is yet to be included in the National health system agenda PM is not referred to in any health institutions except for some questions being asked prior to recommendation of drugs. Yes, there is an interest to conduct research in PM in my center. Yes, PM is being considered as a means to improve the health care system in the country. (NIGERIA)*
- *There are medicine factories at national level which are privately owned. The whole health care system is our national agenda. Yes, the Ethiopian government considered it is the one means to improve the health system. (ETHIOPIA)*
- *Personalized medicine is also known as precision medicine. The Kenya Government does not mention it anywhere in its documents. It is not in the government's agenda and the government does not view it as a means of improving the health of its populations. (KENYA)*
- *PM are allowed where medicines are tailored to a particular patient need, specifically when medications are required in terms of age, disease condition, tolerance, unavailability of formulation in a drug form and preference. Yes, it is a public health system agenda particularly for children's medicines. Personalised medicines are commonly known as individual medicines or therapy. Yes, Yes. (BURKINA FASO)*
- *It is nowhere on its radar screen but should be. A practical example relates to TB where there are substantial multi-and extremely drug resistant strains of Mycobacterium tuberculosis and treatment failure rates are high. By screening individuals to identify drug resistance and drug susceptibility patterns our health services could be more effective in treating and containing TB. (SOUTH AFRICA)*
- *PM is not well known in Kenya, outside of experts. (KENYA)*
- *PM has been an agenda topic for several years, mainly at the DSI and the MRC, less so in the DoH, but it hasn't been progressing with a real thrust. The reasons for this are manifold but include the following: (i) a lack of a coherent understanding of the paradigm, (ii) lack of a coherent strategy, (iii) lack of funding, (iv) 'broad church' approach instead of pragmatic / practical implementation and testing and learning by doing, (v) lack of critical skills. (SOUTH AFRICA)*
- *Under leadership of the SA MRC a platform was started pre-COVID on precision Medicine. This has not progressed well but it is hoped it will gather momentum when normality is restored. (SOUTH AFRICA)*
- *How is the PM perceived in your country? Perceived Positively Is PM in the national health system agenda? YES Is PM referred to or has an alternative name? PM Is there an interest to conduct research in this area? Yes Does your government consider it as a means to improve the health of the population? Yes (SOUTH AFRICA)*
- *it is part of South African MRC driven research agenda (SOUTH AFRICA)*
- *PM is not on the national agenda, currently. It is only talked about in academic settings and few industries (GHANA)*
- *Our ministry of Health in Tunisia, is one of the rare governmental bodies in Africa that is funding health research towards the implementation of Precision medicine in Tunisia and in North Africa mainly with the new project 100% funded by our Ministry of Health (10 M\$) to achieve this goal, the project is entitled Genome Tunisia. (TUNISIA)*
- *Largely directed through the medical research council (SOUTH AFRICA).*
- *PM is a strategic priority as demonstrated with a number of funding programs in Egypt addressing PM in addition to relevant committees. PM is on the agenda of the Medical Research Council in Egypt. Egypt is a member of EraPerMed, GLOPID-R and JPI-AMR among other initiatives that supports directly or indirectly PM projects and activities. On the other front, a national plan is in place for the Egyptian Genome Program which was launched in 2020 with a budget of 1 billion EGP. One component of the program is*

to establish a large genome center that aims to prepare a map of the Egyptian human genome to discover and accurately determine the genetic characteristics of various diseases. (EGYPT).

IN CASE YOU HAVE ANSWERED NO, DO YOU THINK THAT PM COULD BE AN AREA OF INTEREST IN THE FUTURE? (N=29)



