EP PerMed
European Partnership
for Personalised Medicine

EUROPEAN PARTNERSHIP

EP PerMed WP5 Task 5.4

Survey on the awareness of people of Personalised Medicine

Analysis of the results from the multilingual survey launched by the EP PerMed

01.09.2026

Fondazione Toscana Life Sciences (TLS)

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EP PerMed
European Partnership
for Personalised Medicine

Technical References

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EP PerMed
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List of abbreviations

AWP	Annual Work Programme
PE	People Engagement
PEB	People Engagement Board
PES	People Engagement Strategy
CSA	Coordination and Support Action
EC	European Commission
EP PerMed	The European Partnership for Personalised Medicine
ELSA	Ethic, Legal and Social Aspects
EU	European Union
HCP	Healthcare Professional
ICPerMed	The International Consortium for Personalised Medicine
PM	Personalised Medicine
WP	EP PerMed Work Package

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1 Executive Summary

The EP PerMed WP5 Task 5.4 multilingual survey provides a baseline assessment of public awareness, perceptions, expectations and concerns regarding Personalised Medicine (PM).

The survey shows strong support for PM and optimism about its potential benefits, particularly for improving diagnosis and treatment. However, it also reveals a significant gap between positive attitudes and actual awareness, access, and confidence.

- Awareness is relatively high, although likely overestimated because respondents were largely highly educated and connected to health/research networks.
- Most respondents see PM as beneficial, but few have personally experienced PM, and many are unsure whether they can access it.
- Healthcare systems are perceived as not yet fully prepared to deliver PM.
- Trust and data protection are key concerns, particularly regarding genetic data, privacy, misuse, and commercial exploitation. Respondents are more willing to share data with public institutions than private organisations.
- Healthcare professionals are the most trusted source of information, highlighting their important role in communicating PM.
- Equity and inclusion remain challenges, with older people, minority groups, and less educated populations underrepresented in the survey.
- At the moment, the survey is not yet representative of the general population, but provides a useful baseline for understanding perceptions of PM.

Overall, the main challenge seems not to be gaining public support for PM, but rather improving understanding, access, trust, and inclusive communication.

Future efforts should strengthen public engagement, involve healthcare professionals, address data governance concerns, and reach groups currently underrepresented.

2 The European Partnership for Personalised Medicine

According to the definition adopted by the European Council Conclusion on Personalised Medicine (PM) for patients (2015/C 421/03), *"Personalised Medicine refers to a medical model using characterisation of individuals' phenotypes and genotypes (e.g. molecular profiling, medical imaging, lifestyle data) for tailoring the right therapeutic strategy for the right person at the right time, and/or to determine the predisposition to disease and/or to deliver timely and targeted prevention"*.

Since the adoption of this definition and the approval of the First Strategic Research and Innovation Agenda on PM in 2015, the European Union (EU) has supported the creation of an ecosystem of projects and initiatives aimed at boosting research, innovation and implementation of PM, strongly backed by scientific evidence that this is the medical approach of the future, enabling clinical benefits as well as economic, technological and societal ones.

Financial support to early stage as well as translational and, more recently, clinical research, has been provided by the European Commission (EC) through the last Framework Programmes for research and innovation (Framework Programme 7, Horizon 2020 and more recently Horizon Europe). The EC greatly contributed to PM research and development, with more than two billion euros already invested since 2007.

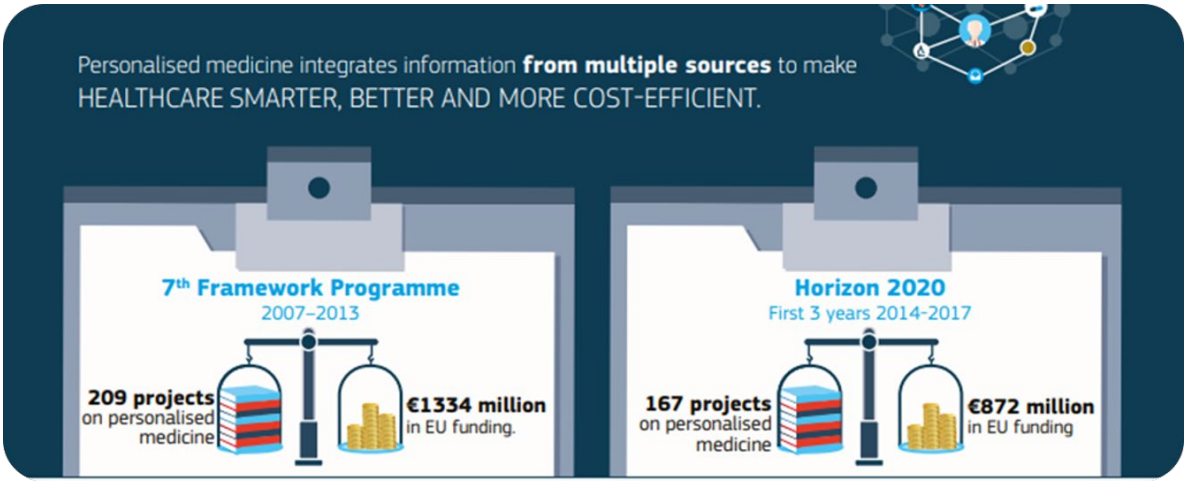


Fig. 1 Funding by EC to PM initiatives from 2007 to 2017. Source **here**.

Member States independently created the International Consortium for Personalised Medicine (ICPerMed), and the ERA-NET co-fund ERAPerMed, which have pushed PM in policy makers' agendas and attracted additional European, regional and national resources on basic and translational PM research. Both received support from the EU through Horizon 2020. Furthermore, effective policy making and guidance, extra-EU collaborations, health economics aspects, regulatory modernisation for PM clinical trials and collaborations between EU regions were supported by dedicated Coordination and Support Actions (CSAs) in Horizon 2020.

ICPerMed and related CSAs have highlighted strengths and weaknesses in the whole PM value continuum, which may be very diverse within EU, and even more so beyond extra-EU, and affected by local political, economic, and Ethics, Legal and Societal Aspects (ELSA). Also, different levels of healthcare implementation of PM approaches among countries have provided opportunities to learn from best-in-class examples and boost a faster and experience-driven development of PM.

All the experience and know-how accumulated through these initiatives have fed into the newly established European Partnership for Personalised Medicine (EP PerMed), launched in November 2023.

EP PerMed is an international coordination platform aiming at improving health outcomes within sustainable healthcare systems through research, development, innovation and implementation of PM approaches for the benefit of patients, citizens, and societies. The partners of EP PerMed are national and regional ministries and funding organisations, agencies and authorities, who are joining efforts to support all these stages of the PM value continuum.

The factors that currently hamper PM development and availability for society are complex and multifaceted and cannot be individually resolved effectively. In response to this, EP PerMed aims to address the issues and bottlenecks in the PM continuum with a holistic approach. Discussion among all stakeholders must be encouraged, to ensure not only the success of the EU strategy for PM implementation, but to secure an informed, sustainable and ethical access to PM for everyone.

3 Importance of People Engagement in the implementation of Personalised Medicine

Among EP PerMed's stakeholders, people are the end-users of these public efforts, and their active participation is important to facilitate the development of PM services by the EU healthcare systems, and to reduce cultural barriers and maximise impact.[1] The recent COVID-19 pandemic demonstrated how public opinion and understanding of health-related matters is crucial for the modernisation of health policies and cannot be neglected. It also showed how health literacy, as well as a correct communication of science and innovation, can heavily influence people's ideas and eventually choices.

While once perceived as passive recipients of medical care, and somehow excluded from the decision-making process, it is now quite evident that people, thanks to social sciences, the AI, the internet, and a generally higher degree of education, are often aware of health matters and might be interested in contributing to better science and better informed clinical decisions. Informing, engaging and involving people on health-related issues should not be considered optional; nor is putting in place an implementation strategy on health issues appropriate, without having first paved the way for an effective understanding and acceptance by the public.

People's voices and actions are therefore important, and they come to play prominently in at least three main stages of the PM value continuum: research, patient access and implementation in the healthcare systems.

Research in PM relies on the accessibility of personal and health data coming from people, who can choose to share them for research, public health and innovation purposes.

Genetic investigation at a population level needs these data and may lead to a better understanding of several pathologies, and to the identification of new ones. This might hopefully turn into new therapies or diagnostic tools focused on people with a particular genetic pattern, for targeted intervention and prevention. Furthermore, this data can serve the development of more evidence-based and effective health policies.

PM cannot advance without this health-related data, which needs appropriate infrastructure and rigorous regulatory frameworks to be shared and accessed. A consequence thereof is that PM research needs the trust and collaboration of the public to develop further, for the benefit of the whole society.[2] Moreover, people should be central in the process and enabled to assess potential risks and benefits of sharing their personal data.

Despite being considered crucial by all stakeholders, People Engagement in PM has been given far less attention compared to its technological development and implementation. A recent study has counted only eight People Engagement activities ongoing between 2015 and 2020, six of which took place in the UK.[3] These results outline a great unmet educational/engagement need towards people, as well as a gap between policy makers and the public, that should be filled with an adequate strategy, under penalty of hampering a wider acceptance of PM.[4]

The importance of ensuring a correct information/education and then collaboration of the public is pivotal for PM and is one of the objectives of EP PerMed.

Education on PM can empower individuals to generate scientific questions and share their data, a key point for PM future development, and to enable studies that would not be accessible without them.[5] Furthermore, in the view of addressing inequalities in PM, an effective education offers an opportunity to involve marginalized groups, such as ethnic, sexual and gender minorities, to shape scientific inquiry through participation.[6,7]

An informed public can extend and enhance the practice of PM, by collaborating with Health Care Professionals to develop scientifically sound approaches.[6,8]

Moreover, well-informed people could contribute to sharing their data through digital technologies, thanks to the widespread use of wearable devices and apps that allow for a continuous and real-time tracking of health parameters and behaviours.

Also, when it comes to clinical research, it has been assessed that involving patients/people in the development of protocols of clinical trials may add considerable financial value to such trials, because patients can offer recommendations that positively affect enrolment, adherence and retention of participants.[9] Yet patients

involvement in research activities is still underestimated and underrepresented, and this might widen the gap between clinicians/researchers' beliefs and what patients really need.[3]

Another key point to be taken into consideration in the people/PM relationship is the acceptance by the public of new medical approaches introduced by PM.

Communication about PM is challenging and has often been approached with very technical language, far from people's way of talking.

If people do not clearly understand and accept the potential benefits of new therapies and diagnostics, how can they be successfully implemented in the healthcare system? Bearing in mind that people are stakeholders in the PM value continuum, we must make sure that an effective communication strategy for their understanding of PM is in place.

In addition, it must also be cemented that people should be well informed of pros and cons of PM approaches and thus can make informed decisions when it comes to their health and their related personal data (for example, the right not to know). Also, the inclusion of minorities and underserved/underrepresented communities in this process must be prioritized to make PM approaches representative of the community/society.

One last aspect to be considered is the power of public opinion in advancing or putting the brakes on health policies. PM raises ethical concerns that often conflict with financial sustainability. In the case of treatments for rare diseases for example, these therapies can dramatically improve health, or even save lives, but only for a very restricted number of people. Here the support of the public opinion could be crucial, for example for the adoption of innovative therapies, pushing healthcare systems to design new reimbursement models.[9]

4 The survey on the awareness of citizens of PM

Many initiatives aimed at understanding the level of education, awareness and sentiment of the population towards PM related matters have been carried out over the last 20 years.[10–13] The focus of a survey is generally oriented specifically on one of the previously mentioned topics of People Engagement in PM

(genetic literacy, public trust, people empowerment…), though some surveys have employed a broader scope when investigating socio-behavioural aspects.

In the context of EP PerMed Work Package 5, Task 5.4 "Disseminate the PM benefits within the society and increase the overall citizen knowledge and engagement on PM", the action A5.3.1 included "Prepare and launch a survey among people to establish a baseline for people awareness of PM". Hereinafter this activity will simply be mentioned as "the survey".

The EP PerMed survey aims at generating data on the awareness and perception of people of PM. This survey would like to investigate whether and how much people are informed about PM, what is their perception of it, their thoughts on its possible benefits and concerns, and ultimately if they are aware of PM initiatives and happened to be involved in one or more of them.

Although genetic literacy among people has been widely associated with a better comprehension of PM, the definition of PM used by the EP PerMed consortium goes well beyond genetics and includes aspects related to technological development, healthcare sustainability and socioeconomics. Therefore, this survey is built not focusing primarily on understanding the level of genetic literacy, but rather on the consciousness of people on local/national PM ecosystems and PM in general.

