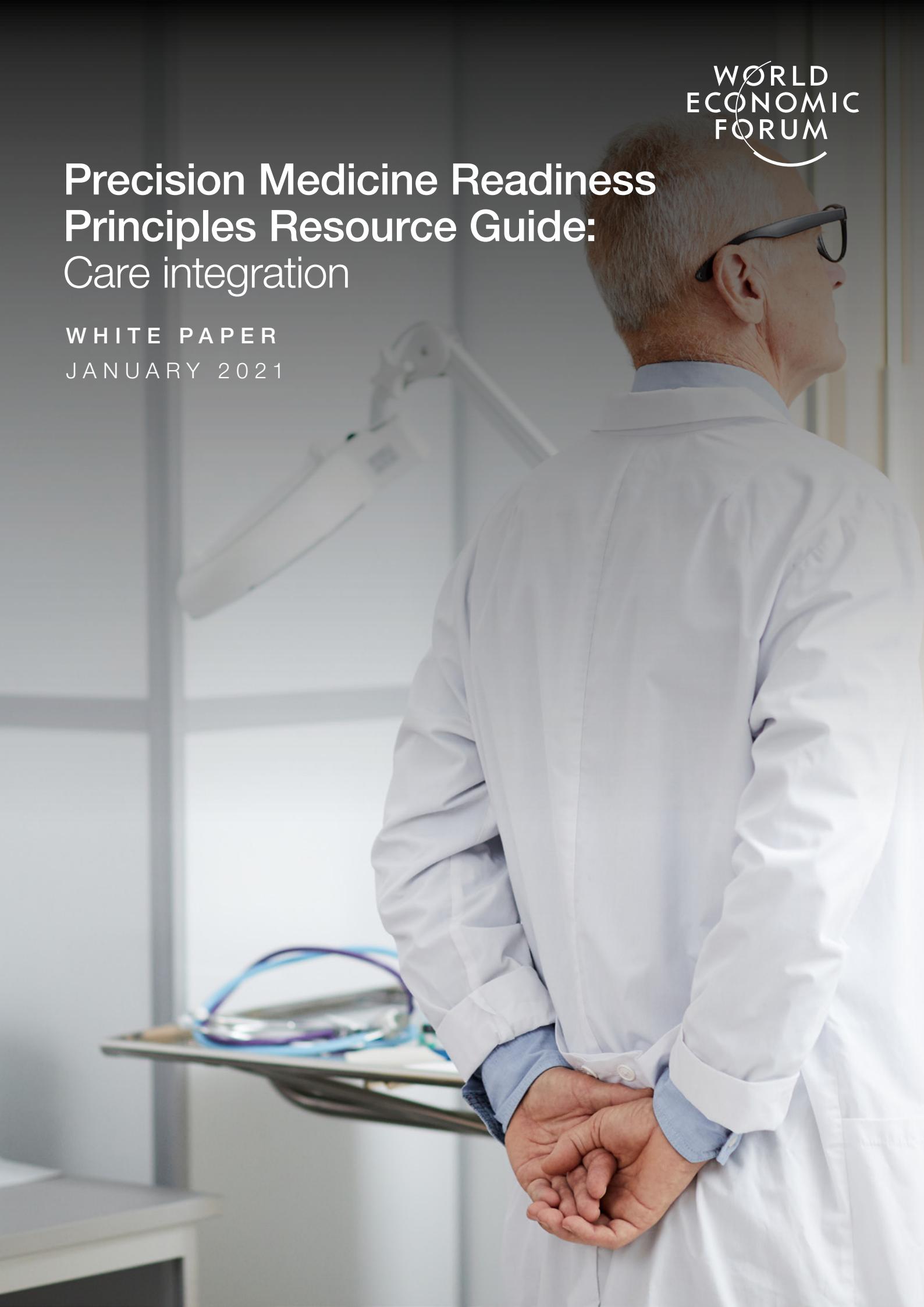


Precision Medicine Readiness Principles Resource Guide: Care integration

WHITE PAPER
JANUARY 2021



Contents

Introduction	3
1 Infrastructure capabilities	4
1.1 Electronic health record	6
1.2 Care accessibility and clinical utility	7
1.3 Reimbursement	8
2 Social capabilities	9
2.1 Patient inclusion and experience	10
2.2 Provider education and training	10
2.3 Policy and ethical considerations	12
3 Precision medicine programmes and implementation	13
Contributors	16
References	17

© 2021 World Economic Forum. All rights reserved. No part of this publication may be reproduced or transmitted in any form or by any means, including photocopying and recording, or by any information storage and retrieval system.

Introduction

Integrating precision medicine into routine care.

Global leaders in policy, business and healthcare, while receptive to the potential of precision medicine applications, often have to pursue these applications without a consistent and standardized framework that allows them to evaluate their health system's readiness for the implementation and integration of precision medicine. Stakeholders in emerging economies, in particular, have requested a guide that includes examples and access to partner communities as they think about how to strategically grow the precision medicine capabilities of their healthcare systems.

Aligned with this need, the World Economic Forum Platform for Shaping the Future of Health and Healthcare launched the Precision Medicine Readiness Principles, a thought leadership project that will begin by developing a living document in which policy-makers and others looking to advance precision medicine in their countries can find benchmarks for readiness. Precision medicine offers a more personalized and targeted approach to preventing disease and screening, diagnosing, treating and curing patients by considering their unique genetic, biological and environmental factors, as well as their lifestyles.

The Readiness Principles will be developed as a roadmap that identifies distinctive precision medicine capabilities denoting three tiers of readiness and five categories of criteria for progress. Informed by the US National Academy of Medicine's discussion paper [Realizing the Full Potential of Precision Medicine in Health and Health Care](#), the roadmap will provide a set of exemplary capabilities by which to evaluate a country's health system, inform policy and investment, and guide sustainable health system development.

One of the five categories is the integration of precision medicine into care delivery – known

as care integration. For the purposes of these principles, care integration is defined as the people, systems and supports required to deliver this more targeted approach to healthcare.

The resource guide was developed to provide an introduction to several of the prevailing studies on and approaches to the implementation of precision medicine in clinical care. The goal is both to offer the reader an introduction to this topic and serve as a primer for the analysis that will be delivered through a white paper on the same topic.

This paper is organized into three sections: infrastructure; societal needs; and the status of precision medicine globally. Infrastructure capabilities include those relating to access to screening, diagnosis and treatment; this also includes technological capabilities such as electronic health record systems, clinical decision support and genetic testing availability. Societal needs include provider education and training, patient and provider engagement, ethics, and policy development at national, regional and organizational levels. The status of precision medicine globally includes summaries of selected lessons and approaches from precision medicine implementation across different countries.

As integration of precision medicine into clinical care is globally nascent, and existing approaches are more often captured under the framework of research than implementation science, the Forum welcomes further contributions to this document. Neither exhaustive nor static, this guide is intended as a dynamic, living document. Case studies from governments or organizations that represent additional information and insight regarding the categories presented are particularly beneficial. Please send your contributions and thoughts to Elissa.Prichep@weforum.org.