COMMENTS

- *There is a large disparity between public and private health care in South Africa. Personalized medicine is still a new concept in our country, even in private practice. I cannot imagine that it is a priority for our government at this time as there are so many areas of basic health care needing attention. Not enough data is available on South African populations and European developed models are often not appropriate. Our access to therapeutics are also limited, therefore identifying the personalized care required does not necessarily translate into the implementation of such care making it a futile exercise. A small number of South African researchers are actively involved in projects related to personalized medicine, this includes multinational collaborations. Due to limited funds, efforts are mostly focused on communicable diseases with a high incidence. (SOUTH AFRICA)*
- *There are other more urgent health/medical priorities right now and the PM has not received much attention from the government. (SOUTH AFRICA)*
- *National Health System (NHS) of Cabo Verde has a huge development last years, but we still have many priority challenges that includes: • The sustainability and resilience of the NHS, by mobilizing more resources for health; • The need for more specialized health human resources; • Accelerating the development of the private health sector; • The development of the health technology sector. (CABO VERDE)*
- *The current government focus on a National Health Insurance (NHI) program will ultimately need to be underpinned by PMed approaches. (SOUTH AFRICA)*
- *They are following global trends and this is where the rest of the world is headed (SOUTH AFRICA)*
- *Due to genetic differences between the traditionally studied white population of the world versus the African population that has not been studied properly, it will be important to investigate whether the stratification strategies in cancer as an example used in the west apply to our African population and if not to allow for development of new strategies (SOUTH AFRICA)*
- *PM is an area of interest in the Country (BOTSWANA)*
- *At the moment the government understandably is focusing on universal health coverage which is a very basic structure of health care provision. After this, I envisage it paying more attention to personalized medicine (KENYA)*

- *the concept sounds interesting and but I think more basic healthcare data systems including patient data system at health facilities should be in place (GAMBIA)*
- *As the field grows in popularity and relevance in Africa, many countries including Nigeria will take it up (NIGERIA)*
- *Our public health systems are not capable of handling personalized medicine. Private sector pockets of personalized medicine exist and will most likely grow. (NAMIBIA)*
- *Patient centered medicine will be necessary in the future (MALI)*
- *We have two large and indigent populations to fairly distribute health resources. Once we have a predominant middle class and a smaller poverty problem we should start thinking about it. (SOUTH AFRICA)*
- *As research advances, it will be critical to address medical issue at a personal level (TANZANIA)*
- *In this context, the national pooling of scientific skills, technical and technological know-how around issues relating to personalized precision medicine appears necessary. It would lead to the creation of a national thematic network operating in the broad field of Personalized Precision Medicine. ATRSSV's membership in the consortium program ``European Africa Personalized Medicine (EU-Africa PerMed) '' appears beneficial both in terms of translational, preclinical and clinical research, and in terms of doctoral training focused on biotechnological innovations and in the near future, the establishment of a unified transdisciplinary professionalizing Master. (ALGERIA)*
- *This is a critical area for SA, considering that Africans have one of the highest genetic diversity. (SOUTH AFRICA)*

2) PLEASE INDICATE IF ANY OF THE LISTED ITEMS ARE APPLICABLE FOR YOUR REGION/COUNTRY (N=47).

ITEM 1: The government has developed a regional/national Personalized Medicine strategy/programme or plans to do so in the coming years

ITEM 2: The government (directly or with external funds managed by the government) funds projects in areas related to PM (i.e., population genetic/genomic studies, molecular diagnosis, and biomarkers, genomic studies in hereditary diseases, bioinformatics, development of molecular diagnostic technologies and kits, gene therapy, clinical trials for novel precision medicines in cancer and rare diseases, genetics in clinical practice, etc.).

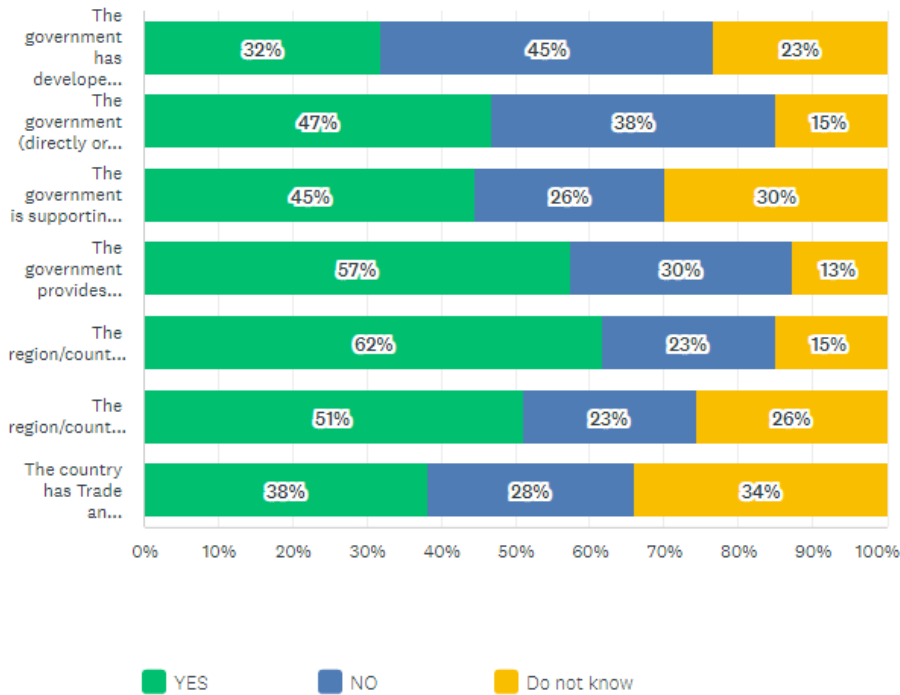
ITEM 3: The government is supporting a national genome project (or is planning to do so) to collect information of the population to improve genetic diagnosis and public health/prevention programmes