The survey includes several closed (multiple options) and open questions. Open questions are fundamental to leave enough freedom of speech to the interviewee and were applied to questions that require a more detailed answer. The survey includes questions on relevant demographic information such as age, sex, gender, education, etc. and everything that might be useful for data analysis and clustering.

The outcomes of the survey, collected in this report, will hopefully provide the EP PerMed, the European Commission and all stakeholders involved in the PM value continuum with a better understanding of the perception that people have of PM

and which are the priorities to address for a wider, faster and more equal access to it.

5 General considerations on the survey

The outreach of the survey is connected to the dissemination strategy adopted, which strongly influences the final panel of participants. For instance, it has been clearly demonstrated how choosing different communication channels automatically selects a certain subgroup of the public.

Social media are nowadays the main way to reach out to the public, as they are free of charge and widespread. Nevertheless, social media target only people with a sufficient degree of digitalization, while excluding for example the elderlies.

Moreover, depending on the nature of contents they offer, social media tend to exacerbate further selection of population subgroups. We can cite LinkedIn, that gathers a community of mostly well-educated and wealthy professionals.

We can thus conclude that, unless the sample is made up by subjects collected combining the widest variety of dissemination (social media, press, classic media, direct advertisement through physicians, etc.) and data collection approaches, any survey is limited to some extent, and this is commonly recognised in the literature.

A panel composed by a large variety of citizens, in terms of age, ethnicity, education, etc. can be assembled by specialised consulting companies or web portals, but these are paid services, thus this strategy was not pursued by the partnership, which decided to rely on its network for the dissemination of the survey.

As a result, the panel of participants to this survey somehow reflects the public which already follows EP PerMed and the activities of its partners, and this can easily be seen from the outcomes of some questions.

To mitigate this, the same survey could be administered in the future to different "groups" relying on different communication channels and data collection approaches, to get a full final picture. Here focus groups or people fora are useful tools, allowing for the inclusion of underrepresented/underserved communities while widening the diversity of the studied public.

These considerations, and the fact that the partnership will conclude its activities in 2033, push EP PerMed to keep the survey open to hopefully increase the number and variety of participants, to get the closest possible to a real representation of the European population, in terms of gender, ethnicity, wealth level, education, etc.

6 Structure of the survey

6.1 Preparation of the survey

The survey was prepared in English by the WP5 Task 5.4 partners. The survey was then translated in 16 different languages using automatic translation (DeepL). The versions were proofread by mother tongue EP PerMed partners, who made sure that the questions were correctly phrased and that the wording was suitable for a lay audience.

The questions were designed from scratch or inspired by other surveys published online or reported in the literature; in these cases, the questions were adapted content wise or rephrased to best fit the purpose of the EP PerMed survey.

Discussion among WP5 Task 5.4 partners and iterative corrections brought to a final version, which was then reviewed by the People Engagement Board (PEB) of EP PerMed to make sure that:

- The questions were well formulated content wise
- The language was friendly and easy to understand for a lay audience
- The survey respects the highest ethical standards

Suggestions from the Board were taken up and the adapted version of survey was finally validated by the Coordination Unit (CU) of EP PerMed.

The survey is composed by a total of 36 questions, of which:

- 31 are multiple options or Likert scale questions
- 5 are open answer questions

It is divided in 4 sections:

- Personal information
- Education and job information
- Questions on PM
- Health Data management

The scope of each section is introduced by a small text, also highlighting why respondent's opinion matters.

Purposely, the survey does not introduce any kind of definition of PM before the last of the above-mentioned sections, in order not to influence the answers. A simple definition of PM is then proposed, allowing anybody, even those with no previous knowledge of PM, to answer the section on PM understanding and awareness.

6.2 Dissemination of the survey

A first version of the survey (pilot) was setup using Microsoft Forms and launched on a smaller scale (i.e. only one country, namely Italy) during the first year of the partnership, in August 2024. This pilot in Italian was prepared by native speakers by translating the original English version. The pilot was disseminated for 2 months, mostly using social media and institutional distribution channels, such as exploiting the communication channels of Regions, Ministries and Research Organizations that are part of EP PerMed. The results of the pilot were included in the Deliverable 5.2 "Citizen Engagement Strategy", published by the EP PerMed. This first survey served, where needed, to fine-tune the next step, i.e. the extension of the survey to other European countries.

The final, multi-language version of the survey was setup using SurveyMonkey and published on the **EP PerMed website on a dedicated webpage**.

The survey is now available in 16 languages, which can be selected when starting the survey:

- Czech
- Danish
- English
- Finnish
- French
- German
- Greek
- Italian
- Norwegian
- Dutch
- Polish
- Portuguese
- Romanian
- Spanish
- Swedish
- Turkish

The multi-language survey was launched in mid-August 2025 (second year of the partnership) and results were analysed one year after, in August 2026 (third year of the partnership). During this time, EP PerMed partners were asked to disseminate the survey via their personal and professional communication channels, mainly through institutional websites, newsletters and social media. EP PerMed regularly included the initiative in its newsletter, social media posts and general communications. After one year, a total number of 354 participants filled out the survey. The results are discussed in the following section. Considering that the survey is still open, results may have slightly varied in the meantime.

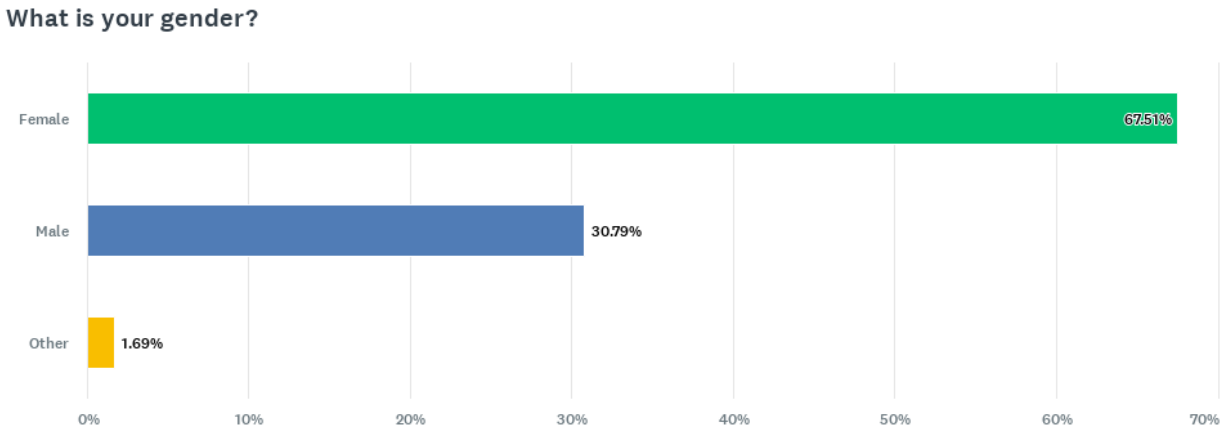
Survey overview

- 36 questions
- Estimated completion time: 13 minutes
- 16 languages
- 354 respondents (as of August 2026)
- Mainly disseminated through EP PerMed's and partners' web-sites, LinkedIn and newsletters
- Results collected after 1 year (August 2025 - August 2026)

7 Results of the survey

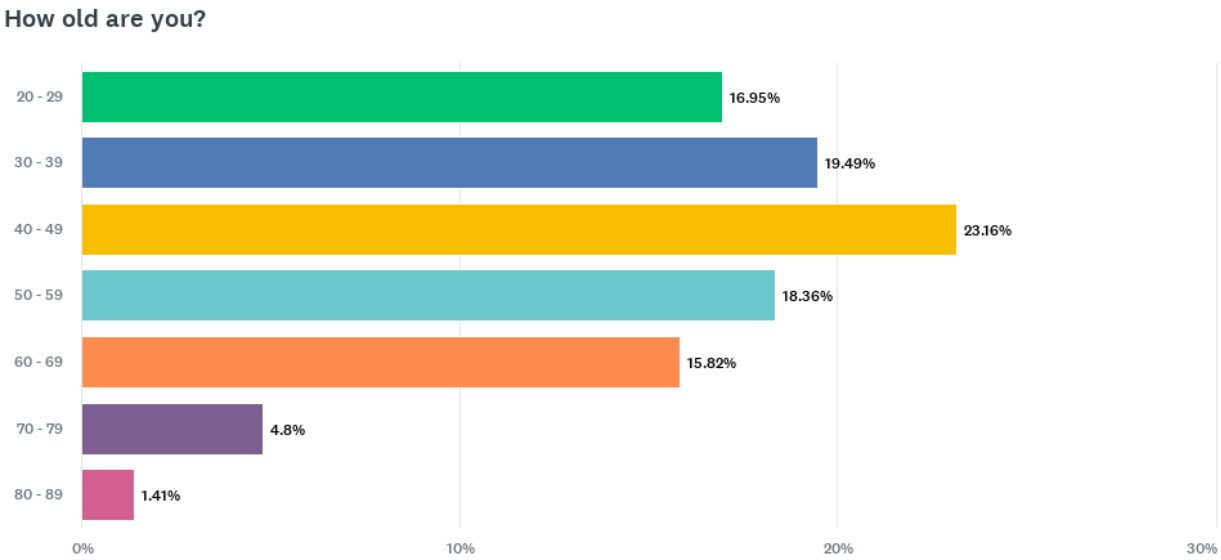
7.1 Personal information and education

7.1.1 Q1: What is your gender?



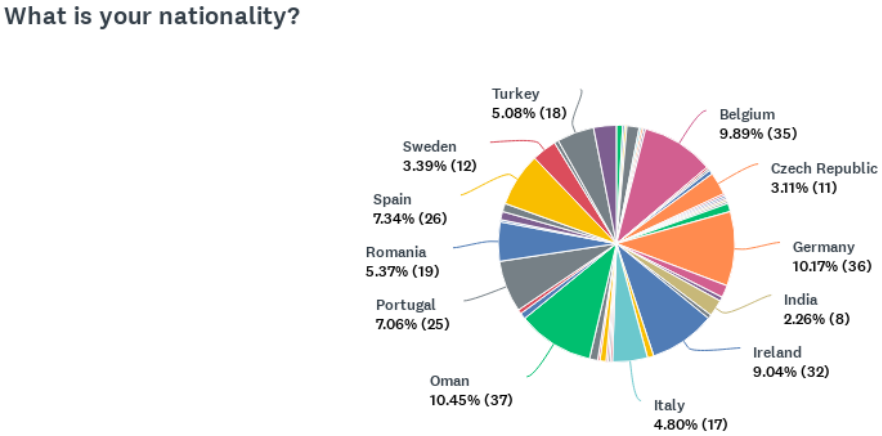
Most of the respondents are women, who account for more than 65% of the total.

7.1.2 Q2: How old are you?



As can be seen from the graph, the sample is quite well distributed among different ages. Elderlies (70+) account only for the 6% of the sample, which probably can be explained by the fact that the survey was only available in digital format online.

7.1.3 Q3: What is your nationality?

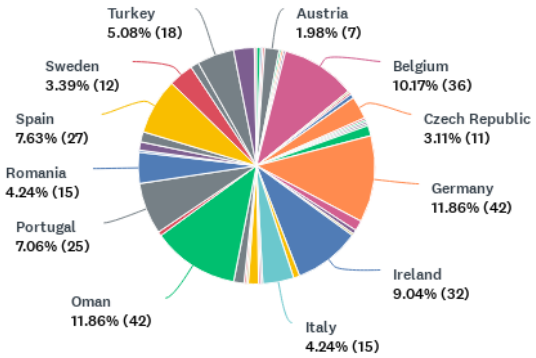


The graph shows a clear prevalence of European respondents, in line with the fact that it was distributed mainly by the EP PerMed partners. A relevant share of

responses came from Oman (about 11%), likely reflecting the dissemination through a specific institutional channel.

7.1.4 Q4: In which country do you live?

In which country do you live?