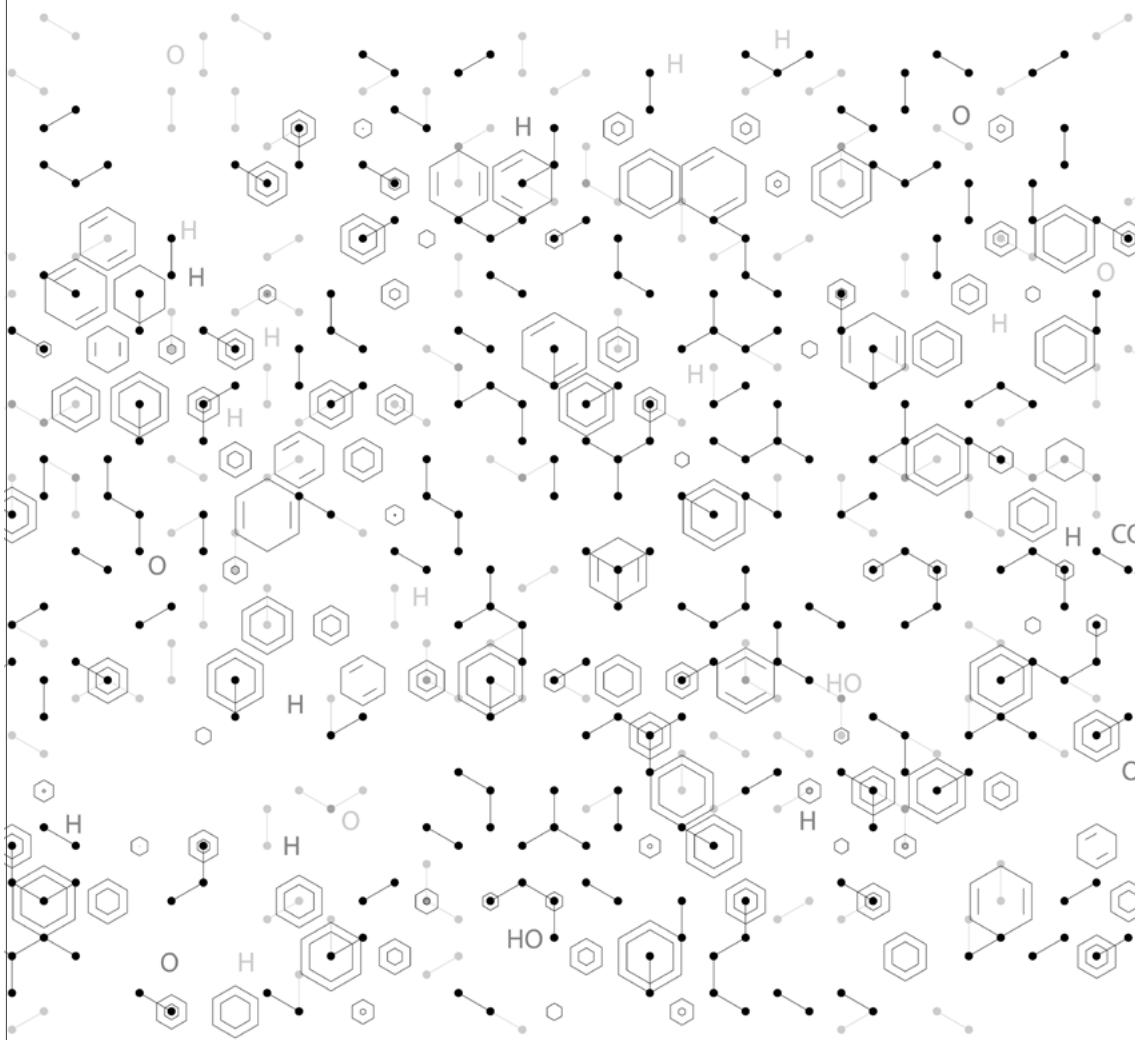


Visit the World Economic Forum Platform for Shaping the Future of Health and Healthcare

1

Infrastructure capabilities

Examining the technological, geographical and financial considerations.

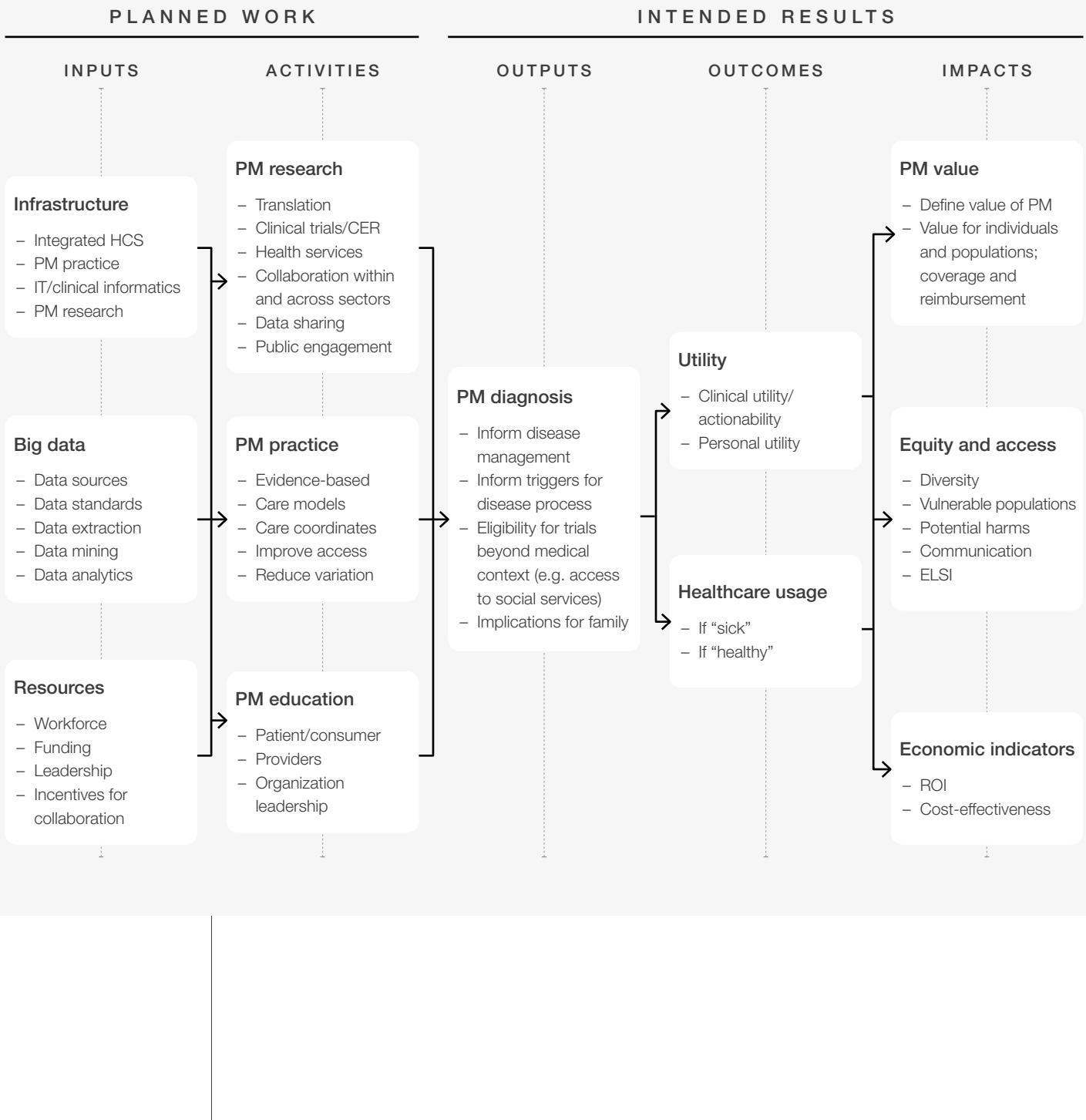


For successful integration of precision medicine into care, a variety of logistical barriers must be overcome. Chanfreau-Coffinier and colleagues (2019) present [a logic model for the implementation of precision medicine](#). Logic models describe the variety of components associated with implementation and classify them into the categories of inputs, activities, outputs, outcomes and impact. Although mostly focused on precision medicine at the United States Department of Veterans Affairs, many concepts are relevant to

care integration in other settings. As seen in the logic model below, various components of planned work (inputs and activities) set the stage for the eventual impact to be realized. Inputs associated with infrastructural barriers include genetic testing development and electronic health record data usability. Activities include addressing access issues such as drug and provider availability, as well as policy standardization in support of access to equitable care.

FIGURE 1

Logic model for precision medicine implementation informed by key stakeholders



Concepts and associated themes identified from transcript coding of the conference proceedings were arranged into a logic model for precision medicine implementation. The logic model can be used by a health-care organization to inform the planned work (inputs and activities) and intended results (outputs, outcomes, and impact). Assumptions underlying the logic model include: precision medicine will improve health outcomes; precision medicine has value beyond clinical utility; and the confluence of clinical care and research is critical for successful precision medicine implementation. *IT* information technology, *PM* precision medicine, *CER* comparative effectiveness research, *ELSI* ethical legal and social issues, *HCS* health-care system, *ROI* return of investment.