ITEM 4: The government provides funding to relevant research infrastructure, such as: Biobanks, 'omics technologies such as genetic sequencing equipment or hardware for data management and processing, etc.

ITEM 5: The region/country has international or private donors who fund or support biomedical and health research including PM

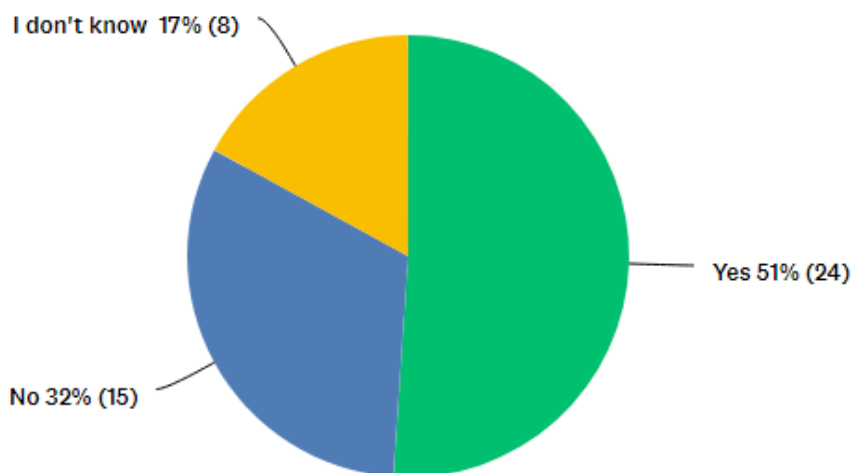
ITEM 6: The region/country has or/is developing formal legislation/policy such as ethical, social, legal or regulatory frameworks for the use of clinical/genetic/lifestyle data in research: data sharing, ownership, privacy/ security/protection.

ITEM 7: The country has Trade and Industry Policy that regulates the implementation of health innovation products and services



TO COMPLEMENT THE MAPPING, WE ARE INTERESTED IN KNOWING ABOUT TRAINING ACTIVITIES RELATED TO PM IN YOUR COUNTRY/REGION. THE INFORMATION WE RECEIVE WILL GUIDE US WHEN WE PLAN AND EXECUTE CAPACITY BUILDING ACTIVITIES IN THE PROJECT.

3) ARE THERE ANY TRAINING ACTIVITIES ON PM IN YOUR COUNTRY/REGION? (THESE COULD ALSO BE DEGREES, OR COMPONENTS OF DEGREES, AT UNIVERSITIES AND TECHNIKONS) (N=47)



3.1) IF YES, CAN YOU GIVE DETAILS OF ANY TRAINING ACTIVITY YOU MAY BE AWARE OF.

- Integrated into clinical genetics and genetic counseling degrees. University degrees might benefit from a refocus of teaching from traditional fact transfer to conveying

science in an applied manner such as teaching genetics and molecular biology in the context of utility such as PM. (SOUTH AFRICA)