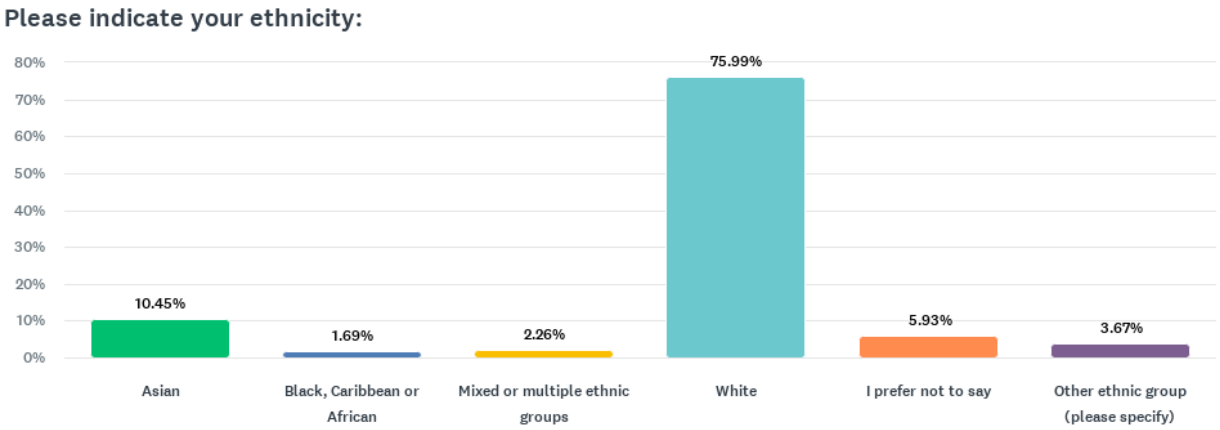
Nationality and country of residence greatly correspond.

7.1.5 Q5: If any, please indicate major personal/family medical history happenings

The 39% of respondents reported major personal/family medical history happenings, among which:

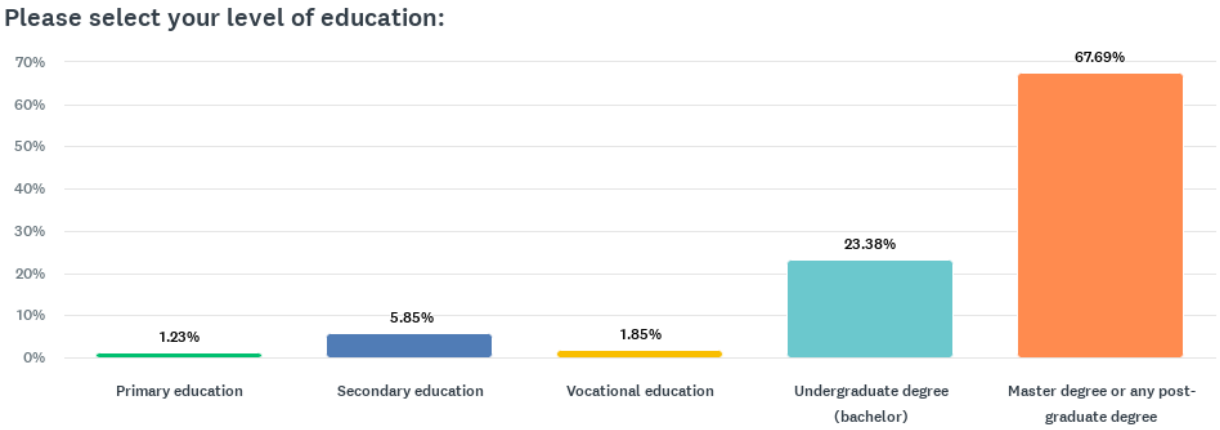
- Cardiovascular, 38%
- Cancer, 33%
- Mental disorders, 15%
- Diabetes, 11%
- Autoimmune syndromes, 7%
- Rare diseases, 4%

7.1.6 Q6: Please indicate your ethnicity:



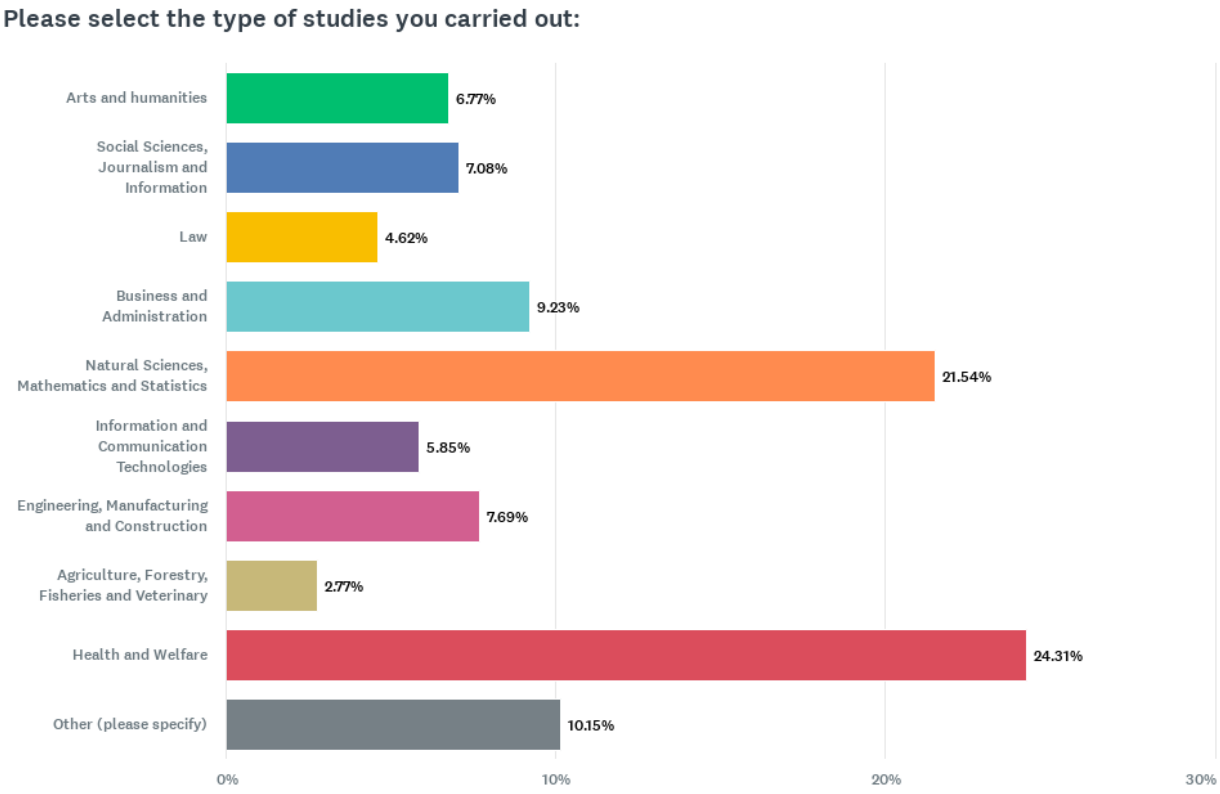
The graph shows a great prevalence of white respondents. This was quite expected, as the communication channels used for the dissemination of the survey tend to target the so-called "WEIRD" (Western, Educated, Industrialized, Rich, and Democratic) population.

7.1.7 Q7: Please select your level of education:



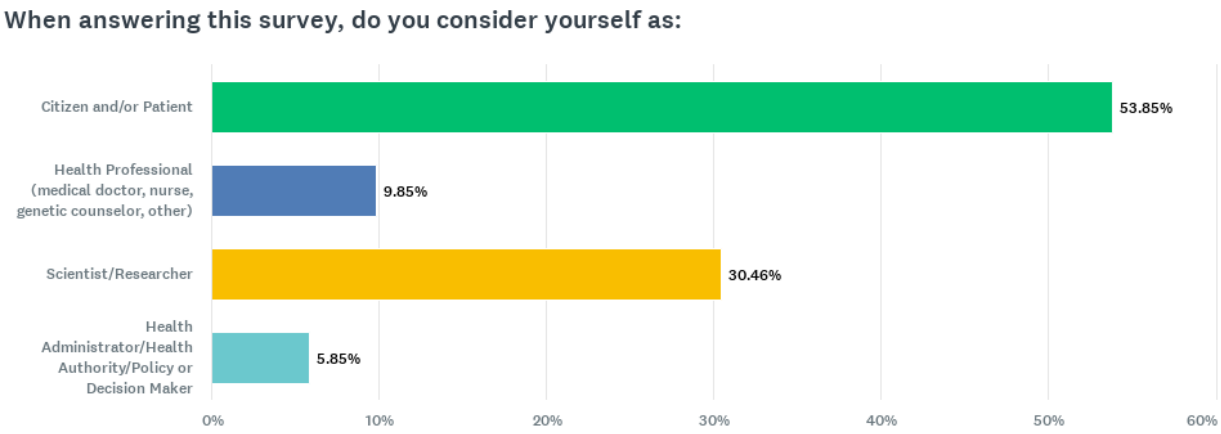
As expected from the dissemination channels employed, the sample is strongly skewed towards highly educated respondents: 91% hold a tertiary qualification (short-cycle, bachelor's, master's or doctorate), against **34.3% of the EU population aged 25–74 in 2025.** This should be taken into account when interpreting the answers on PM familiarity (Q12) and on the availability and understandability of information (Q27, Q28).

7.1.8 Q8: Please select the type of studies you carried out:



As can be seen from the graph, respondents cover a wide range of curricula. Considering the **EC's latest Education and Training Monitor 2025**, the percentage of respondents educated in STEM is only slightly higher than what reported (35% vs 27%, considering the sum of sciences, engineering and information & communication technologies). Nevertheless, a consistent part of respondents is educated on health-related topics. Overall, this might contribute to an average better awareness of PM.

7.1.9 Q9: When answering this survey, do you consider yourself as:

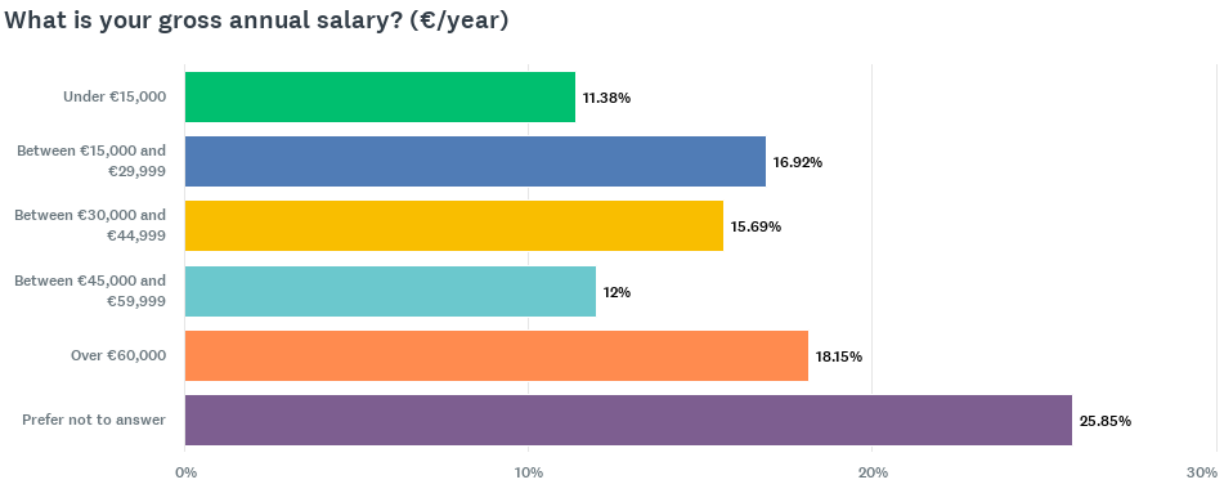


More than half of respondents consider themselves "citizens", while nearly half of the sample (46%) reported a professional role in science, healthcare or health policy. This composition should be considered when interpreting the high levels of PM familiarity reported in Q12. This again is not surprising, considering that EP PerMed communications target also a well-established health research community, which follows the partnership and its funders.

