Precision Medicine
Shaping the **Future of Health and Healthcare**

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# Leapfrogging with Precision Medicine

Delivering the policies and frameworks needed to accelerate a precision medicine-ready health system

## The Challenge

Advancing precision medicine in a way that is equitable and beneficial to society means ensuring that healthcare systems can adopt the most scientifically and technologically appropriate approaches to a more targeted and personalized way of diagnosing and treating disease. In certain instances, countries or institutions may be able to bypass, or "leapfrog", legacy systems or approaches that prevail in developed country contexts.

The World Economic Forum's **Leapfrogging with Precision Medicine** project will develop a set of tools and case studies demonstrating how a precision medicine approach in countries with greenfield policy spaces can potentially transform their healthcare delivery and outcomes. Policies and governance mechanisms that enable leapfrogging will be iterated and scaled up to other projects.

## The Opportunity

Participating in this project will help partners and stakeholders elucidate foundational elements necessary to develop a precision medicine-ready healthcare system in an emerging economy country, and the necessary policies to support the development and sustainability of these elements. Participants will be able to host or join different pilots in different countries.

### Anchor Project
This pilot project will develop a case study on diagnostic capacity building for cancer treatment in Rwanda. The project is designed to address the policy barriers and gaps around accelerating a precision medicine approach in a healthcare system with rising rates of non-communicable diseases.

Diagnostics function as a compass for precision medicine. With the support of appropriate policies and governance mechanisms, countries can innovatively address limited diagnostic equipment, laboratory facilities and human capacity that contribute to delayed cancer diagnoses. Genetic and biological information generated through diagnostics helps ensure early and accurate treatment, thereby avoiding incorrect treatments, wasted time and unnecessary costs.

Additional impacts from leapfrogging to cancer diagnostics could include innovative approaches to informed consent, culturally relevant genetic education and counselling, expansion of laboratory networks, biobanks and genomic sequence databanks, and research to understand the unique genomic features of the Rwandan population.

### Workstream 1: Genomic Data Policy and Ethics Framework
Genomic data is an especially sensitive form of health data, and its collection and use support scientific research, improved diagnosis and disease treatments that underscore precision medicine. Genomic data collection is accelerating, including in low- and middle- income countries (LMICS), to fill critical gaps in understanding of populations not traditionally included in genomics and precision medicine. Without future-looking data policies, countries face two main risks: 1) their genomic data do not inform scientific research that may lead to more population-relevant diagnostics and treatments; or 2) their genomic data may be used by and benefit primarily outside parties.

This workstream will develop a framework on genomic data policy, addressing the topics of consent, privacy, data access, and benefit sharing, as well as tools to help address the ethical tensions inherent in these topics. These will be tested with governments in their own context.

By proposing approaches to genomic data policy and ethics and testing them in real world situations, this workstream will develop a set of case studies and

a community of experts to inform the establishment of foundational policies for precision medicine in emerging economies.

## Workstream 2: Precision Medicine Readiness Principles
This project will develop a living document from which policy-makers and others looking to advance precision medicine in their countries can find benchmarks for readiness. A critical aspect of this project will be an exposition of the key components of a healthcare ecosystem that need to be in place in order to be "ready" for precision medicine and to enable its continued growth.

This will be developed as a roadmap that identifies distinguishing precision medicine capabilities denoting different tiers of readiness and categories of criteria for progress. The roadmap will provide a set of capabilities by which to evaluate a country's health ecosystem, inform policy and investment, and guide sustainable health ecosystem development. It will be tested and iterated over time through material pilots and case studies.

## Impact

The Leapfrogging with Precision Medicine project will enable the testing of scalable mechanisms to support design, implementation and evaluation of precision medicine in emerging economies.

Enabling precision medicine in such contexts, potentially by leapfrogging existing or prevailing practices, means that vastly more people will have access to personalized treatments designed to improve outcomes, and streamline and reduce costs.

Anticipated impacts for government, society and industry of the leapfrogging project are to:

– Test, refine and scale up policies and frameworks that support building the fundamental components of a precision medicine-ready healthcare system
– Provide a "sandbox" for experts and practitioners grappling with best models of addressing ethical, legal, social issues related to access to cutting-edge or the most appropriate precision medicine approaches in emerging economies
– Innovate how to incorporate user/patient-centred design principles into precision medicine-ready systems in emerging economies
– Gain a community of partners and stakeholders with which to share best practices and collaborate on approaches to leapfrogging to more targeted and personalized screening, diagnosis and treatment of diseases
– Evaluate how leapfrogging can lead to more efficient and effective approaches to improving health outcomes in low- to medium-resource countries versus the status quo

## Key Achievements

### Summer 2019
– Expand partner community for the anchor pilot - project on BRCA testing in Rwanda
– Hold workshop on genomic data policy
– Share genomic data policy resource list

## Next Steps

### Fall 2019
– Hold consultative workshop on genomic data policy with the Rwanda Ministry of Health
– Finalize the anchor pilot project proposal for Rwanda government approval
– Gain input on and draft Genomic Data Policy and Ethics whitepaper

### Winter 2019/2020
– Publish toolkit for Leapfrogging with Precision Medicine, to include a data policy and ethics framework, precision medicine readiness principles and other resources
– Hold second consultative workshop on genomic data policy with Rwanda Ministry of Health
– Publicize and scale up leapfrogging approaches

## Key Upcoming Dates

*November 2019*: Roundtable on Governance of Human Genome Sequencing, Dubai, UAE
*November 2019*: Roundtable on Ethical Tensions in Genomic Data, San Francisco, USA

## How to Engage

*Send a project fellow*: Nominate an individual from your company to work full- or part-time at the Centre to play an integral role in shaping this initiative

*Scale up the project*: Test and refine policies, toolkits, frameworks and models through your government, business or community

*Contribute expertise*: Serve as an adviser on the project and workstreams

## Contact

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