- *Bioinformatics training, Laboratory training (TANZANIA)*
- *The topic is addressed during formal tertiary education programs (e.g. BSc, MBChB) and postgraduate programs. It is mostly offered as a module and not a stand-alone course. (SOUTH AFRICA)*
- *We have the latest next-generation diagnostic, sequencing, and tagging facilities. This training is offered independently, as well as as part of degree programs. (SOUTH AFRICA)*
- *IN 2021, the Chinhoyi University of Technology (CUT) in collaboration with the African Institute of Biomedical Science and Technology (AIBST) started an MSc in Genomics and Precision Medicine. The 2-year program has 9 students in its first intake - one from Benin, 2 from Nigeria, 3 from Kenya and 3 from Zimbabwe. (ZIMBABWE)*
- *Medical training in national universities (KENYA)*
- *University of Cape Town Computational Biology postgraduate programme University of the Western Cape Bioinformatics training modules Several PM programmes available at other universities – Wits, University of Pretoria, University of KwaZulu-Natal, Stellenbosch University (SOUTH AFRICA)*
- *Not sure (KENYA)*
- *Elements of PM are included in medical curricula and in science curricula. MSc and PhD research projects in several departments include a focus on PM. At the Wits SBIMB, we run a 3 day course on PM for clinicians and scientists. The H3Africa BioNet offers many Bioinformatics courses. <https://www.h3abionet.org/training/courses-and-events> An online PM course is run for nurses, with the intention to expand it to other healthcare workers. (AGMT) Clinicians can specialize in Medical Genetics (4 years post medical degree training) and register as a specialist with the HPCSA. We have 2 Universities that offer MSc degrees in Genetic Counseling. (SOUTH AFRICA)*
- *The MSc training in Molecular Biology and Genomics at Redeemer's University offers that focus on PM. (NIGERIA)*
- *Courses related to PM are offered at the University of Botswana. (BOTSWANA)*
- *Mainly through post graduate programs at universities. (SOUTH AFRICA)*
- *Project - based training modules within the H3Africa Consortium such as the Neurobiobank ELSI project. (NIGERIA)*
- *There are training programs but they lack scope and scale. For example, there are perhaps a total of 20 genetic counselors in the country and perhaps as many clinical geneticists. This is a miniscule HR base in view of a population of 60M. Similarly, training at the technical level (wet and dry lab) is lacking. But, there are some training programs. (SOUTH AFRICA)*
- *Natural Science faculties offer biochemistry and genetics courses. Medical schools offer limited training in this area. (SOUTH AFRICA)*
- *Training on sequencing and the use of Next Generation Sequencer to increase capacity to genomic medicine (NIGERIA)*
- *Master and Doctorate Degree in Biotechnology and Molecular Pathology Master and Doctorate Degree in Biotechnology and Health (ALGERIA)*
- *MSc and PhD programs (SOUTH AFRICA)*
- *Conferences debates by The city of Sciences (<http://www.cst.rnu.tn/fr/article/conference-a-la-cite-des-sciences-autour-du-theme-de-la-genomique-medicale-a-la-medicine-personnalisee-549?id=549>) Some training given by Institut Pasteur of Tunis (TUNISIA) (http://www.pasteur.tn/index.php?option=com_content&view=article&id=391:de-la-genomique-medicale-a-la-medecine-personnalisee&catid=41:actualites&Itemid=147)*
- *Master and PhD program (SOUTH AFRICA)*

- Postgraduate students research projects (SOUTH AFRICA)
- Master degree in genomics medicine Master degree in Bioinformatics (TUNISIA)
- Part of medical genetics, genetic counseling and undergraduate medical curriculum as well as some postgraduate courses (SOUTH AFRICA)
- It exists as part of postgraduate or undergraduate studies (mostly in relation to pharmacogenomics), example:
http://catalog.aucegypt.edu/preview_course_nopop.php?catoid=29&coid=67279
Some specific centers in Egypt provides relevant training/degrees such as the Center of Excellence for Stem Cells Research and Regenerative Medicine and the Center for Genomics at Zewail University
https://www.zewailcity.edu.eg/main/content.php?lang=en&alias=cesc_mission
(EGYPT)