7.1.10 Q10: What is your job title?

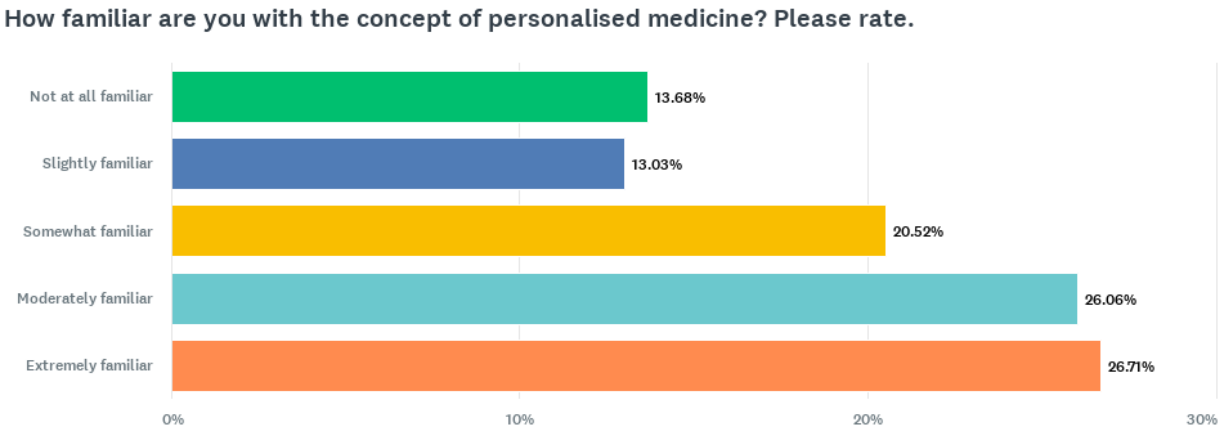
Responses to the job title question reveal a wide range of professional backgrounds. A few respondents work in human resources, management, support roles, or academic research, while others represent health policy, laboratory, medical, technical, and executive fields. Some responses did not fit a clear category. Overall, the group is professionally diverse, with no single field dominating the responses, reflecting varied perspectives relevant to the topic of personalised medicine awareness among citizens. No strong central theme emerged from the job titles provided.

7.1.11 Q11: What is your gross annual salary? (€/year)



According to the latest Eurostat data, **the average annual gross full-time adjusted salary** in the European Union for 2024 was €39,800 per year. A high percentage of respondents opted out this question.

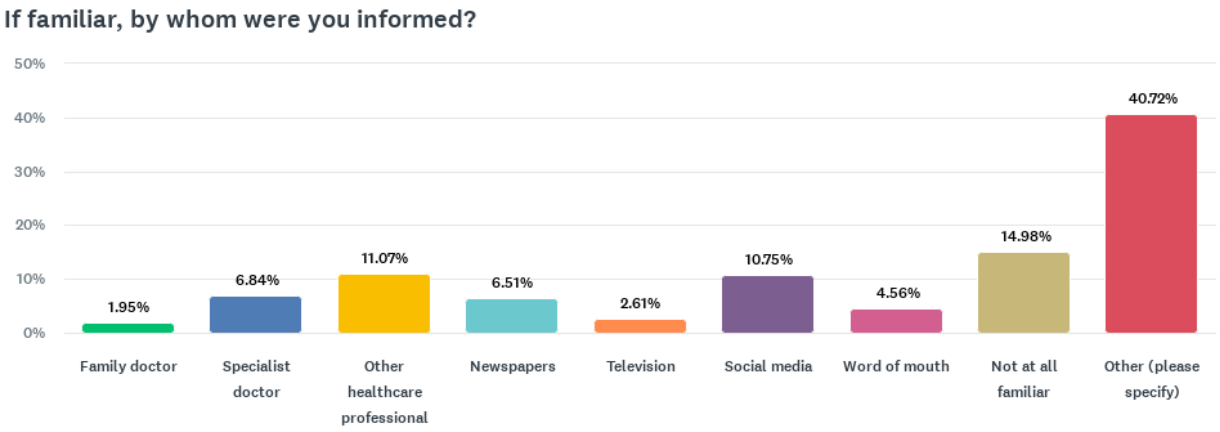
7.1.12 Q12: How familiar are you with the concept of personalised medicine? Please rate.



More than 50% of respondents to this survey know about PM (moderately + extremely familiar). This is in contrast with the results of the first pilot survey in Italian launched by the partnership in 2024, where the majority of people knew little or nothing about PM. Interestingly, the Italian survey was spread also in non-

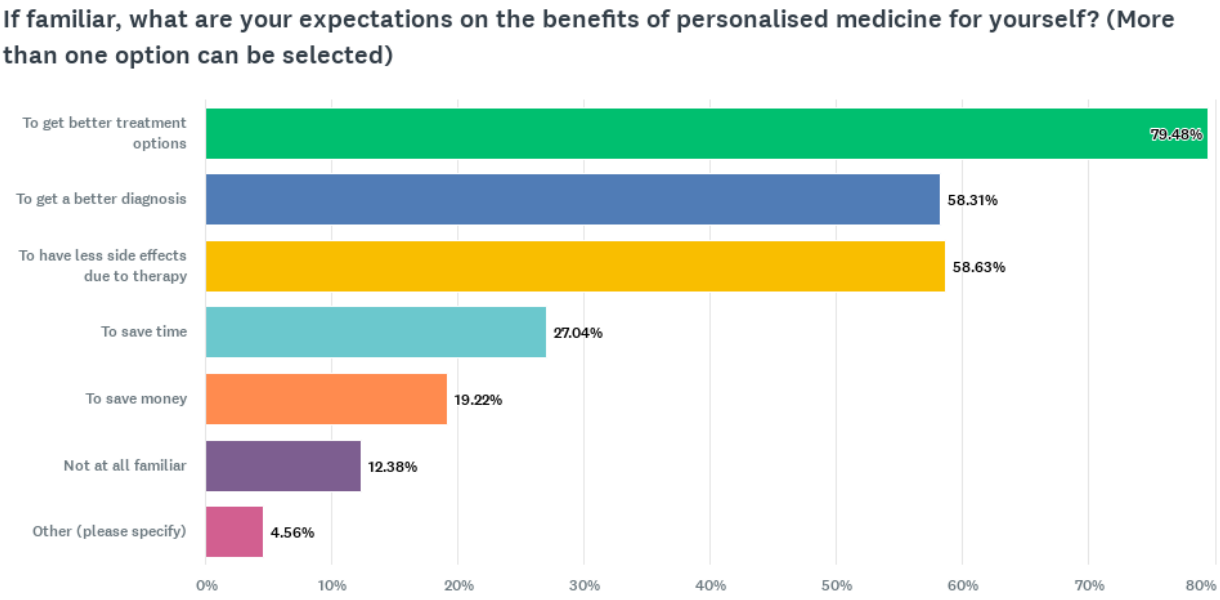
scientific environments and through word of mouth, and this can have contributed to a wider outreach, outside the scientific community. Besides, many studies report a general low level of genetic literacy in the public, so it is unlikely that such a high percentage of people know about PM. All in all, this points towards results from this survey being overestimated for this question.

7.1.13 Q13: If familiar, by whom were you informed?



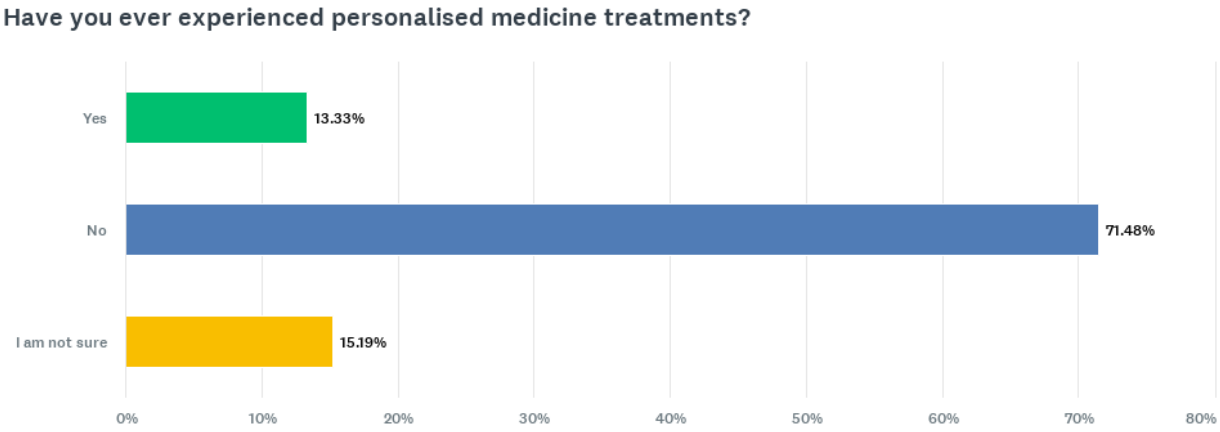
The sources of information on PM are quite widespread, as can be seen from the graph. Sources indicated under the "Other" category included scientific literature, workplace and patient associations.

7.1.14 Q14: If familiar, what are your expectations on the benefits of personalised medicine for yourself? (More than one option can be selected).



Respondents expect that PM will bring them better diagnosis and better treatments with less side effects. On the other hand, saving time and money were not seen as the main benefits that PM will introduce.

7.1.15 Q15: Have you ever experienced personalised medicine treatments?



A vast majority of the respondents has never benefitted from PM treatments, or it is not sure about that.

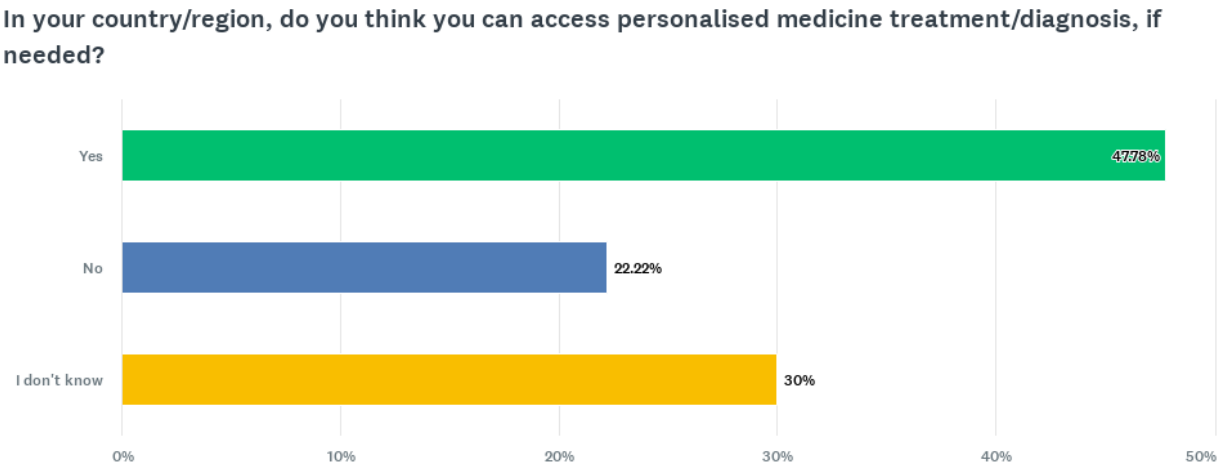
7.1.16 Q16: If yes to the previous question, for what purpose did you experience personalised medicine treatments?

According to the survey, the most common purposes for experiencing personalised medicine treatments are:

- Genetic Assessment and Testing (21%)
- Medical Consultation and Prevention (19%)
- Cancer Treatment (17%)
- Chronic Disease Management (13%)

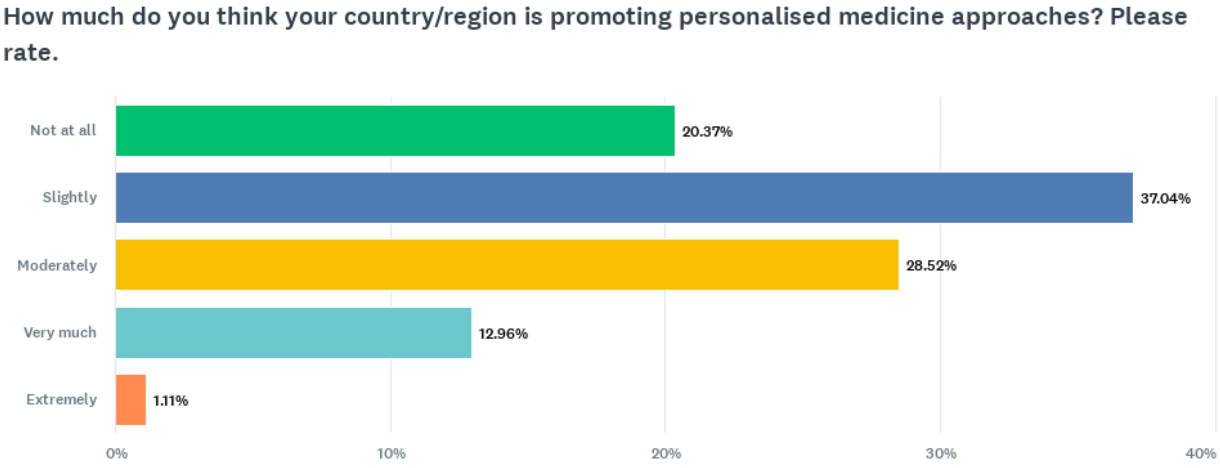
Personal Health Management, Family Health History, and Cancer Screening are also mentioned, but less frequently. Only a small number of responses (10%) could not be assigned a specific category.