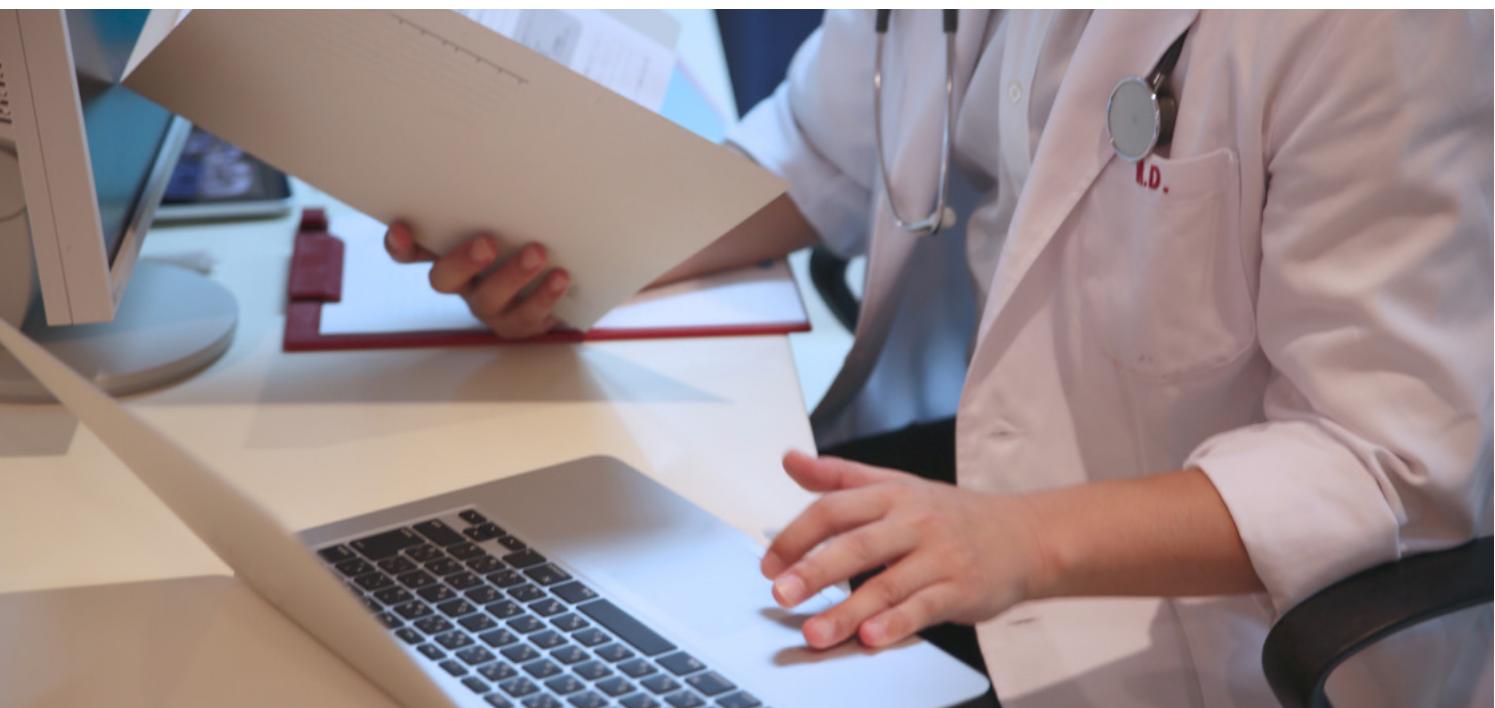
A similar publication (2018) from a [workshop sponsored by the National Academies of Sciences, Engineering, and Medicine](#) described the factors associated with various genomic screening programmes, including evidence generation, cost and electronic health record integration. As with much of the available literature on precision medicine programmes, this article focused on screening programmes conducted through clinical research studies. Overcoming financial barriers for coverage of care is an essential step in moving precision medicine from the research realm to clinical care. Without comprehensive strategies for compiling, storing and retrieving health information, precision medicine remains difficult to integrate into routine clinical care.

1.1 Electronic health record

Specifically addressing the needs of electronic health record storage, Madhavan et al. (2018) describe the [challenges of integrating precision medicine data into the health record](#). Most genetic information is provided in PDF format, creating challenges for searching and storing. Fundamentally, genomic data, including test results and family health history, must be stored securely yet in a way that provides accessibility to all members of a healthcare team. Health record accessibility must also translate to the community healthcare level, where many people receive care, especially in oncology. The use of a third-party vendor to facilitate data sharing between tertiary and community care settings proved to be a successful tool for health record sharing at Swedish Medical Center (Washington, US). Despite the potential barriers of health record storage, the

authors posit that adoption of precision medicine is an essential aspect of routine clinical care and should be incorporated.

While many countries still grapple with ways to make stored health information accessible and usable, Estonia has created an ambitious and highly regarded method for health data storage. Through a single ID number, each Estonian has his or her [entire health history on a single platform](#). More than 99% of health information (e.g. clinic visit notes, prescriptions, billing) is recorded digitally, and all Estonian providers have access to the e-record. Important information such as allergies, medical diagnoses and genomic information are available to each patient and his or her provider, facilitating the ability to deliver personalized care.



1.2 Care accessibility and clinical utility

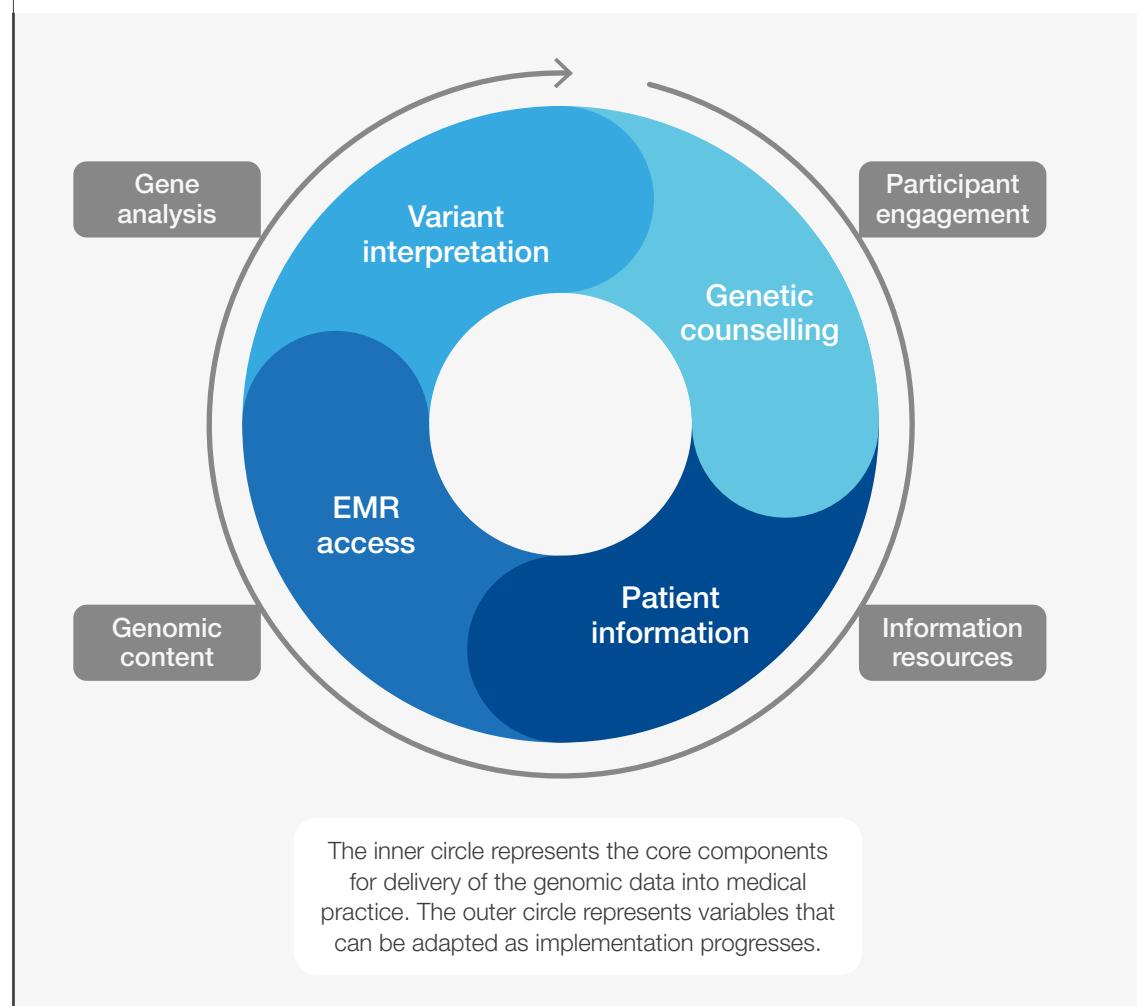
In order to realize the value of precision medicine on a global scale, international experts in precision medicine rationalize that [equitable access to research and care is necessary](#) (2020). Due to various factors, including historically high consumer cost and abuse within past research efforts, access to both research and clinical care has been inequitable across populations. Precision medicine's lack of equitable access creates problems for minority representation in research, which translates into medical recommendations and genetic test results with limited applicability in underrepresented populations. To better understand health and disease, it is necessary to study diverse populations. To achieve both increased understanding and access to clinical care, the SignHealth Duke-NUS Institute of Precision Medicine (PRISM) was established to provide Asian-specific genomic data and help advance precision medicine efforts. As part of PRISM's effort, one of their [studies \(SPECTRA\) is focused on enrolling 10,000 Singaporeans](#) to undergo whole genome sequencing. This will provide a better understanding of the disease implications in those of South-East Asian ancestry, as well as evidence