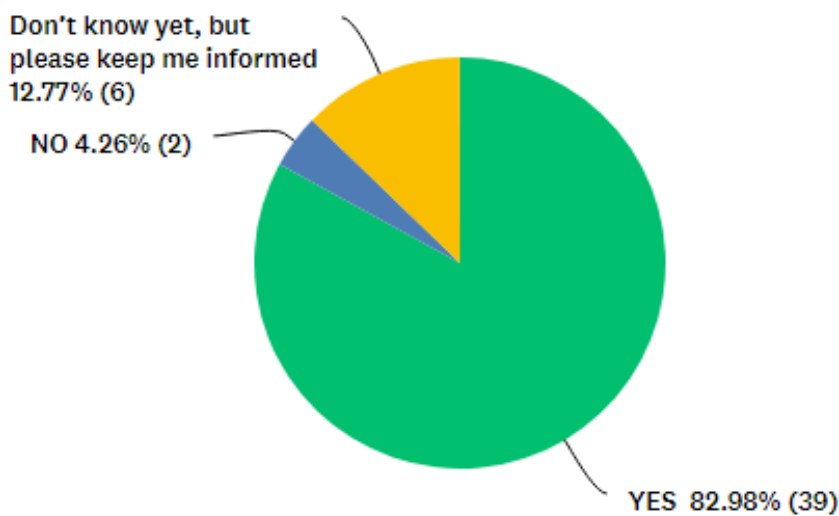
4) FROM YOUR PERCEPTION, WHAT ARE THE PRIORITY TRAINING NEEDS FOR PM EXPERTS IN YOUR COUNTRY? THESE NEEDS MAY INCLUDE, BUT ARE NOT LIMITED TO, CLINICAL GENETIC PROGRAMMES, BIOINFORMATICS, GENOMICS DATA SCIENCE AND HEALTH SYSTEMS AMONG OTHER RELEVANT PM AREAS.(FREE TEXT)

- *In fact, I work for a sub-regional institution which brings together 8 French-speaking countries of West Africa which share in common the CFA franc and French. So, I don't have any country information on this. Therefore I do not know their needs at this subject, which seems new to me (BURKINA FASO)*
- *I do not know (Burkina Faso)*
- *Clinical genetics, bioinformatics, genomic data science and health systems (NIGER)*
- *Individuals are still too focused on academic research and not translation into economic innovation. Perhaps this is because research funds are available, and there is a lack of insight/risk taking/investment in driving applied research. Training needs should be transformative from academic into operationalization. (SOUTH AFRICA)*
- *Laboratory based training, clinical genetics, bioinformatics, genetic counseling and ELSI (TANZANIA)*
- *In my opinion, the training needs are met. There is rather a need for better coordinated research strategies and an integrated electronic health system which will assist in demonstrating the need for a PM strategy to the government and also to facilitate research by providing access to longitudinal patient data. Qualified and capable clinical geneticists, genetic counselors, bioinformaticians and molecular scientists are produced but career opportunities are limited. (SOUTH AFRICA)*
- *Would support training in genomics data science (SOUTH AFRICA)*
- *Considering the few human resources specialized in the areas of interest to the PM, I think it would be necessary to carry out a comprehensive training program that encompasses all these areas. Initially, more basic formations that would later evolve into more complex ones. (CAPE VERDE)*
- *Biostatics, statistical genetics, and bioinformatic training. Clinical genetics training. Neuropsychiatric genetics training. (SOUTH AFRICA)*
- *Agree with training needs particularly in bioinformatics, genomics and data science. Also clinical genetics, health systems. One cannot think of the human host and disease and not emphasize immunology - a good grounding in understanding immunology is in my opinion essential. (SOUTH AFRICA)*
- *All of the above! (SOUTH AFRICA)*
- *Clinical Genetic programs including genetic counseling, Electronic health Records Systems to support PM, Bioinformatic and genomic data science to support PM programs. (ZIMBABWE)*
- *Not enough is spent on basic training, there is a shortage of bioinformatics expertise (SOUTH AFRICA)*
- *Bioinformatics, genomics data science and health systems (SOUTH AFRICA)*