7.1.17 Q17: In your country/region, do you think you can access personalised medicine treatment/diagnosis, if needed?



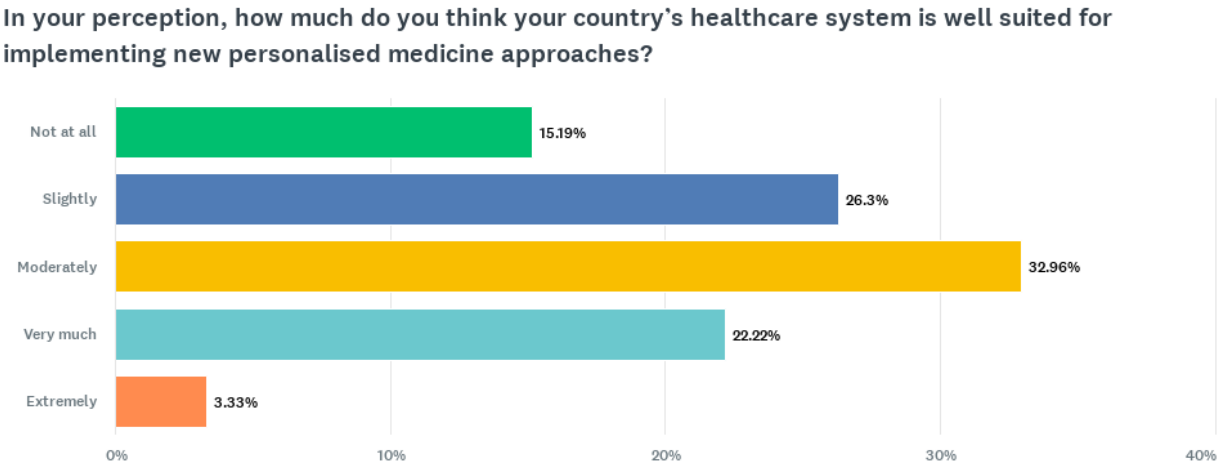
Even with an average good knowledge of PM, respondents don't think or are not sure that they can access PM treatments. This might highlight a communication gap even in those countries where PM has been widely adopted. In healthcare systems, PM approaches are often in place without being defined PM. The vocabulary around PM is too wide and still not internationally aligned. Furthermore, oftentimes citizens do not understand medical jargon and therefore they are not fully aware of which healthcare services they are receiving.[14] These aspects might hamper a clear understanding by people of the progresses that healthcare systems have done or are doing to implement PM solutions.

7.1.18 Q18: How much do you think your country/region is promoting personalised medicine approaches? Please rate.



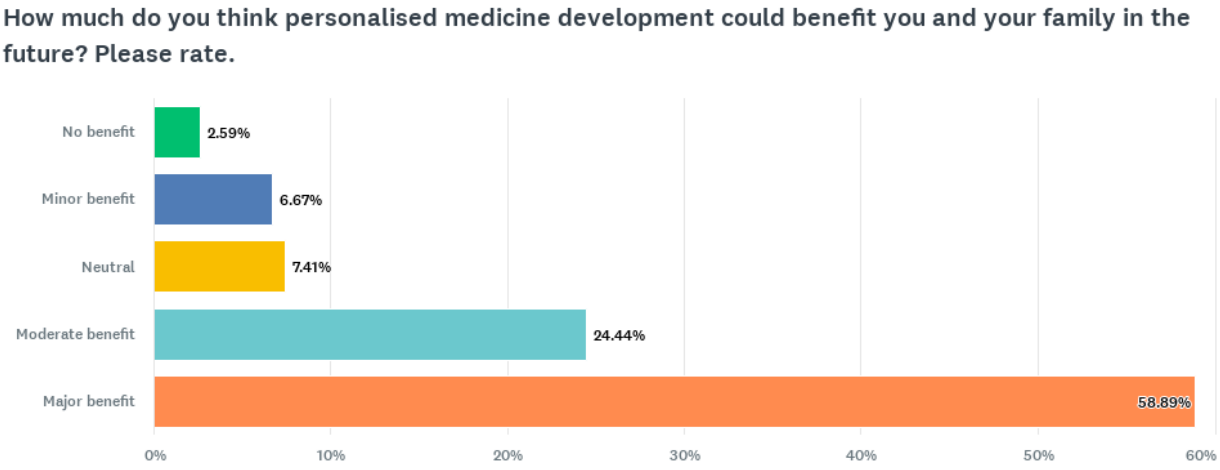
Respondents believe that their country/region currently is not promoting personalised medicine approaches enough. This correlates with Q17, highlighting once again the need for a stronger communication around PM.

7.1.19 Q19: In your perception, how much do you think your country's healthcare system is well suited for implementing new personalised medicine approaches?



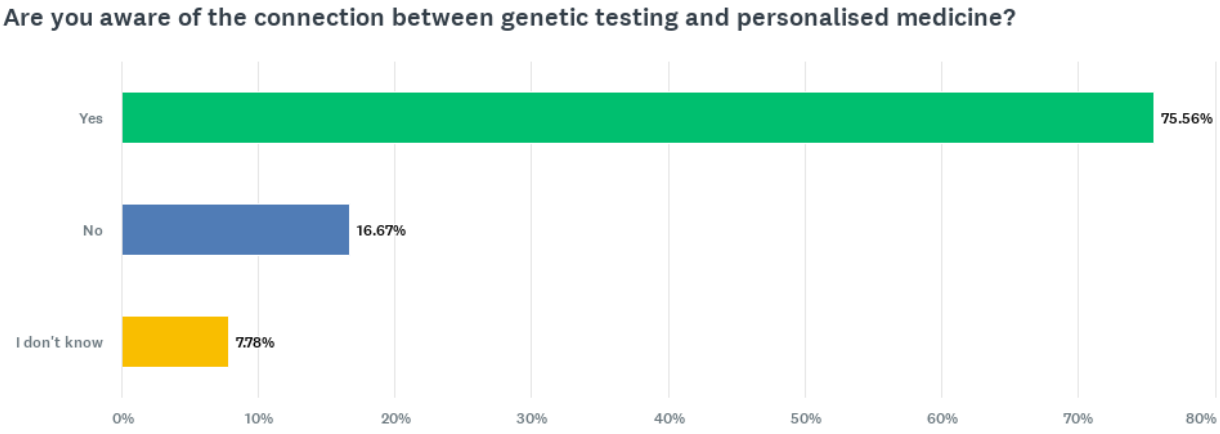
On the preparedness of healthcare systems to adopt PM solutions, respondents believe that their healthcare systems are still not fully prepared. It is also worth considering this "perception" of unpreparedness in the light of Q17: people are not sure they access PM approaches or think they cannot access them at all (Q17), and at the same time they think that their healthcare systems are not suited to implement them. This might indicate a certain degree of mistrust in the local healthcare systems, even though not necessarily linked to PM.

7.1.20 Q20: How much do you think personalised medicine development could benefit you and your family in the future? Please rate.



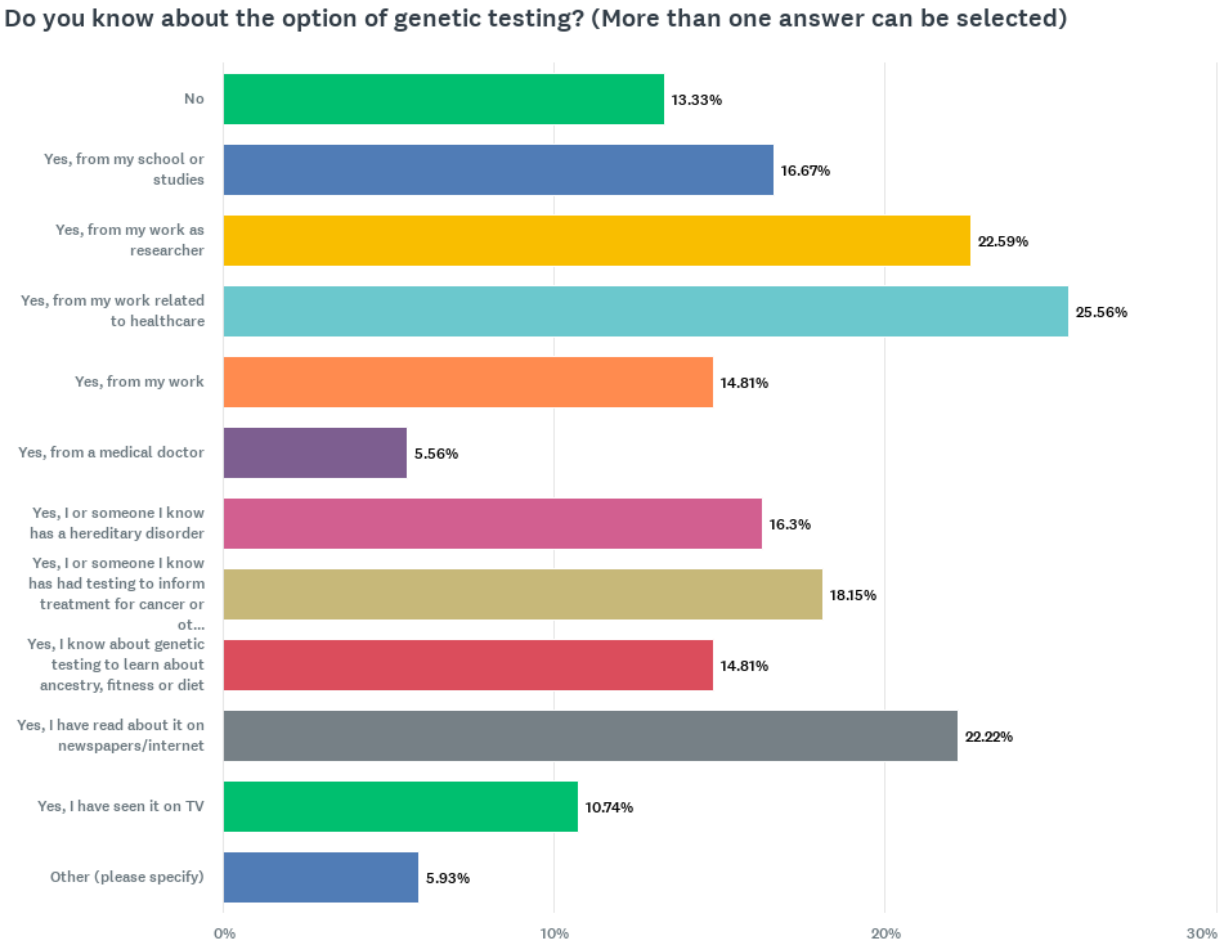
A vast majority of respondents are sure that they will benefit from PM.