on the utility of genomic medicine. As the figure below demonstrates, the PRISM model considers access to both genetic counselling and electronic medical record as variables in care integration. Given the project's emphasis on whole genome screening, variant interpretation – or interpretation of the results – is also an important access point to assure clinically relevant and usable genetic testing.

Precision medicine currently remains inaccessible for many people. This is especially true for patients with a lower socioeconomic status or remote geographical location and/or who are racially or ethnically diverse. An [examination of three US state public health programmes](#) (2019) described the need for targeted outreach to engage underserved populations, increased provider education, and implemented safeguards to provide healthcare when a genetic risk is identified. To provide affordable access to follow-up care with various specialties, depending on diagnosis, policy changes by the payers (insurers) of the health system will be essential to developing reimbursement strategies that result in improved coverage of genetic services.

FIGURE 2

PRISM genomics implementation model



1.3 Reimbursement

Another challenge faced by both payers and providers is the quickly evolving nature of new technologies deployed in achieving a precision medicine approach to healthcare delivery.

Ambiguity about or complete lack of reimbursement policies are additional barriers to the integration of precision medicine into clinical care. In 2016, participants in a National Academies of Science, Engineering, and Medicine workshop [applied an implementation science approach to genomic medicine](#), discussed a field known as “reimbursement science” and explored reimbursement challenges for precision medicine, specifically in relation to the current multi-payer system in the United States. Reimbursement science aims to develop processes and standards for assessing value and effectiveness of products covered by public and private health plans. Certain medical specialties, such as oncology, have formed policy groups that outline guidelines for payers on the value of genetic tests; but the clinical efficacy of genetic testing and panels in other medical specialties are not always as clear. Another challenge faced by both payers and providers is the quickly evolving nature of new technologies deployed in achieving a precision medicine approach to healthcare delivery. To address some of the issues raised, it was suggested that an effort should be made to showcase ideal or proven reimbursement policies that would apply to key stakeholder groups such as payers.

In some countries, the traditional fee-for-service model of healthcare reimbursement is shifting to value-based alternative payment models (APMs). This shift could [encourage the adoption of evidence-based precision care](#) (2018) when evaluated for both quality and cost savings. The variety of genetic tests and the impact on outcome can vary greatly in terms of the amount of short-term cost savings compared to lifetime benefits to the individual patient or healthcare system. The creation of clinical protocols and pathways is incentivized by many APMs, but simple, one-size-fits-all models may not align with the goals of precision medicine. Progress is being made in oncology, where stakeholder groups are generating evidence using real-time data-sharing technologies and big data analytics that are accessible at the point-of-care for providers to guide clinical decision support. There is an increasing number of examples of healthcare systems, national physician associations, insurers and other stakeholders having success with integrating precision medicine into value-based care models.



2

Social capabilities

Putting the focus on the patient and provider.



In addition to logistical barriers related to infrastructure and technology needs, a variety of social capabilities need to be addressed if precision medicine is to be fully integrated into clinical care. These social aspects can

strengthen a patient-centred approach, focusing on experience and inclusion, provider education and training, as well as the ethical considerations surrounding precision medicine.

2.1 Patient inclusion and experience

From both medical and ethical perspectives, the importance of increasing [equity in precision medicine](#) has become a focus for many. Minority populations are often under-represented in research and a large number of patients may have limited access, both geographically and financially, to centres that prioritize precision medicine. Because of a history of mistreatment, many minority populations may now be hesitant to participate in research that is needed to accelerate the delivery of precision medicine. [Building trust is an essential element](#) for all populations, but especially for those from historically marginalized groups. The development of trust between patients, providers and researchers is essential if a reduction in health disparities is to be seen in the precision medicine arena.

One element of providing an inclusive environment is patient experience. Due to the shift of healthcare from a provider-centric to a patient-centric system, it is important to address [patient experience within clinical care](#) as well as [patient experience in research](#) as essential elements in the successful delivery of precision medicine. Patient experience can generally be described as the combination of all of the interactions a patient has and how those interactions influence his or her perceptions of both the care received and

the organization. Often measured in the form of patient surveys, patient experience considers all aspects of the patient visit (e.g. cleanliness of the facility, wait time, professionalism and knowledge of the staff). When patient experience and provider communication were evaluated, quality of care was positively associated with communication skills. Improving the patient experience – and subsequently quality – is possible when providers are attuned to the elements of patient experience and can provide their patients with a more positive and inclusive experience.