- *Bioinformatics and clinical genetic programmes (KENYA)*
- *Bioinformatics data and health system strengthening trainings (SOMALIA)*
- *Training of genetics nurses, genetics counselors, medical geneticists, medical scientists, bioinformaticists, biostatisticians and forensic scientists (SOUTH AFRICA)*
- *Health systems in the context of PM (KENYA)*
- *Need training at all levels. Basic sciences: Undergraduate and postgraduate degrees in genetics and bioinformatics Health case workers: Undergraduate curricula and continuous professional development. Not everyone needs to become a bioinformatician, they need to know where to find information, what it means, and how to apply it in different situations. (SOUTH AFRICA)*
- *Clinical genetics, bioinformatics, and basic cell biology/molecular biology at MSc and PhD level (SOUTH AFRICA)*
- *Advanced cell and Molecular Biology, Functional Genomics, Research Techniques, Bioinformatics, Pharmacogenomics, Bioethics and Biosafety (NIGERIA)*
- *Bioinformatics, genomics data sequencing (BOTSWANA)*
- *Clinical genetic programs, health systems data management, bioinformatics, emergency health care system, health infrastructure management and utilization (ETHIOPIA)*
- *Priority training needs include clinical genetic programmes, genomics and bioinformatics (KENYA)*
- *I don't know if we have any PM experts in The Gambia (GAMBIA)*
- *1. Train in individualized drug formulations 2. Clinical genetic programmes 3. Health Systems Strengthening 4. Bioinformatics 5. Knowledge transfer of current technology in PM (BURKINA FASO)*
- *All aspects (SOUTH AFRICA)*
- *All areas listed above (NIGERIA)*
- *Bioinformatics (KENYA)*
- *All of the above (NAMIBIA)*
- *Clinical genetic programmes, bioinformatics, genomics data science, Pharmacokinetics, Pharmacogenomics (MALI)*
- *Training of medical professionals who can operate at the interface of technology, science, data interpretation and patient engagement • centers of PM excellence where scarce resources concentrate • clear focus areas where PM is implemented with a clear understanding of utility and cost/benefit, not driven by mega Genomics programs that sound great but may remain elusive • ongoing training and education, physically and virtually, in all areas, to create a cohort of Precision Medicine practitioners – who can work together in a virtually networked manner (SOUTH AFRICA)*
- *Our clinical genetics services are inadequate to serve the entire country currently. Universities have adequate specialized services for research. (SOUTH AFRICA)*
- *The traditional disciplines mentioned are in place. However PM should be seen as broader than that and nuclear medicine based diagnostic imaging is a good alternative where a patient dose and tolerance for a therapeutic drug can be individually determined prior to treatment (SOUTH AFRICA)*
- *1. Genomics 2. Bioinformatics 3. Human genetics and clinical genetics including genetic counselling. 4. Big data management 5. Statistics with a focus on genetic/genomic data (TANZANIA)*
- *It includes genomic data science, Bioinformatics and clinical genetics (NIGERIA)*
- *Genomic/ Proteomic Metabolomic Bio-Informatic Bioethic (ALGERIA)*
- *All the above as the field is still nascent. (SOUTH AFRICA)*
- *All these needs (TUNISIA)*
- *Clinical genetic programmes, bioinformatics, genomics data science and health systems (SOUTH AFRICA)*

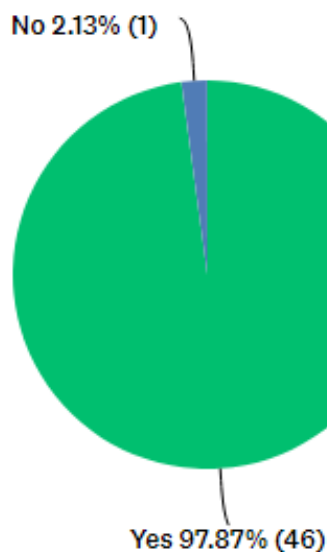
- Clinical genetics programmes, -omics data science, bioinformatics, PM methods, translation of patient profiles into health care recommendations (SOUTH AFRICA)
- Clinical genetics, bioinformatics genomics data science (GHANA)
- Health systems, policy making related to research in health, governance, leadership (TUNISIA)
- Clinical genetics and data science (SOUTH AFRICA)
- Data science, health systems, clinical genetic programs (EGYPT)

5) AS A PROJECT ACTIVITY, WE PLAN TO ORGANIZE AN ONLINE STAKEHOLDER WORKSHOP BY THE END OF THE YEAR (OCT/NOV 2021), TO DISCUSS THE RESULTS OF THE MAPPING WORK AND EXPLORE, TOGETHER WITH AFRICAN STAKEHOLDERS, FIRST IDEAS ABOUT THE CHALLENGES OF DEVELOPING AND IMPLEMENTING PM IN AFRICA AND HOW THE COLLABORATION WITH EUROPE IN THIS AREA CAN BE STRENGTHEN. WOULD YOU BE INTERESTED IN PARTICIPATING IN THIS EVENT?



6) WOULD YOU BE

INTERESTED IN RECEIVING INFORMATION ABOUT THE EU-AFRICA PERMED PROJECT (NEWSLETTERS, INFORMATION ABOUT PROJECT ACTIVITIES SUCH AS WORKSHOPS AND TRAINING EVENTS, PROJECT RESULTS, ETC.)?