7.1.21 Q21: Are you aware of the connection between genetic testing and personalised medicine?



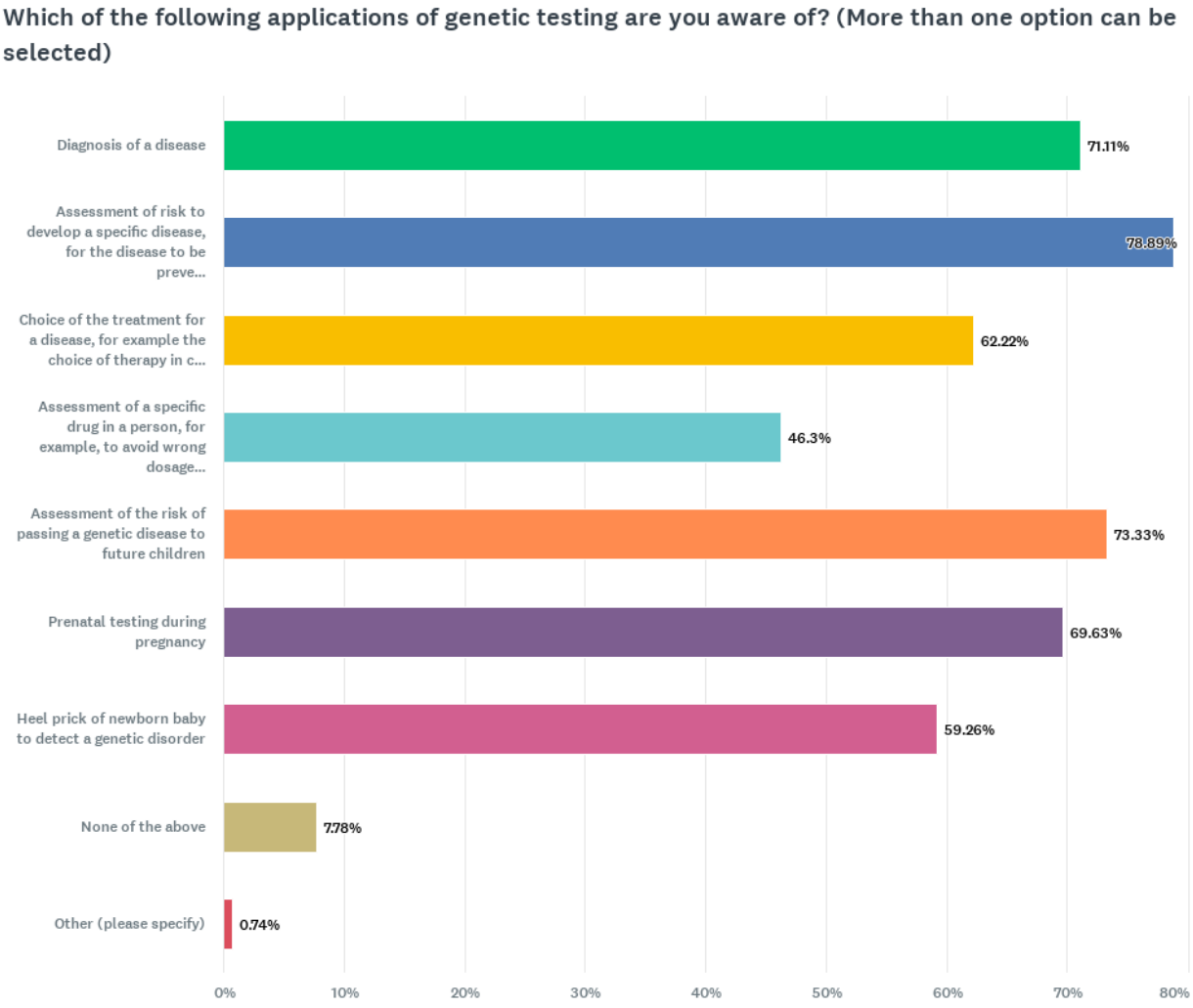
More than 75% of respondents are aware of the connection between PM and genetic testing.

7.1.22 Q22: Do you know about the option of genetic testing? (More than one answer can be selected).



The graph shows that the awareness of genetic testing comes from variety of sources. Studies/work seem to be the predominant sources of information in this case, but also awareness rising from direct or indirect contact with genetic testing for different purposes is well represented.

7.1.23 Q23: Which of the following applications of genetic testing are you aware of? (More than one option can be selected).



In general, respondents seem to have quite clear what's the purpose of genetic testing.

7.1.24 Q24: Are there aspects of personalised medicine that you are concerned about?

The most common themes of concern among respondents to this question are:

- Personalised Medicine Costs (10%)
- Genetic Data Security and Misuse (8%)
- Healthcare Access Equity (8%)
- Ethical and Misuse Concerns (5%)
- Data Protection Regulations and Personal Data Privacy (each 4%)
- Healthcare System Integration (3%)

A large portion (43%) of responses did not fit into a specific theme.

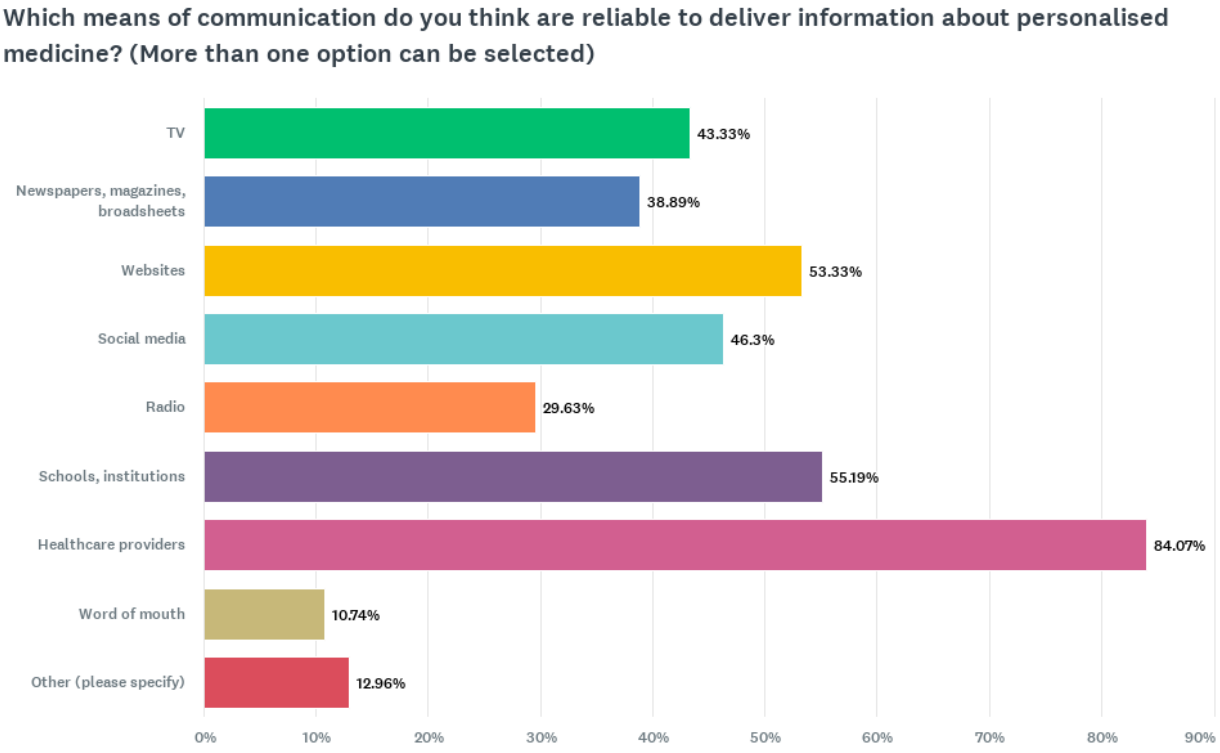
7.1.25 Q25: Are there aspects of personalised medicine that you are curious about?

The most common themes identified in the responses include:

- Personalised Treatment Effectiveness (9%)
- Healthcare System Implementation (5%)
- Disease Prevention and Early Detection (5%)
- Genetic and Risk Testing (5%)
- Gene and Cell Therapy Technologies (4%)
- Access and Equity in Personalised Medicine (3%)
- Artificial Intelligence and Data Integration (3%)

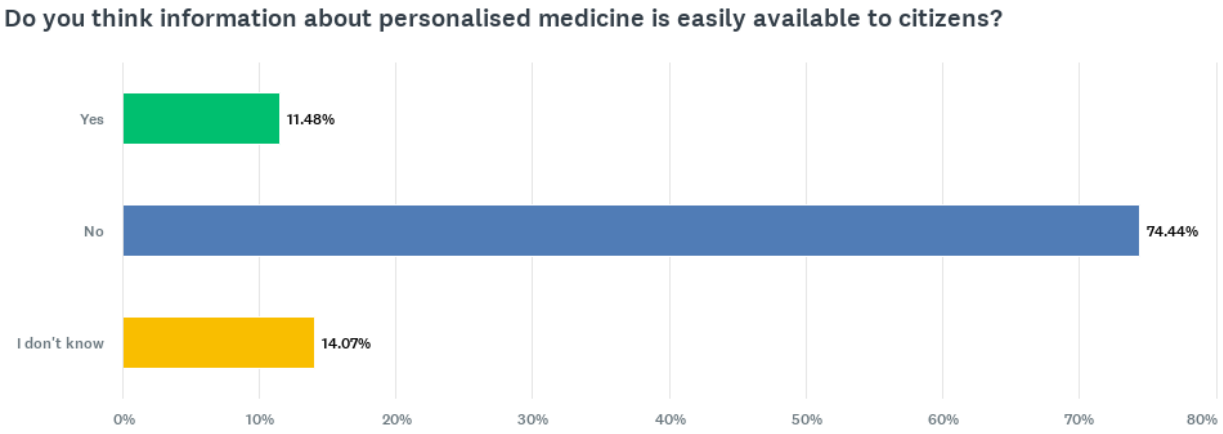
Many respondents indicated that they are curious to know more in general about PM.

7.1.26 Q26: Which means of communication do you think are reliable to deliver information about personalised medicine? (More than one option can be selected).



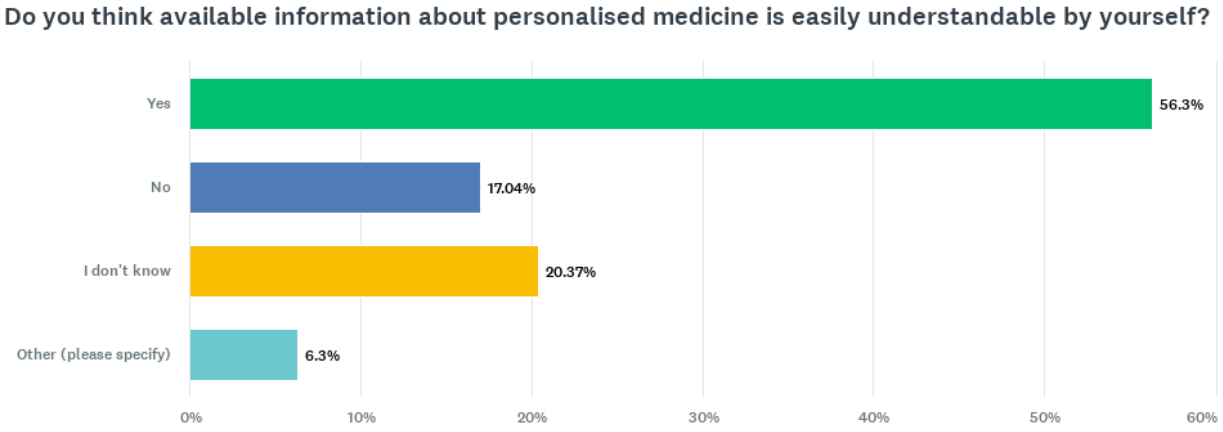
HCPs are the preferred way to get information about PM, even though other channels such as school, websites, social media and TV are well represented. The outcomes of this question highlight the role of the HCP as a connector between healthcare services and the awareness of the public about them.

7.1.27 Q27: Do you think information about personalised medicine is easily available to citizens?



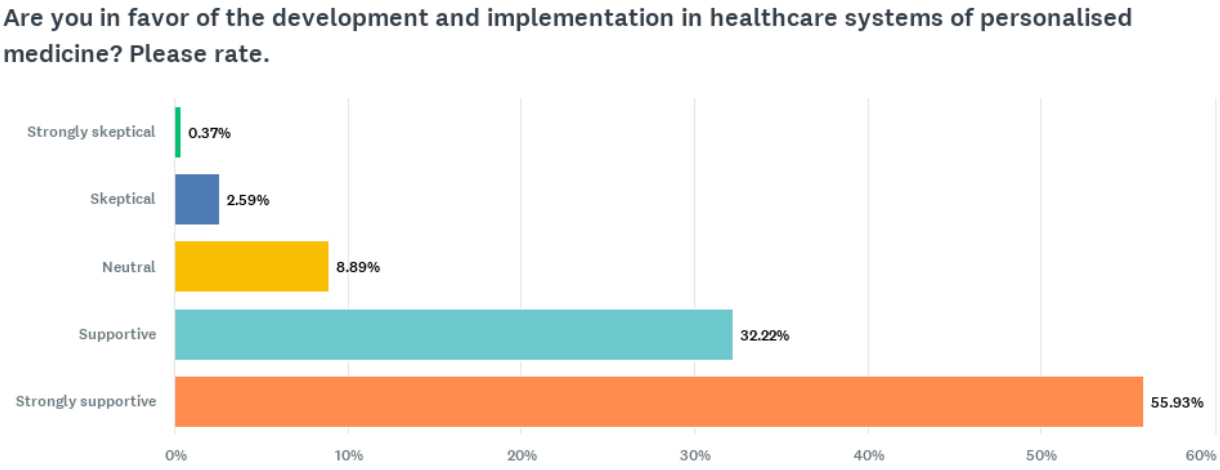
To be considered that, as seen from Q12, literacy of PM among the respondents of this survey is high, yet 75% of them thinks that information about PM is not easily available. This again might highlight a scarce communication around the topic, where medical approaches are often not clearly labelled as "PM".