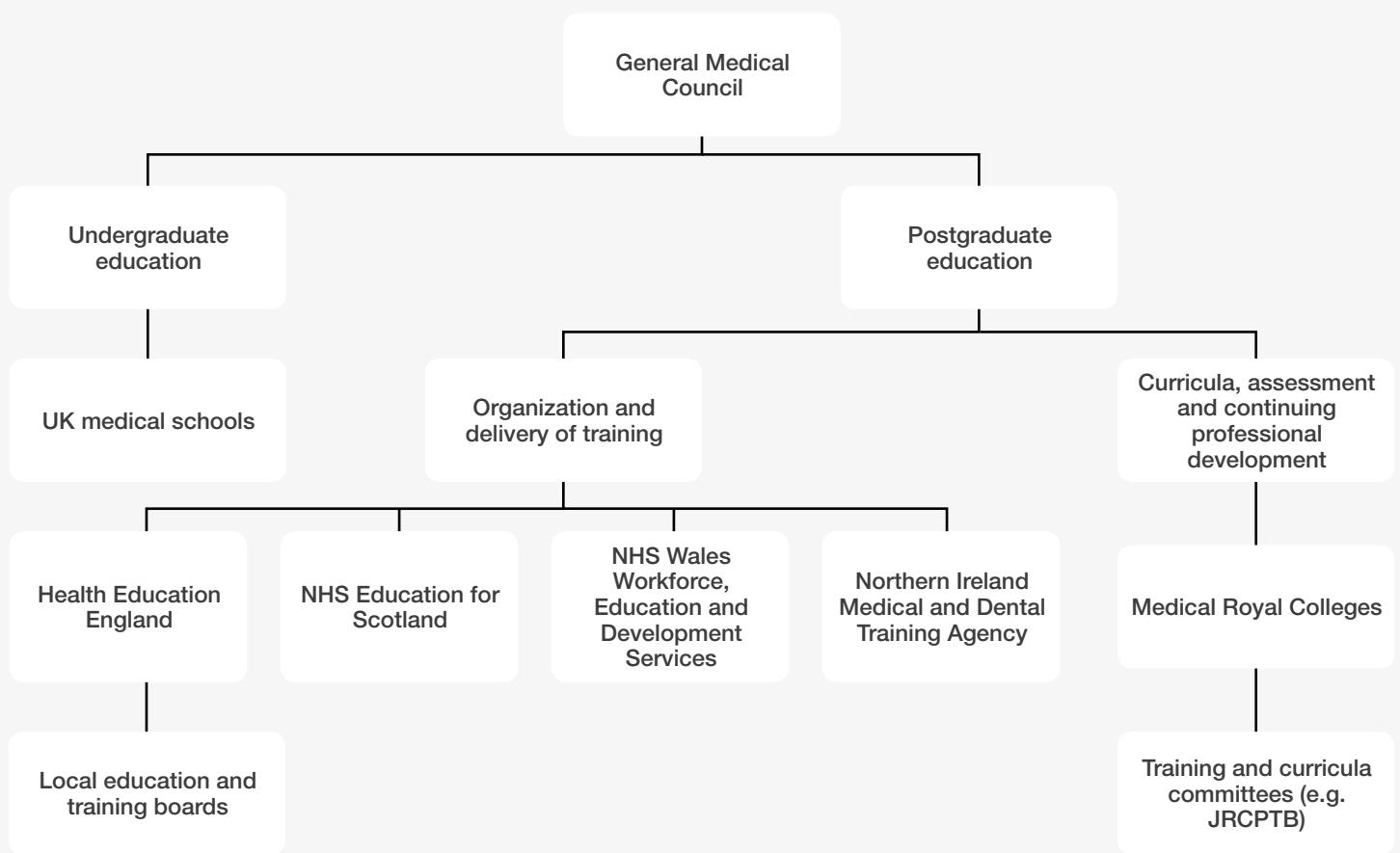
Ensuring a positive patient experience is particularly necessary in precision medicine due to the sensitivity of the data required to facilitate this approach to healthcare. In addition to improving the routine interactions with a healthcare system, a patient-centric healthcare system is reliant on an ongoing, continued relationship extending beyond routine appointments or screenings to build – and keep – the trust of patients. Particularly for people facing chronic diseases such as rare diseases or cancers, genetic testing can reveal an unprecedented level of personal information. This deep, inherently individualized data is incredibly powerful in aiding precision medicine applications but must be properly managed to uphold patient trust.

2.2 Provider education and training

Precision medicine requires attention to patients as unique individuals, taking into account their personal health history, lifestyle and potential genetic contributions. Providers are well-versed in taking personal health histories and accounting for lifestyle factors; however, the tenets of genomic medicine (e.g. genetic testing and family health history) present more of a challenge. A number of distinct and diverse projects have recently been funded by the National Institutes of Health's National Human Genome Research Institute (NHGRI). [When six such studies were evaluated](#) in 2017, provider knowledge and beliefs about genomic medicine was cited as one of the three areas that all studies identified as a challenge. Increased focus on genetic education and outreach programmes were offered as potential solutions to overcoming this barrier.

The formal training of providers in the area of precision medicine is still developing across the globe. As a 2016 [UK study demonstrates](#), genomics education for medical professionals, and specifically physicians, is still evolving. A variety of organizational bodies, such as universities and national certifying organizations, are responsible for influencing, advertising and providing this education (see image below). To ensure that providers have continued support for genomics training, harmonization between the various groups involved in genomics education is key to success. In combination with sustained resources, increased education and training is one way to help promote genomics literacy and confidence in precision medicine.

FIGURE 3 | The structure of medical training in the UK



JRCPTB = Joint Royal Colleges of Physicians Training Board

Source: Figure adapted from Royal College of Physicians

A 2016 article describes [the next revolution](#) in medical care as one that involves precision medicine, but without empowered medical providers, this revolution will be limited. Similar to the previously referenced UK study, improvements to medical training will be an essential aspect of providers feeling empowered and equipped to provide clinical care that incorporates precision medicine methods. As a rapidly evolving field, precision medicine will also require a programme of ongoing education and training if it is to succeed. The training of specialists who have a broad understanding of the various aspects of precision medicine (including non-traditional assays such as RNA sequencing, epigenomics and proteomics) will be especially valuable as the breadth of personalized medicine tests evolves. Pharmacogenomics (testing to determine how a person reacts to medication) and genetic testing of every part of a patient's genetic code (whole genome sequencing) are two examples of tests increasingly being used to support the delivery of personalized medicine. Provider training and understanding of genetic and genomic principles will be necessary for precision medicine to become routine clinical care.

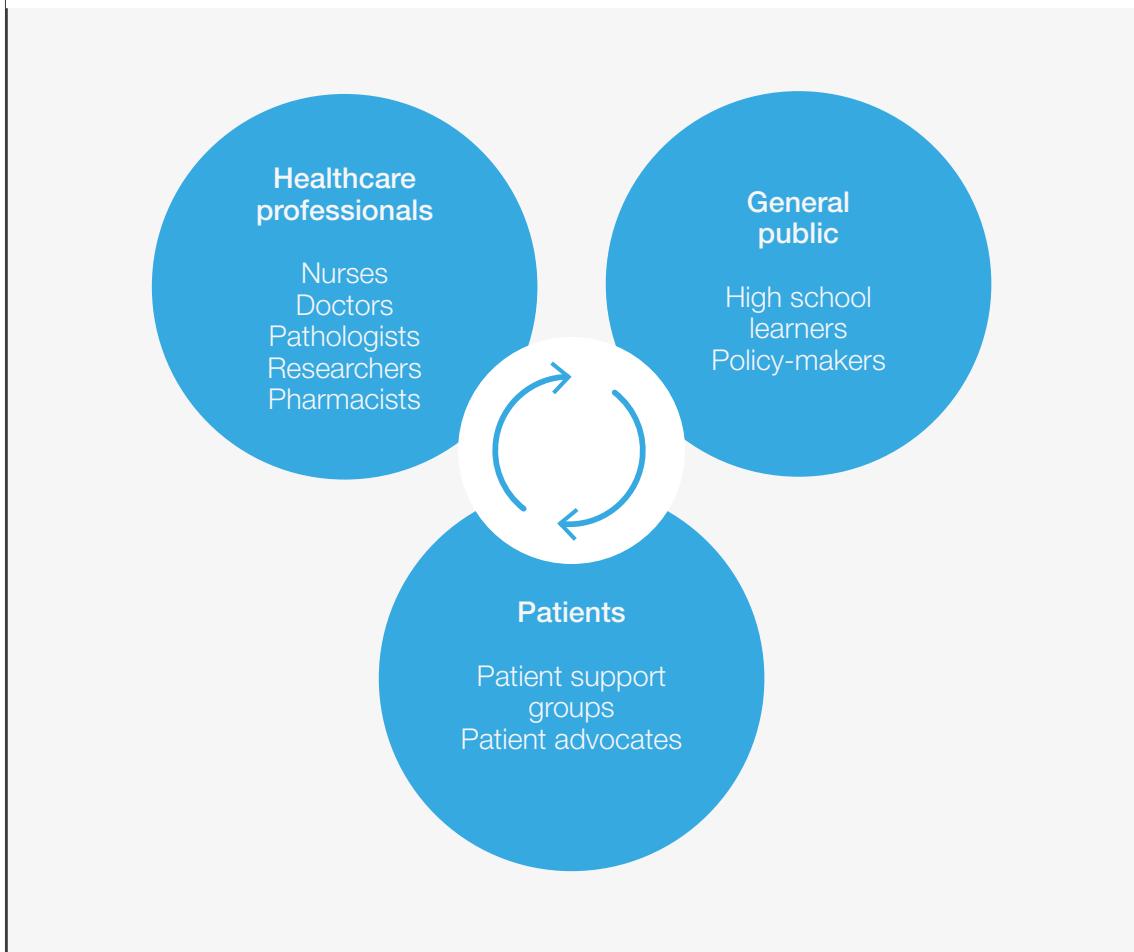
A lack of genetically trained providers is a barrier to the integration of precision medicine care. However,

traditionally trained genetics providers (such as medical geneticists or genetic counsellors) are few in number and cannot realistically provide care to all individuals who need genetics care. Therefore, training options have developed as a way to ensure that patients have access to providers who understand genomics and the value of precision medicine. The [African Genomic Medicine Training Initiative \(AGMT\)](#) was created to tailor existing educational material to the competencies and needs of the African population. The AGMT was initially targeted at nurses, and provided education and training through a blended learning model and eventual certification of skills. However, the education was not solely focused on healthcare providers, as patients and the general public were also important, as seen below.