Appendix 2:

**COPY OF QUESTIONNAIRE SENT TO AFRICAN STAKEHOLDERS IN THE EU-AFRICA
PerMed SURVEY**



EU-Africa PerMed policy mapping survey

In the context of the EU-Africa PerMed project, we will like to kindly request your collaboration to help us identify policies and programmes in African countries supporting and promoting health R&I, identify priority areas for health research, and specifically to know if there are any specific policies/programmes/initiatives that support Personalised Medicine (PM) activities (research projects, training, infrastructure, innovation, industry already present or operational etc.). Please note that the following questions are requesting your perception or understanding of activities taking place within the continental region in which you are situated and the country you reside in."

PERSONALISED MEDICINE (PM) refers to a medical model using characterisation of individual profiles based on physical, genetic and lifestyle traits (e.g. molecular profiling, medical imaging, and lifestyle data) to tailor the right therapeutic strategy for the right person at the right time, and/or to determine the predisposition to disease, and/or to deliver timely and targeted prevention. A frequently synonym used for 'personalised medicine, is 'precision medicine', but sometimes other terms as 'individualised medicine', 'personalised precision medicine', 'genomic medicine', etc., are also used. EU-Africa PerMed project website

* Could you please provide us with your contact details?

Your Name and Surname

Position

Organization

Country

Email

* **Please note** that Personal Data disclosed in this survey will only be utilized to support the mapping activities of the project. Contact details will be archived securely and only used with your informed consent. A request for consent is required prior to responding the survey. Should our analysis, identify you as an important stakeholder, this may include contacting you in the future, with a request for your further involvement. Please reach out to us should you require additional information about the project (erika.sela@innovatec.es)

I read and agree on the privacy statement for this survey (link to the privacy statement <https://www.euafrika-permed.eu/policy-mapping-survey/>)

*** 1) To your knowledge, is it a strategic objective/priority for your government to develop and implement Personalised Medicine (PM) in your region/country?**

- Yes
- No
- I don't know

In case you have answered **YES**, to question 1, please elaborate on your response by conveying your perspective on: How is PM perceived in your country? Is PM in the national health system agenda? Is PM referred to or has an alternative name? Is there an interest to conduct research in this area? Does your government consider it as a means to improve the health of the population?

In case you have answered **NO**, Do you think that PM could be an area of interest in the future?

- YES
- NO
- I don't know

Please add any comment to justify your response.

*** 2) Please indicate if any of the listed items are applicable for your region/country.**

	YES	NO	Do not know
The government has developed a regional/national Personalised Medicine strategy/programme or plans to do so in the coming years	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If yes, can you please give details to support your answer, for example name of plans, legislation, origin of funds, projects, infrastructures funded, etc. and/or links to webpages /documents	<div style="border: 1px solid #ccc; height: 40px; margin: 0 auto; width: 80%;"></div>		

The government (directly or with external funds managed by the government) funds projects in areas related to PM (i.e., population genetic/genomic studies, molecular diagnosis, and biomarkers, genomic studies in hereditary diseases, bioinformatics, development of molecular diagnostic technologies and kits, gene therapy, clinical trials for novel precision medicines in cancer and rare diseases, genetics in clinical practice, etc.).

