

**World Economic Forum Precision Medicine Project:** Guest Speaker: Project Lead Elissa Prichep

The WEF is almost 50 years old and its core focus is to solve global problems through public private cooperation.

- (A) Accelerate the development and implementation of policy frameworks and governance mechanisms;•Could include regulations, standards, protocols, taxes and tariffs, private partnerships, leadership board toolkits, certifications, labeling procurement guidelines, legislation, law and more
- (B) Co-design pilot projects with governments, business leaders, academia, international organizations and civil society•User centred design philosophy•Pilot projects are scoped for approx. 18 month timelines

The WEF Centre for the Fourth Industrial Revolution will achieve its goals through eight strategic portfolios. Precision medicine is one of the portfolio's. Team: Project Head, two Project leads, one community specialist and Fellows

The team works with stakeholders to develop policy pilot projects that develop, test, iterate and scale policy and governance frameworks that will advance precision medicine rapidly and beneficially across the world

Precision Medicine, as defined for the purpose of our projects, is a more targeted and precise way of screening, diagnosing and treating disease based on an understanding of one's genetic and biological make-up

Policy challenges facing Precision Medicine

- Evidence generation of efficacy
- Data sharing and infrastructure
- Regulatory systems
- Integration into clinical practice
- Cost, coverage and reimbursement

Hopes to:

Prevent drastic disparities in access to health care advances

Facilitate the implementation of new technologies through rapid policy adjustment so that opportunities are not missed

The Precision Medicine Project is being piloted in Rwanda as there is "greenfield Policy space" or government will to leapfrog the implementation of Precision Medicine into healthcare systems. The WEF Precision Team is keen to work with any individual or organization who may want to pursue a similar implementation in their country.

Elissa's Contact: <https://weforum.ent.box.com/s/axutga7teuz3rr9lqobsfya33tzgzvt5>

Questions:

How are these co-piloted projects funded? (Mogomotsi Matshaba)

Answer:

WEF does not provide funding, the onus/ownership is on the government or organization willing to invest in such a project. WEF provides support through its Precision Medicine Portfolio through items (A & B)

#### **GA4GH Driver Project-Next Steps**

G4GH-driver project-a webinar will be organized for more background and insight on how people can volunteer for specific tasks. Upcoming meeting in Hinxton end of May. There will be breakout sessions: technical, clinical, ethics, Steering Committee meeting  
Where H3Africa should be represented. Boston meeting immediately after ASHG

#### **Working Groups:**

H3Africa Consortium Biospecimen Sharing, Access and Release Policy: Discussion & Vetting (Erisa Sabakaki; Michele Ramsay)

<https://docs.google.com/document/d/17nMXEQQuHSYBAbtkdNo0bSFyXoAhARdt-oQztdNujLI/edit?usp=sharing> **(All to read and add comments)**

Background: The Biorepository Working Group Realised that a comprehensive policy on biospecimen sharing was needed even though Material Transfer Agreements (MTAs), application forms, DBAC Guidelines are in place. (Christine Beiswanger)

#### **General guidelines-**

- Prioritise sharing with projects that have a strong African capacity building component (Michele Ramsay)
- How many layers to sharing? Seems to be another level of sharing within the Consortium?
  - This may be text left from the initial policy draft (Christine Beiswanger)
- How many types of Biospecimens are there? Isn't it only DNA? (Michele Ramsay)

#### **Specific Guidelines**

- Address the issue of Data-Which data will be accessible from the biobank phenotype/genotype
  - only minimal data (Christine Beiswanger)
- Provide clarifying text on what is available in the catalogue, from EGA what data can be applied for. (Nicky Mulder)
- How does the Data/Biospecimen request form work?
- How does the DBAC secretariat fit into the Data/Biospecimen access pipeline?

#### **Monitoring:**

- Broaden section on breaches-there may be other kinds of breaches-contact relevant authority or the responsible people is preferable
- Last sentence on benefit sharing requires input from Steering Committee.
- Get some expertise on the wording (Christine Beiswanger)

#### **4. Consortium Meeting**

- **Special Guest Speakers: call for nominations**
  - Samantha Nicholson (PhD): Application Specialist: Advanced Genomics and Cellular Biology | Field Marketing for Africa  
Merck Millipore International | EMEA, could give an expert talk on CRISPR technology/ ethical implications of the technology or she could recommend an academic
  - **Timothy Rebbeck** (nominated at Agenda WG) (attachment)  
Presentation: role of genomics in cancer disparities in Africa and African Americans including MADCaP study and present recent data on population genomics of breast and prostate cancer, and their role in disparities by race.

Decision: Keener on the first option. Timothy Rebbeck is in touch with Nicky Mulder and would like to continue engaging H3Africa

**Draft 13<sup>th</sup> Meeting Agenda (attached)** (Michelle Skelton)

Please review the Agenda and let Michelle know of any clashes in advance.

**H3ACC Updates (H3ACC)**

The H3Africa Travel Fellowship applications have been reviewed and the outcome will be released soon.

**Action:**

- Share Elissa Pritchep's contact and presentation, PI's to reach out if they are interested. (Done)
- Update the H3Africa Consortium Biospecimen Sharing, Access and Release Policy with recommended changes. (Biorespository WG) (Done)
- Reach out to Samantha Nicolson on CRISPR presentation (Michelle Skelton) (Done)
- Review draft 13<sup>th</sup> Meeting Agenda (all)