Another [genomics training programme](#) (2018) was created to provide front-line healthcare workers, specifically community healthcare workers, with the ability and knowledge to provide personalized recommendations based on family health history. The authors suggest this framework could serve as a model to help providers in rural and underserved areas feel empowered to provide care.

FIGURE 4

Illustration of key target trainees in genomic medicine for AGMT in the near future: healthcare workers, patients and the general public



2.3 Policy and ethical considerations

Due in part to the lack of inclusion of under-represented populations in genomic research, precision medicine could increase health disparities. In 2018, a group of experts in law, genomics and clinical care met [to analyse the legal barriers to health equity in precision medicine](#). They discussed issues, threats and the relevant laws affecting precision medicine, including historical and persistent discrimination and bias; equitable participation barriers such as privacy and anti-discrimination protections; lack of health coverage for follow-up care; and practices by research sponsors that tolerate disparities. Because of the potential for increased inequalities, the establishment of legal protections and overarching policies to address health disparities can and should be considered in precision medicine implementation.

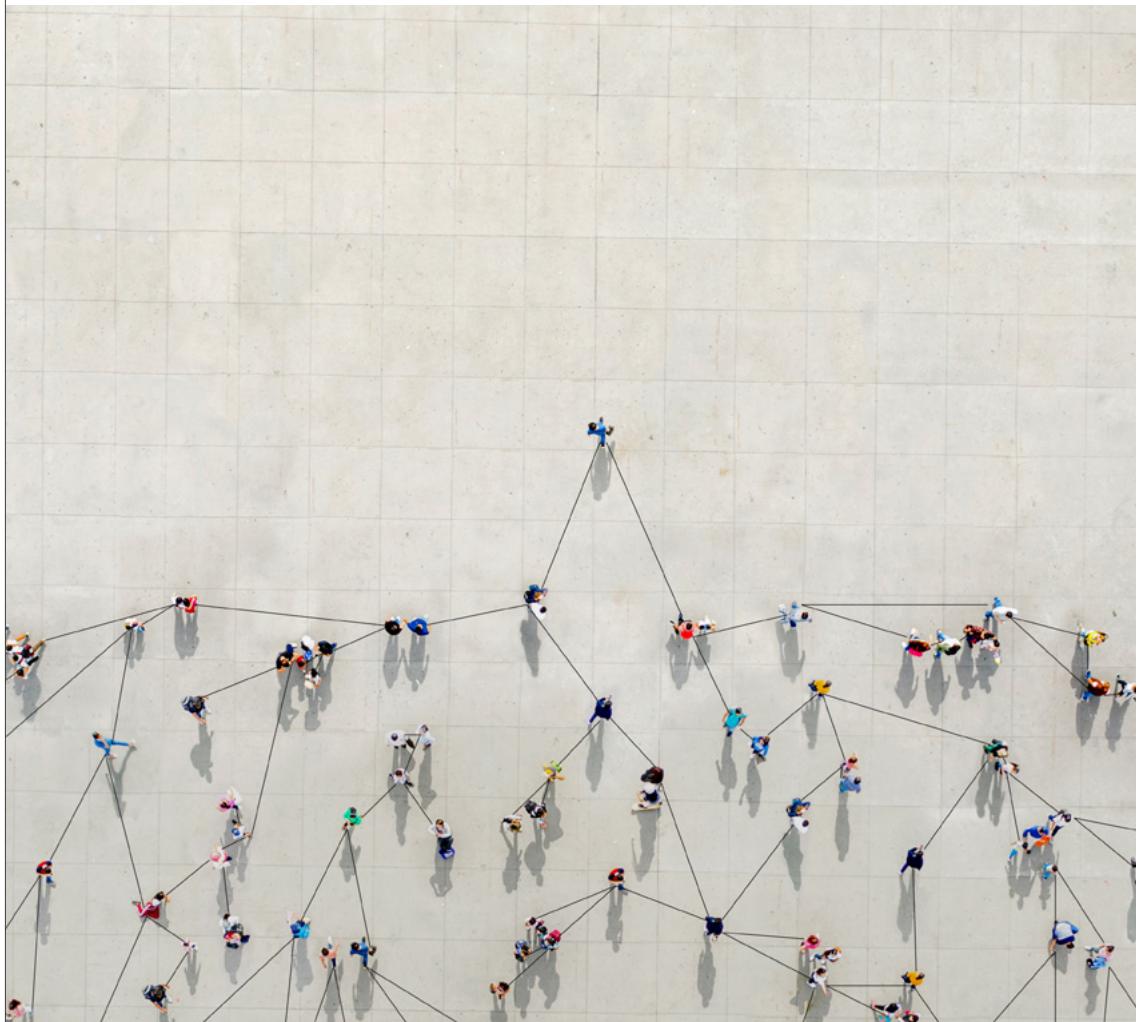
Policy and ethical strategies for implementing precision medicine are complex, and differences

can create challenges in the real world. [The national approaches to precision medicine of the USA, the UK and Japan](#) were evaluated in an article in 2018. All three countries have initiated major precision medicine initiatives, but have very different healthcare systems. The issues discussed included ethical, cultural and regulatory factors. Despite their differences, consistent themes emerged across all three, including the push and pull of ethics and policy, the handling of unexpected findings through research on healthy populations, and the funding of precision medicine efforts. Implementing precision medicine is multidimensional and should include the establishment of public trust, the development of financial stability, legal regulations and attention to issues of social justice and equity. These structures are essential to prevent misuse or abuse of the information discovered through precision medicine programmes.

3

Precision medicine programmes and implementation

Learning from each other.



Despite the variety of challenges, there is continued interest in implementing precision medicine programmes and a variety of implementation options.

The interplay of research, data and engagement is essential as all are supporting features of integrating precision medicine into care. Even in 2020, the [global landscape of precision medicine implementation](#) continues to see challenges clustered around information management, workforce skills, and the ethical, legal and social implications.

It is important to note that the majority of published research on precision medicine implementation is from the US and the UK; this is particularly noteworthy given that both of these countries have prioritized precision medicine initiatives. There is less published research and fewer case studies from low- and middle-income countries (LMIC) by comparison, though there are ongoing efforts to host summits and galvanize research representing the global efforts, challenges and successes of integrating precision medicine into routine care.

During a 2015 summit hosted by the National Academy of Medicine and NHGRI, 25 international groups met to discuss the [current global landscape of precision medicine](#) programmes and common barriers. Nearly all participants described some level of genomic medicine capabilities. This predominant focus on genomic medicine in precision or personalized medicine is concerning because these capabilities are present in specialized centres and not widely accessible to the general population in LMIC countries.

Integrating precision medicine into care also requires the alleviation of existing challenges to data collection, interpretation and implementation, as referenced in 2019 by [Lee et al.](#) Specifically, the lack of data on clinical utility, practice standardization and hospital informatics infrastructure needs to be addressed before widespread implementation can be pursued. The article [Early Lessons from the Implementation of Genomic Medicine Programs](#) also describes barriers based on technology and informatic systems and the additional importance of engagement and support by all stakeholders (including and especially patients and families) for implementation success.