7.1.28 Q28: Do you think available information about personalised medicine is easily understandable by yourself?



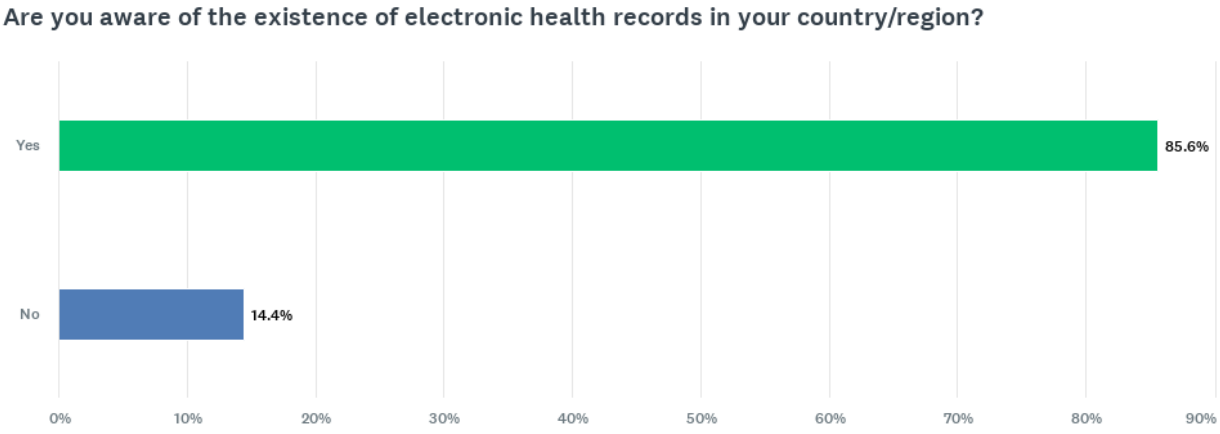
More than 50% of respondents thinks that they are able to understand the available information related to PM.

7.1.29 Q29: Are you in favor of the development and implementation in healthcare systems of personalised medicine? Please rate.



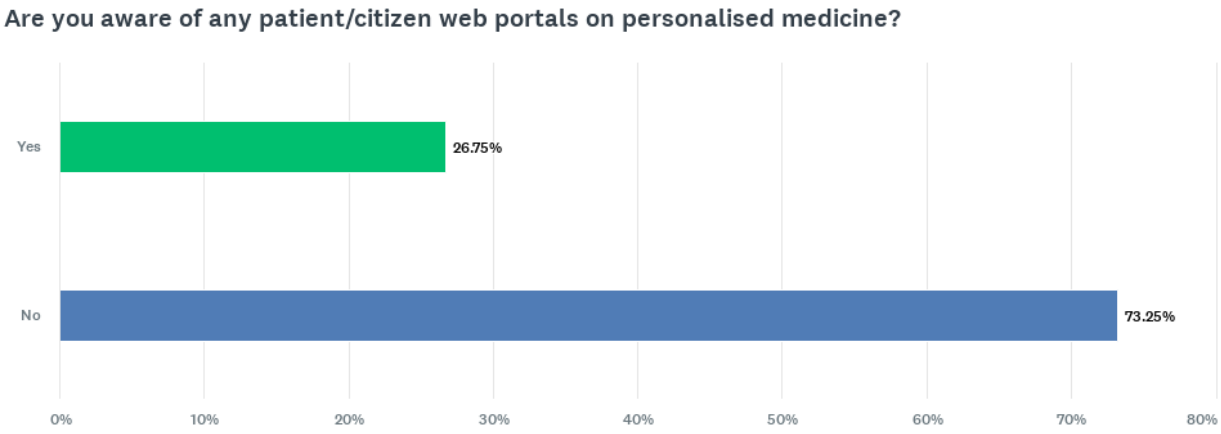
The vast majority of respondents is supportive towards the implementation of PM in healthcare systems.

7.1.30 Q30: Are you aware of the existence of electronic health records in your country/region?



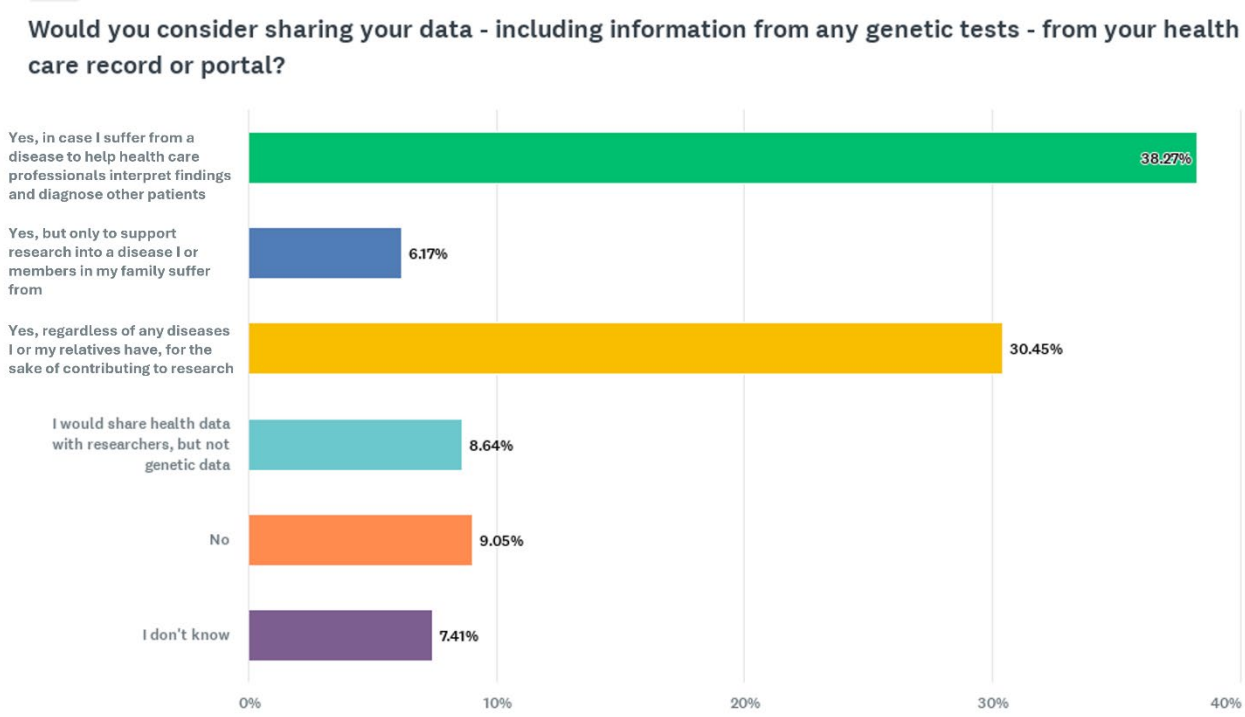
Respondents are well aware of the existence of electronic health records in their country/region.

7.1.31 Q31: Are you aware of any patient/citizen web portals on personalised medicine?



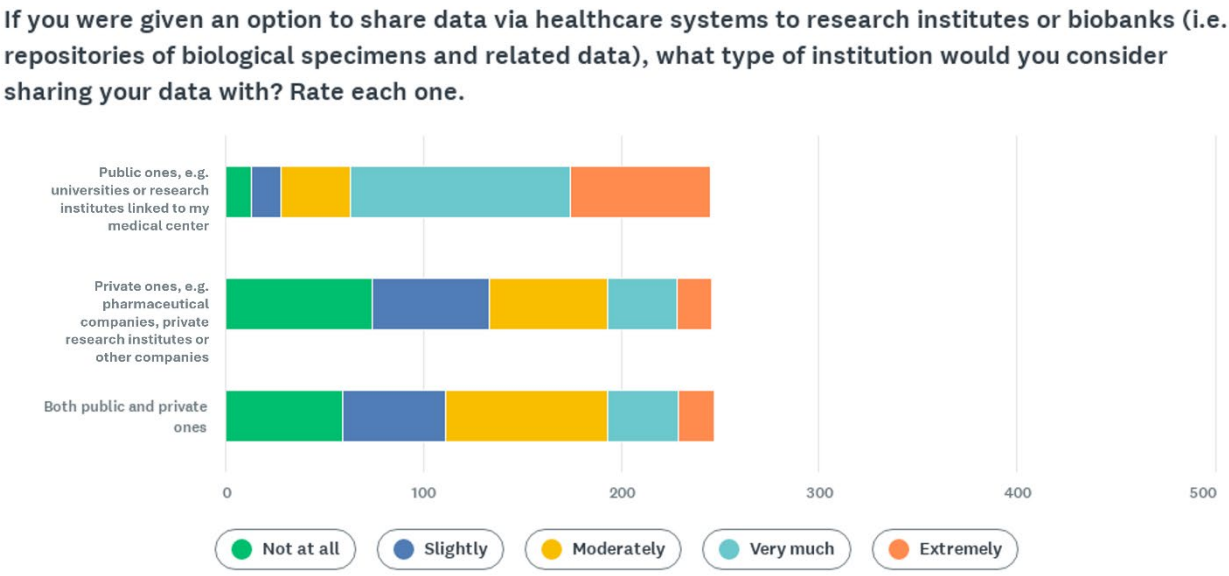
Web portals on PM are generally not known, even if respondents have in general a good awareness of PM.

7.1.32 Q32: Would you consider sharing your data - including information from any genetic tests - from your health care record or portal?



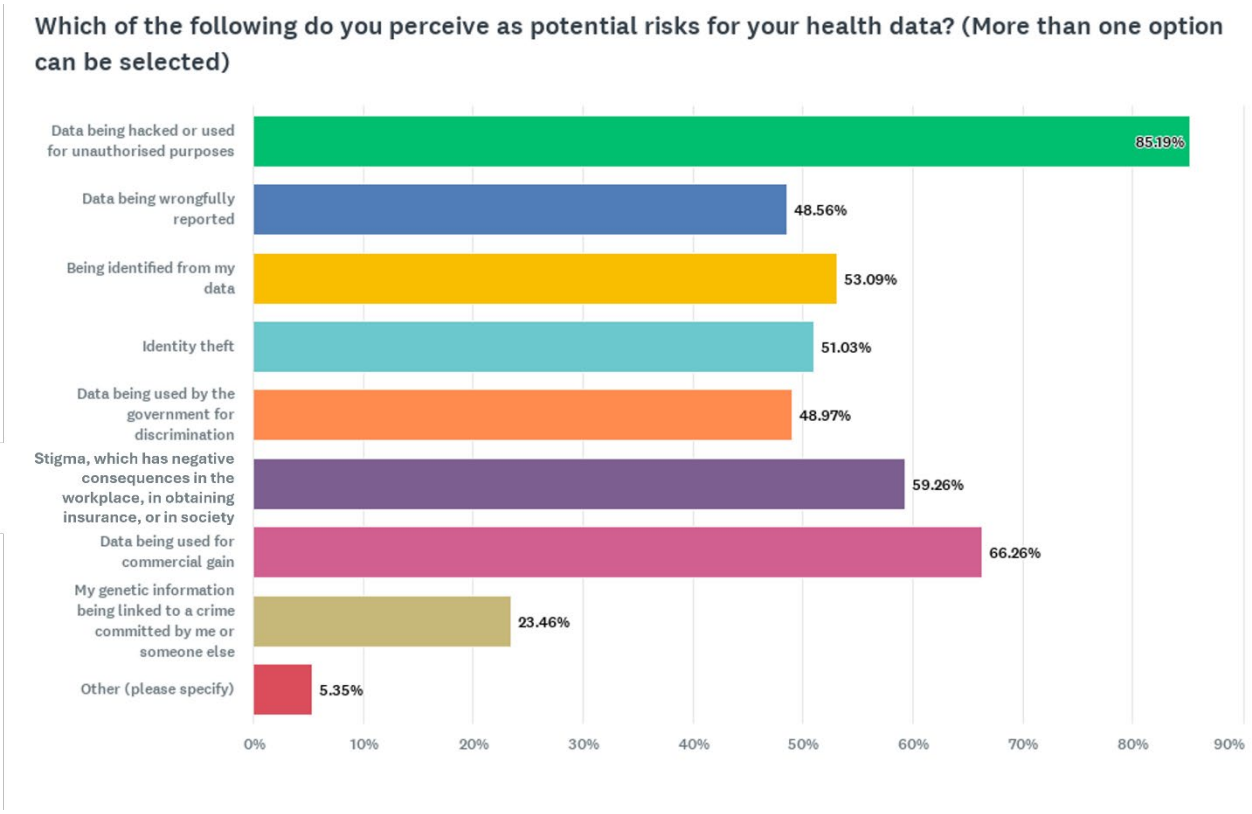
On the willingness to share their health data, genetic ones included, opinions diverge. Almost 40% of respondents answered that they would do so conditionally, in the case they were sick, for getting a better diagnosis/treatment. On the other hand, more than 30% would be keen to share their data for research regardless of their personal or familiar circumstances. Around 15% would share their data only under specific conditions (limited to their own disease, or excluding genetic data), while about 16% declined or were undecided.