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	YES	NO	Do not know
<p>If yes, can you please give details to support your answer, for example name of plans, legislation, origin of funds, projects, infrastructures funded, etc. and/or links to webpages /documents</p> <div style="border: 1px solid #ccc; height: 40px; width: 100%;"></div>			
<p>The government is supporting a national genome project (or is planning to do so) to collect information of the population to improve genetic diagnosis and public health/prevention programmes</p> <p style="text-align: center;"> <input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> Do not know </p>			
<p>If yes, can you please give details to support your answer, for example name of plans, legislation, origin of funds, projects, infrastructures funded, etc. and/or links to webpages /documents</p> <div style="border: 1px solid #ccc; height: 40px; width: 100%;"></div>			
<p>The government provides funding to relevant research infrastructure, such as: Biobanks, 'omics technologies such as genetic sequencing equipment or hardware for data management and processing, etc.</p> <p style="text-align: center;"> <input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> Do not know </p>			
<p>If yes, can you please give details to support your answer, for example name of plans, legislation, origin of funds, projects, infrastructures funded, etc. and/or links to webpages /documents</p> <div style="border: 1px solid #ccc; height: 40px; width: 100%;"></div>			
<p>The region/country has international or private donors who fund or support biomedical and health research including PM</p> <p style="text-align: center;"> <input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> Do not know </p>			
<p>If yes, can you please give details to support your answer, for example name of plans, legislation, origin of funds, projects, infrastructures funded, etc. and/or links to webpages /documents</p> <div style="border: 1px solid #ccc; height: 40px; width: 100%;"></div>			
<p>The region/country has or/ls developing formal legislation/policy such as ethical, social, legal or regulatory frameworks for the use of clinical/genetic/lifestyle data in research: data sharing, ownership, privacy/ security/protection.</p> <p style="text-align: center;"> <input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> Do not know </p>			
<p>If yes, can you please give details to support your answer, for example name of plans, legislation, origin of funds, projects, infrastructures funded, etc. and/or links to webpages /documents</p> <div style="border: 1px solid #ccc; height: 40px; width: 100%;"></div>			
<p>The country has Trade and Industry Policy that regulates the implementation of health innovation products and services</p> <p style="text-align: center;"> <input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> Do not know </p>			

YES

NO

Do not know

If yes, can you please give details to support your answer, for example name of plans, legislation, origin of funds, projects, infrastructures funded, etc. and/or links to webpages /documents

To complement the mapping, we are interested in knowing about training activities related to PM in your country/region. The information we receive will guide us when we plan and execute capacity building activities in the project.

*** 3) Are there any training activities on PM in your country/region? (These could also be degrees, or components of degrees, at Universities and Technicons)**

Yes

No

I don't know

3.1 IF YES, can you give details of any training activity you may be aware of.

*** 4) From your perception, what are the priority training needs for PM experts in your country? These needs may include, but are not limited to, clinical genetic programmes, bioinformatics, genomics data science and health systems among other relevant PM areas.**

*** As a project activity, we plan to organize an ONLINE STAKEHOLDER WORKSHOP by the end of the year (Oct/Nov 2021), to discuss the results of the mapping work and explore, together with African stakeholders, first ideas about the challenges of developing and implementing PM in Africa and how the collaboration with Europe in this area can be strengthen.**

Would you be interested in participating in this event?

- YES
- NO
- Don't know yet, but please keep me informed

*** Would you be interested in receiving information about the EU-Africa PerMed project (newsletters, information about project activities such as workshops and training events, project results, etc.)?**

- Yes
- No

Please indicate names, position and email of other people from your organization who you think may be interested in receiving information about the project.

Thank you very much for your time in responding to this questionnaire, please feel free to add any comments in the free space available below.

Online Survey Privacy Statement

This survey is managed by *Sociedad para el fomento de la Innovación tecnológica*, INNOVATEC on behalf of the EU-Africa PerMed project consortium. Please be aware that we take your concerns about privacy seriously and we make every reasonable effort to respect it.

Computerized Research and your privacy

We are committed to protecting your personal information and respecting your privacy. Personal information is defined as any details that will enable you to be identified, such as ID numbers, telephone numbers, address, email address etc.

When designing and executing our work in the project, it is our policy to take all necessary steps to ensure that personal information you provide is processed fairly and lawfully. Only authorised staff has access to personal information and they are obliged to respect its confidentiality. We do not sell, rent or exchange any personal information supplied by you to any third party. Nor do we use any of the information you provide for direct marketing or other activities.

What we do with the information that we gather from survey responses

In obtaining your cooperation to participate in the survey, we undertake not to mislead you in any way about the nature of the work we are conducting, the way in which the data is collected and the use that will be made of the survey results.

All of the information that you provide will be treated as confidential and will only be used for project purposes. Your comments will not be identified as belonging to you, instead they will be combined with those gathered from other survey participants, and will be analysed as part of a group. We do not use any of the information you provide for direct marketing or other activities.

If we ask you for personal information that enables you to be identified - e.g. your name, position, e-mail address or telephone number, we will clearly state why we are asking for it and for your permission to use it for that purpose. Your participation is voluntary. You are entitled to ask that part, or all, of the record of your involvement in the survey be deleted or destroyed.

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Contacting us

If you have any questions about this survey please email erika.sela@innovatec.es