To determine the necessary elements to implementation and sustainability of precision medicine programs, the [IGNITE \(Implementing GeNomics In pracTicE\) Network](#) facilitated a formal evaluation in 2018. The [IGNITE Network](#), made up of research institutions and community

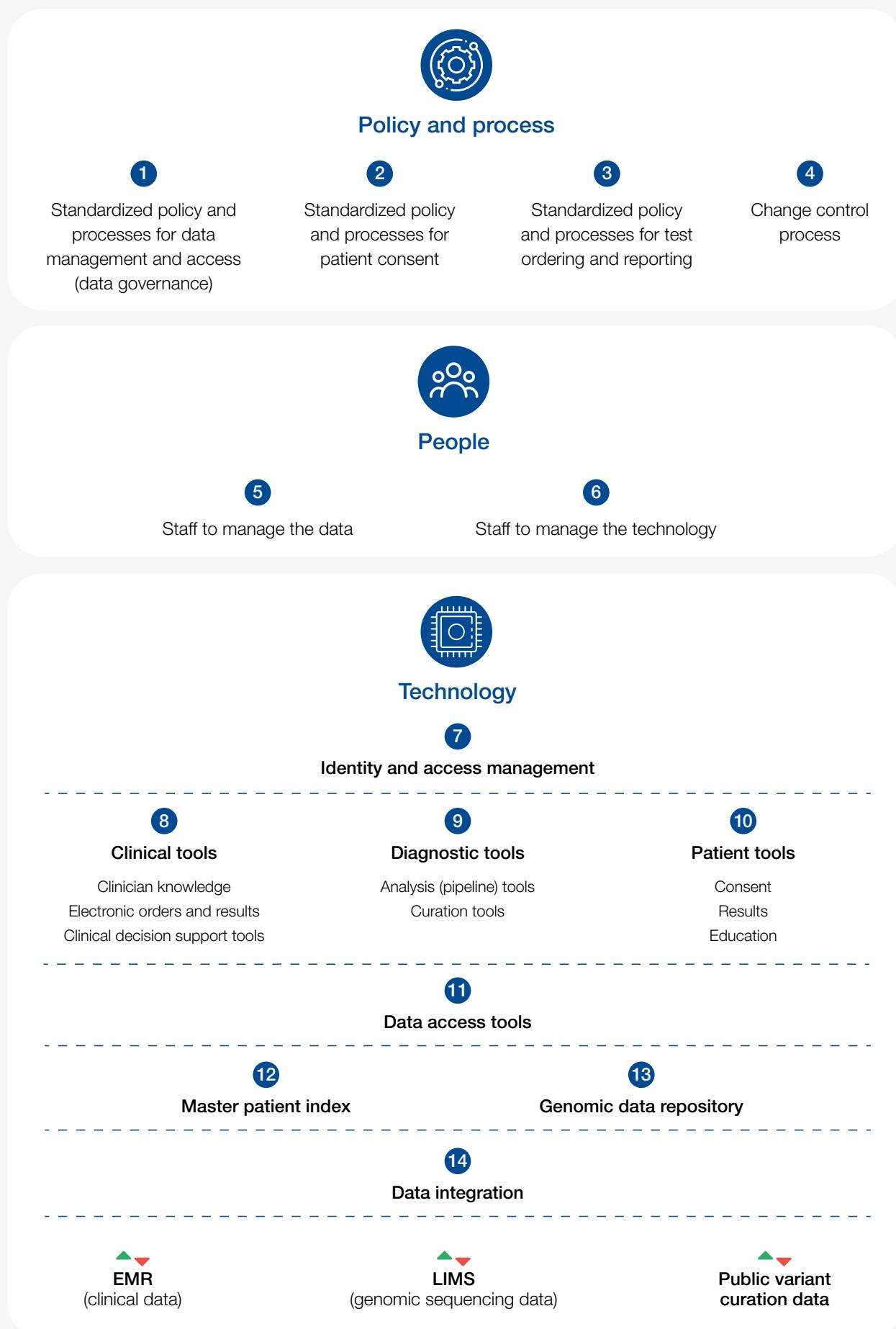
partners from across the United States, develops and explores methods for incorporating genomics into diverse clinical settings. The top three factors identified as critical for sustainable genomic medicine practice were: provider training and education; clinical decision support (CDS) tools in the electronic health record; and reimbursement strategies. The priorities for various systems or hospitals may be different, depending on the current state and projected needs of successfully implementing and sustaining a genomic medicine programme.

Despite the variety of challenges, there is continued interest in implementing precision medicine programmes and a variety of implementation options. The implementation of precision medicine varies in large part due to the differing priorities of stakeholder groups, including patients, healthcare systems and society at large. The importance of accounting for the various stakeholder opinions and value assessments was supported by the [Personalized Precision Medicine Special Interest Group](#) (2020). In addition, [Melbourne Genomics Health Alliance's demonstration project](#) provided evidence to support the necessity of stakeholder engagement, the creation of supportive policies, technological integrations and cost-effectiveness for precision medicine integration into clinical care.

Precision medicine integration is not a one-size-fits-all model and requires a variety of approaches to integration in care, including population-wide genomic screening, localized efforts based on need and disease burden, and coordination of research programmes. But, amid diverse needs and populations, there is significant benefit to multinational collaboration, including identification of gaps and sharing existing efforts.

While the focus of this resource guide has been on the capabilities surrounding care integration, successfully implementing any precision medicine programme involves a spectrum of readiness principles, including engagement, actionable health data, evidence generation and innovation. Ginsburg and Miller (2018) describe a [precision medicine ecosystem](#) focused on connecting patients with providers, researchers and clinical laboratories. This ecosystem is supported by logistical needs such as curated databases, electronic health records and research data. Through global collaborations, support and education, healthcare systems can continue to integrate precision medicine into routine care for patients.

FIGURE 5 | Conceptual diagram of the Melbourne Genomics Health Alliance shared information management platform for future implementation (adapted)



The core of the common genomic data management platform is the genomic data repository – a central place to store genomic sequence data. The clinical tools and patient tools are shared by the Alliance members and integrate with their own systems, including EMR and LIMS.

Contributors

Author

Katherine Dunn

Project Fellow, World Economic Forum; Laboratory Genetic Counselor, Intermountain Healthcare

Contributors

Elissa Pritchep

Lead, Shaping the Future of Health and Healthcare,
World Economic Forum

Emylie Seamen

Senior Operations Manager, Translational Science Center, Intermountain Precision Genomics