7.1.33 Q33: If you were given an option to share data via healthcare systems to research institutes or biobanks (i.e. repositories of biological specimens and related data), what type of institution would you consider sharing your data with? Rate each one.



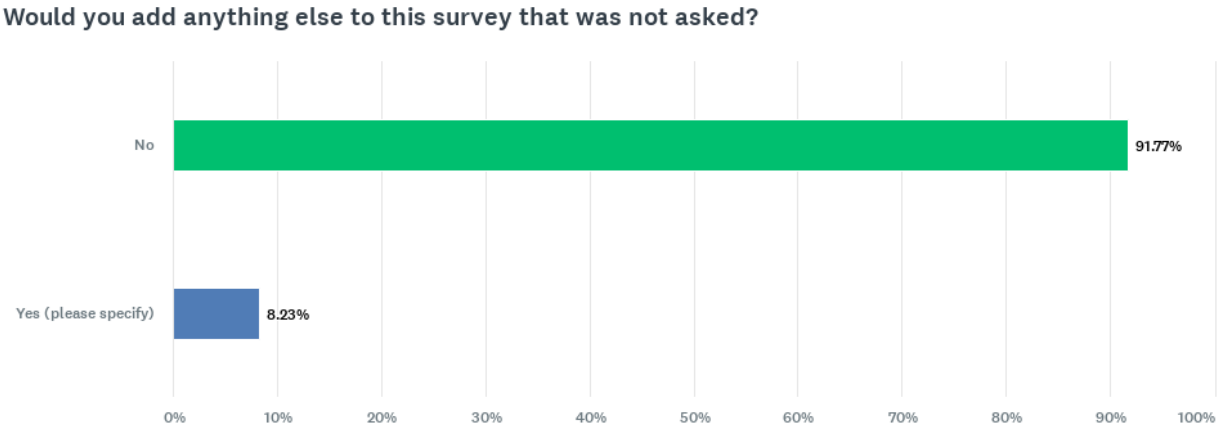
While most of respondents are willing to share their data with public research institutions, the situation is completely reversed in the case of private companies, marking a certain scepticism in entrusting them data that could potentially be used to make profit. This is a common trend, well described in the literature. Notably, respondents with higher education and greater awareness of PM appeared to be more reluctant to share data with private companies, although this trend was not tested for statistical significance.

7.1.34 Q34: Which of the following do you perceive as potential risks for your health data? (More than one option can be selected).



Data being hacked represent the most pressing concern when sharing health data. Very interesting the fact that, despite options with serious consequences like identity theft, data breach, identity reveal and related stigma, the second most worrisome option is that data are being used for commercial gain.

7.1.35 Q35: Would you add anything else to this survey that was not asked?



7.1.36 Q36: Do you have any comment/feedback?

Answers to this question span from PM access and future (5%), to is implementation (4%), but also to education and awareness related to PM (3%). Data privacy and security is again mentioned (2%). Some answers are linked to the survey, like its data quality and relevance (3%) and accessibility and design (3%).

Other themes such as healthcare system funding, survey feedback, and research collaboration were also mentioned by a small number of respondents.

8 Cross-analysis of selected questions

Below we report some considerations that were made by cross analysing two different questions of the survey. Additional data are needed to make these conclusions statistically sound, but nevertheless they can already provide the reader some interesting food for thought.

8.1.1 What is the level of support for personalised medicine development (Q29) among different age groups (Q2)?

Support for the development of personalised medicine is high across all age groups, with the majority in each group being either 'Strongly supportive' or 'Supportive.' The 50-59 and 40-49 age groups show the highest counts of strong support, while even the youngest (20-29) and oldest (80-89) groups display

more support than scepticism. Neutral or sceptical responses are minimal in all age brackets, indicating broad and consistent favourability regardless of age.

8.1.2 How do perceptions of healthcare system suitability for personalised medicine (Q19) differ by country of residence (Q4)?

Perceptions of healthcare system suitability for personalised medicine vary notably by country. Respondents in Belgium and Germany show relatively high confidence, with many rating their systems as 'Very much' or 'Extremely' suited. In contrast, countries like Ireland, Portugal, Spain, and Italy have more respondents selecting 'Slightly' or 'Not at all,' indicating scepticism about their systems' readiness. Oman stands out with a mix of positive and negative views, while smaller countries or those with fewer responses show more moderate or mixed perceptions. Overall, Western European countries tend to be more optimistic, while Southern European countries are more critical.

8.1.3 How do having experienced personalised medicine approaches (Q15) influences respondents' view on its accessibility (Q17)?

There is a positive association between having experienced personalised medicine treatments and perceiving them as accessible. Among those who have experienced such treatments, the majority believe they are accessible (26 out of 36), while only a small number think they are not accessible or are unsure. Conversely, among those who have not experienced personalised medicine, opinions are more divided, with a significant portion unsure or believing access is not available. This suggests that direct experience with personalised medicine increases confidence in its accessibility.

8.1.4 How do perceptions of healthcare system suitability for personalised medicine (Q19) differ by type of respondent (Q9)?

Perceptions of healthcare system suitability for personalised medicine vary by respondent type. Citizens/patients are divided, with most responses clustering around 'Moderately' and 'Slightly' suitable, and fewer seeing the system as 'Very much' or 'Extremely' suitable. Scientists/researchers and health professionals also tend to rate suitability as 'Moderately' or 'Slightly', with very few choosing the most positive options. Health administrators are somewhat more optimistic, with most responses in the 'Moderately' to 'Very much' range. Overall, few

respondents in any group view their healthcare system as 'Extremely' well suited for personalised medicine.

8.1.5 Are people's expectations on the benefits introduced by personalised medicine (Q20) influenced by their previous experience of personalised medicine treatments (Q15)?

Respondents who have experienced personalised medicine treatments are slightly more likely to expect major or moderate future benefits from its development, but high expectations are common across all groups. Among those with experience, 31 out of 36 anticipate major or moderate benefits. Even among those without experience, the majority (157 out of 193) also expect major or moderate benefits. Those unsure about their experience tend to be optimistic as well. Overall, positive expectations for future benefits are widespread, regardless of prior experience.

We can also add that, overall, optimism about the future benefits of personalised medicine is strong across all respondent roles, irrespective if they consider themselves citizens, healthcare professionals/administrator or researchers (Q9).

8.1.6 What are the concerns about personalised medicine (Q24) among respondents with different education levels (Q7)?

Concerns about personalised medicine vary by education level. Respondents with a master's or postgraduate degree most frequently mention costs, genetic data security and misuse, healthcare access equity, and ethical concerns. Those with undergraduate degrees also highlight access equity and data security, but to a lesser extent. Respondents with secondary, vocational, or primary education levels report fewer specific concerns, with most indicating no particular theme. Overall, higher education levels are associated with a broader and more detailed range of concerns.

8.1.7 How does awareness of the connection between genetic testing and personalised medicine (Q21) vary by respondent role (Q9)?

Awareness of the connection between genetic testing and personalised medicine is highest among scientists/researchers (about 89% answered 'Yes'), followed by health professionals (84% 'Yes'), and health administrators/policy makers (87% 'Yes'). Citizens and/or patients show lower awareness, with 62% answering 'Yes'

and a higher proportion responding 'No' or 'I don't know.' Overall, professional roles in science, healthcare, or policy are associated with greater awareness compared to the general public, as expected.

8.1.8 How does the perceived promotion level of personalised medicine (Q18) vary by respondents' nationality (Q3)?

Perceptions of how much personalised medicine is promoted vary widely by nationality. Respondents from Germany and Spain are among the few to rate promotion as 'Extremely' high. In Belgium and Germany, many rate promotion as 'Very much' or 'Moderately,' while in countries like Ireland, Portugal, and Romania, more respondents select 'Slightly' or 'Not at all,' indicating lower perceived promotion. Overall, most nationalities lean toward 'Moderately' or 'Slightly,' with only a few reporting strong promotion efforts in their country.

8.1.9 How does level of education (Q7) correlate with the willingness to share health data with different actors (Q33)?

Willingness to share data varies by education level and the type of institution. Respondents with a master's or postgraduate degree are most willing to share data with public institutions, with high counts for 'Extremely' and 'Very much.' Their willingness drops for private institutions, where 'Not at all' is the most common response. Those with undergraduate or lower education levels show moderate willingness overall, but are also more hesitant with private actors. Across all education levels, trust is highest for public institutions and lowest for private ones.

8.1.10 How does ethnicity (Q6) influence the willingness to share health data (Q33)?

Willingness to share data varies by ethnicity and by the type of institution. Respondents who identified themselves as White show the highest willingness to share data with public institutions, with many selecting 'Extremely' or 'Very much.' For private institutions, all ethnic groups - including White, Asian, Black, Mixed, and Other - are more hesitant, with higher counts for 'Not at all' or 'Slightly.' Asian and Mixed groups display moderate willingness for both public and private institutions, but overall, trust is consistently higher for public actors across all ethnicities, while private institutions face more reluctance.

8.1.11 How does ethnicity (Q6) influence the opinion on the accessibility of personalised medicine (Q17)?

Perceptions of accessibility to personalised medicine differ by ethnicity. Respondents identifying themselves as White are most likely to believe personalised medicine is accessible, but a significant number are unsure or think it is not accessible. Asian respondents are divided, with similar numbers answering 'Yes' and 'I don't know,' and fewer saying 'No.' Other ethnic groups (Black, Mixed, Other, and those preferring not to say) tend to be less certain, with responses more evenly split among 'Yes,' 'No,' and 'I don't know.' Overall, uncertainty about accessibility is notable across minority groups.

9 Conclusions

The results of the EP PerMed multilingual survey provide an important baseline for understanding public awareness, perceptions and expectations regarding PM. Although the survey sample is not yet representative of the general European population, owing to the dissemination channels used and the high proportion of highly educated respondents, the findings offer valuable insights into the opportunities and challenges that accompany the implementation of PM.

Overall, respondents expressed strong support for the development and implementation of personalised medicine and recognised its potential to improve diagnosis, treatment and disease prevention. At the same time, many participants perceived that PM is not yet sufficiently promoted, that healthcare systems are not fully prepared for its implementation, and that information about PM remains difficult to access. These findings point to a substantial communication gap between ongoing developments in PM and public awareness of them.

Trust emerged as a central factor influencing acceptance of personalised medicine. Participants showed greater willingness to share health and genetic data with public institutions than with private organisations, while concerns about data security, misuse, commercial exploitation and equitable access remained prominent. Addressing these concerns through transparent governance, robust data protection measures and clear communication will be essential to maintaining public confidence.

The survey also confirms the key role of healthcare professionals as trusted sources of information. Future communication strategies should therefore combine healthcare providers with educational institutions, digital platforms and public engagement initiatives to improve health literacy and foster informed participation. Particular attention should be devoted to reaching groups that are underrepresented in this survey, including people with lower educational attainment, older adults and minority communities.

The present survey should be regarded as a living baseline rather than a definitive assessment. As the survey remains open and additional responses are collected, future analyses will enable more robust statistical comparisons across countries

and demographic groups. Repeated surveys over the lifetime of EP PerMed will also allow monitoring of changes in awareness, trust and acceptance as PM becomes more widely implemented across Europe.

In conclusion, the findings reinforce that successful implementation of PM depends not only on scientific and technological progress but also on informed, engaged and confident people. Continued investment in education, communication, public engagement and trustworthy governance of health data will be fundamental to ensuring that the benefits of PM can be realised equitably across European healthcare systems.

10 Acknowledgements

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- **Marie Nugent**, Community Manager at Genomics England (former member)

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