Right: Unsplash/Drew Hyes

References

1. Addie, S., Olson, S. and Beachy, S. H. (2016). Roundtable on Translating Genomic-Based Research for Health Board on Health Sciences Policy Health and Medicine Division, <https://www.ncbi.nlm.nih.gov/books/NBK373697/> (link as of 18/12/20).
2. Ahmed, F., Burt, J. and Roland, M. (2014). Measuring Patient Experience: Concepts and Methods. *The Patient*, 7(3), 235–241, <https://doi.org/10.1007/s40271-014-0060-5> (link as of 18/12/20).
3. Belcher, A., Ginsburg, G. S. and Ward, R. (2020). Global Approaches to Genomic Medicine Implementation. *Science Translational Medicine*, 12(563), eaax0911, <https://stm.sciencemag.org/content/12/563/eaax0911.full> (link as of 18/12/20).
4. Bylstra, Y., Davila, S., Lim, W. K. et al. (2019). Implementation of Genomics in Medical Practice to Deliver Precision Medicine for an Asian Population. *npj Genom. Med.* 4(12), <https://doi.org/10.1038/s41525-019-0085-8> (link as of 18/12/20).
5. Chanfreau-Coffinier, C., Peredo, J., Russell, M. M. et al. (2019). A Logic Model for Precision Medicine Implementation Informed by Stakeholder Views and Implementation Science. *Genetics in Medicine*, 21(5), 1139–1154, <https://pubmed.ncbi.nlm.nih.gov/30353149/> (link as of 18/12/20).
6. Chen, L. S., Zhao, S., Stelzig, D. et al. (2018). Development and Evaluation of a Genomics Training Program for Community Health Workers in Texas. *Genetics in Medicine*, 20(9), 1030–1037, <https://www.nature.com/articles/gim2017236> (link as of 18/12/20).
7. Edwards, T. L., Breeyear, J., Piekos, J. A. and Edwards, D. R. V. (2020). Equity in Health: Consideration of Race and Ethnicity in Precision Medicine. *Trends in Genetics*, 36(11), 807–809, [https://www.cell.com/trends/genetics/fulltext/S0168-9525\(20\)30167-0](https://www.cell.com/trends/genetics/fulltext/S0168-9525(20)30167-0) (link as of 18/12/20).
8. Faulkner, E., Holtorf, A. P., Walton, S. et al. (2020). Being Precise about Precision Medicine: What Should Value Frameworks Incorporate to Address Precision Medicine? A Report of the Personalized Precision Medicine Special Interest Group. *Value in Health*, 23(5), 529–539, <https://www.sciencedirect.com/science/article/pii/S1098301520300929> (link as of 18/12/20).
9. Gaff, C. L., Winship, I. M., Forrest, S. M. et al (2017). Preparing for Genomic Medicine: A Real World Demonstration of Health System Change. *NPJ Genomic Medicine*, 2(16), <https://www.nature.com/articles/s41525-017-0017-4> (link as of 18/12/20).
10. Ginsburg, G. S. and Phillips, K. A. (2018). Precision Medicine: From Science to Value. *Health Affairs*, 37(5), 694–701, <https://pubmed.ncbi.nlm.nih.gov/29733705/> (link as of 18/12/20).
11. Report of the Council on Medical Service, Integrating Precision Medicine into Alternative Payment Models, <https://www.ama-assn.org/sites/ama-assn.org/files/corp/media-browser/premium/csaph/integrating-precision-medicine-alternative-payment-models.pdf> (link as of 18/12/20).
12. Kraft, S. A., Cho, M. K., Gillespie, K. et al. (2018). Beyond Consent: Building Trusting Relationships with Diverse Populations in Precision Medicine Research. *The American Journal of Bioethics*, 18(4), 3–20, <https://pubmed.ncbi.nlm.nih.gov/29621457/> (link as of 18/12/20).
13. Lee, J., Hamideh, D. and Nebeker, C. (2019). Qualifying and Quantifying the Precision Medicine Rhetoric. *BMC genomics*, 20(1), 868, <https://bmcbioinformatics.biomedcentral.com/articles/10.1186/s12864-019-6242-8> (link as of 18/12/20).
14. Levy, K. D., Blake, K., Fletcher-Hoppe, C. et al. (2019). Opportunities to Implement a Sustainable Genomic Medicine Program: Lessons Learned from the IGNITE Network. *Genetics in Medicine*, 21(3), 743–747, <https://www.nature.com/articles/s41436-018-0080-y> (link as of 18/12/20).
15. Madhavan, S., Subramaniam, S., Brown, T. D. and Chen, J. L. (2018). Art and Challenges of Precision Medicine: Interpreting and Integrating Genomic Data into Clinical Practice. *American Society of Clinical Oncology Educational Book*, 38, 546–553, https://ascopubs.org/doi/full/10.1200/EDBK_200759 (link as of 18/12/20).
16. Manolio, T. A., Abramowicz, M., Al-Mulla, F. et al. (2015). Global Implementation of Genomic Medicine: We Are Not Alone. *Science Translational Medicine*, 7(290), 290ps13, <https://stm.sciencemag.org/content/7/290/290ps13.full> (link as of 18/12/20).
17. McGrath, S. and Ghersi, D. (2016). Building Towards Precision Medicine: Empowering Medical Professionals for the Next Revolution. *BMC Medical Genomics*, 9(1), 1–6, <https://bmcmedgenomics.biomedcentral.com/articles/10.1186/s12920-016-0183-8> (link as of 18/12/20).
18. McGuire, A. L., Gabriel, S., Tishkoff, S. A. et al. (2020). The Road Ahead in Genetics and Genomics. *Nature Reviews Genetics*, 21(10), 581–596, <https://www.nature.com/articles/s41576-020-0272-6> (link as of 18/12/20).
19. Minari, J., Brothers, K. B. and Morrison, M. (2018). Tensions in Ethics and Policy Created by National Precision Medicine Programs. *Human Genomics*, 12(1), 1–10, <https://humgenomics.biomedcentral.com/articles/10.1186/s40246-018-0151-9> (link as of 18/12/20).

20. Moving Beyond Population Averages: A Patient-Centered Research Agenda Advancing Personalized Medicine (2020), http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/PMC_Moving_Beyond_Population_Averages_A_Patient-Centered_Research_Agenda_Advancing_Personalized_Medicine1.pdf?_zs=0FCka&_zl=PJfd2 (link as of 18/12/20).
21. National Academies of Sciences, Engineering, and Medicine (2018). Implementing and Evaluating Genomic Screening Programs in Health Care Systems: Proceedings of a Workshop. National Academies Press, <https://www.nationalacademies.org/our-work/implementing-and-evaluating-genomic-screening-programs-in-health-care-systems-a-workshop> (link as of 18/12/20).
22. Nembaware, V., African Genomic Medicine Training Initiative and Mulder, N. (2019). The African Genomic Medicine Training Initiative (AGMT): Showcasing a Community and Framework Driven Genomic Medicine Training for Nurses in Africa. *Frontiers in Genetics*, 10, 1209, <https://www.frontiersin.org/articles/10.3389/fgene.2019.01209/full> (link as of 18/12/20).
23. Senier, L., Tan, C., Smollin, L. and Lee, R. (2019). Understanding the Potential of State-Based Public Health Genomics Programs to Mitigate Disparities in Access to Clinical Genetic Services. *Genetics in Medicine*, 21(2), 373–381, <https://www.nature.com/articles/s41436-018-0056-y> (link as of 18/12/20).
24. Sikkut, R. (2019). Learning from the Estonia e-health System. *Health Europa Quarterly*, 8, 82–85, <https://www.healtheropa.eu/estonian-e-health-system/89750/> (link as of 18/12/20).
25. Slade, I., Subramanian, D. N. and Burton, H. (2016). Genomics Education for Medical Professionals – the Current UK Landscape. *Clinical Medicine*, 16(4), 347, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6280204/> (link as of 18/12/20).
26. Sperber, N. R., Carpenter, J. S., Cavallari, L. H. et al. (2017). Challenges and Strategies for Implementing Genomic Services in Diverse Settings: Experiences from the Implementing GeNomics In pracTicE (IGNITE) Network. *BMC Medical Genomics*, 10(1), 1–11, <https://bmcmedgenomics.biomedcentral.com/articles/10.1186/s12920-017-0273-2> (link as of 18/12/20)
27. Williams M. S. (2019). Early Lessons from the Implementation of Genomic Medicine Programs. *Annual Review of Genomics and Human Genetics*, 20, 389–411, <https://doi.org/10.1146/annurev-genom-083118-014924> (link as of 18/12/20).
28. Williams, M. S., Buchanan, A. H., Davis, F. D. et al. (2018). Patient-Centered Precision Health in a Learning Health Care System: Geisinger's Genomic Medicine Experience. *Health Affairs*, 37(5), 757–764, <https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2017.1557> (link as of 18/12/20).
29. Wolf, S. M., Bonham, V. L. and Bruce, M. A. (2019). How Can Law Support Development of Genomics and Precision Medicine to Advance Health Equity and Reduce Disparities?. *Ethnicity & Disease*, 29(Supp), 623–628, <https://www.ethndis.org/edonline/index.php/ethndis/article/view/1268/1710> (Link as of 18/12/20).



COMMITTED TO
IMPROVING THE STATE
OF THE WORLD

The World Economic Forum, committed to improving the state of the world, is the International Organization for Public-Private Cooperation.

The Forum engages the foremost political, business and other leaders of society to shape global, regional and industry agendas.

World Economic Forum
91–93 route de la Capite
CH-1223 Cologny/Geneva
Switzerland

Tel.: +41 (0) 22 869 1212
Fax: +41 (0) 22 786 2744
contact@weforum.org
www.weforum.org