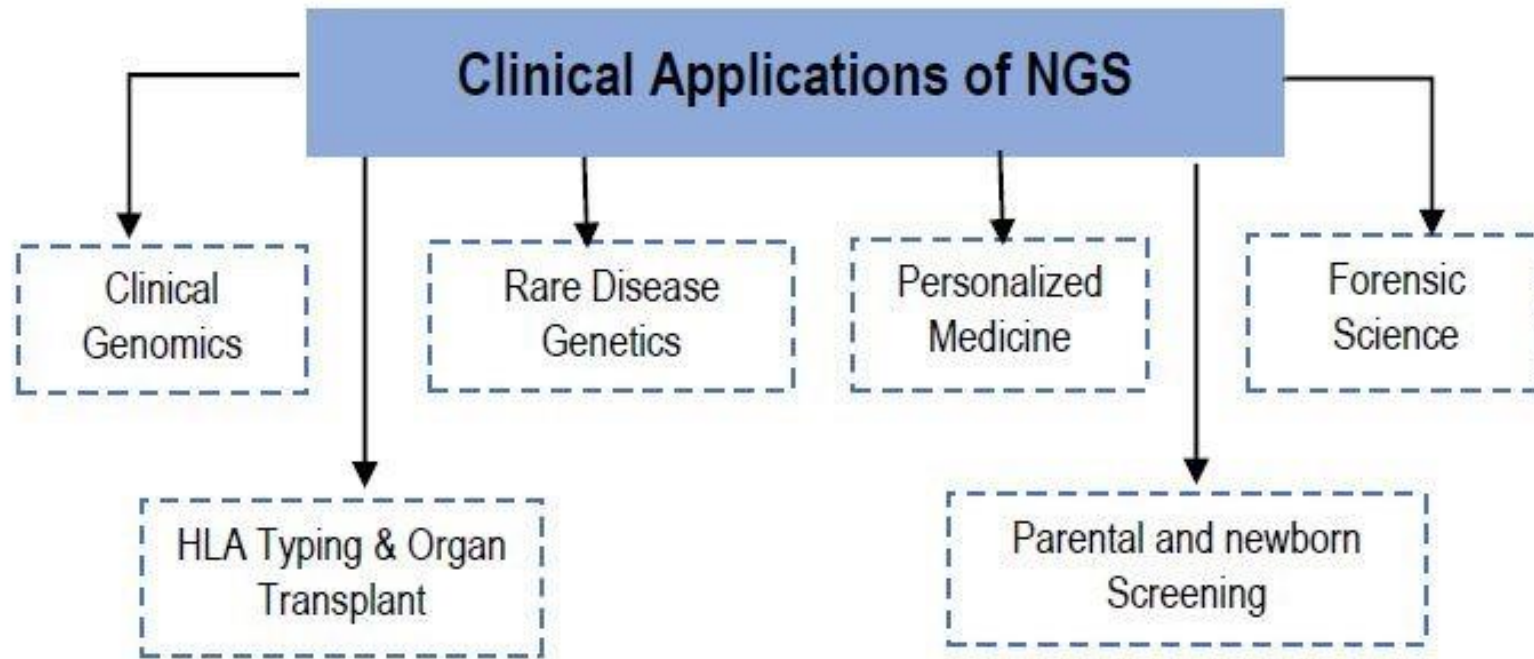


# **Ethical Challenges In Integrating Genomics Information For Health Care.**

**Prasit Palittapongarnpim, M.D.**

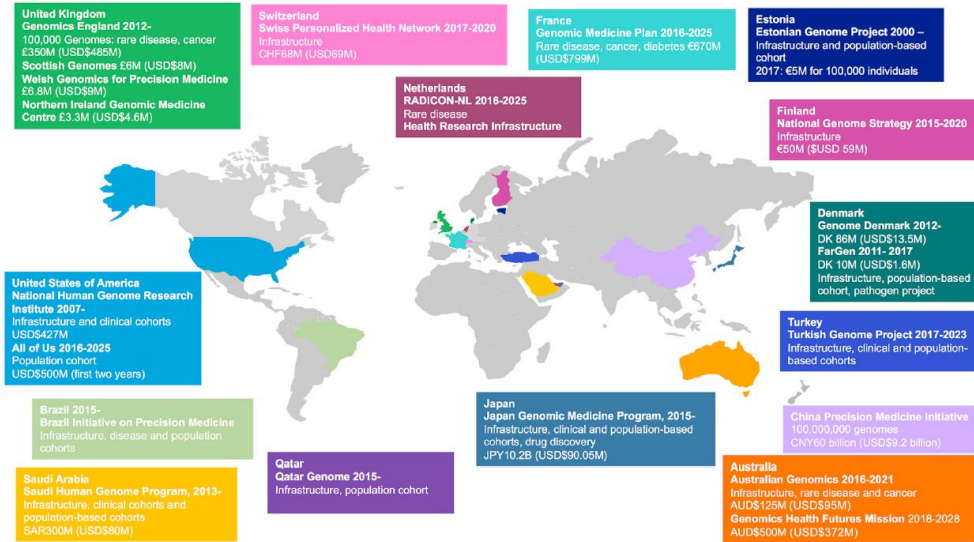
**Pornchai Matangkasombut Center for Microbial Genomics  
(CENMIG), Department of Microbiology, Faculty of Science,  
Mahidol University, Bangkok, Thailand.**

# Applications of Genomic Sequencing in Health Care



# Some Government Genomics Projects

Stark Z et al. Integrating Genomics into Healthcare: A Global Responsibility. Am J Hum Genet. 2019 Jan 3;104(1):13-20. doi: 10.1016/j.ajhg.2018.11.014.



**All of Us Research Program Makes Nearly 250,000 Whole Genome Sequences Available to Advance Precision Medicine**

April 20, 2023

**Data Now Available in the Researcher Workbench**

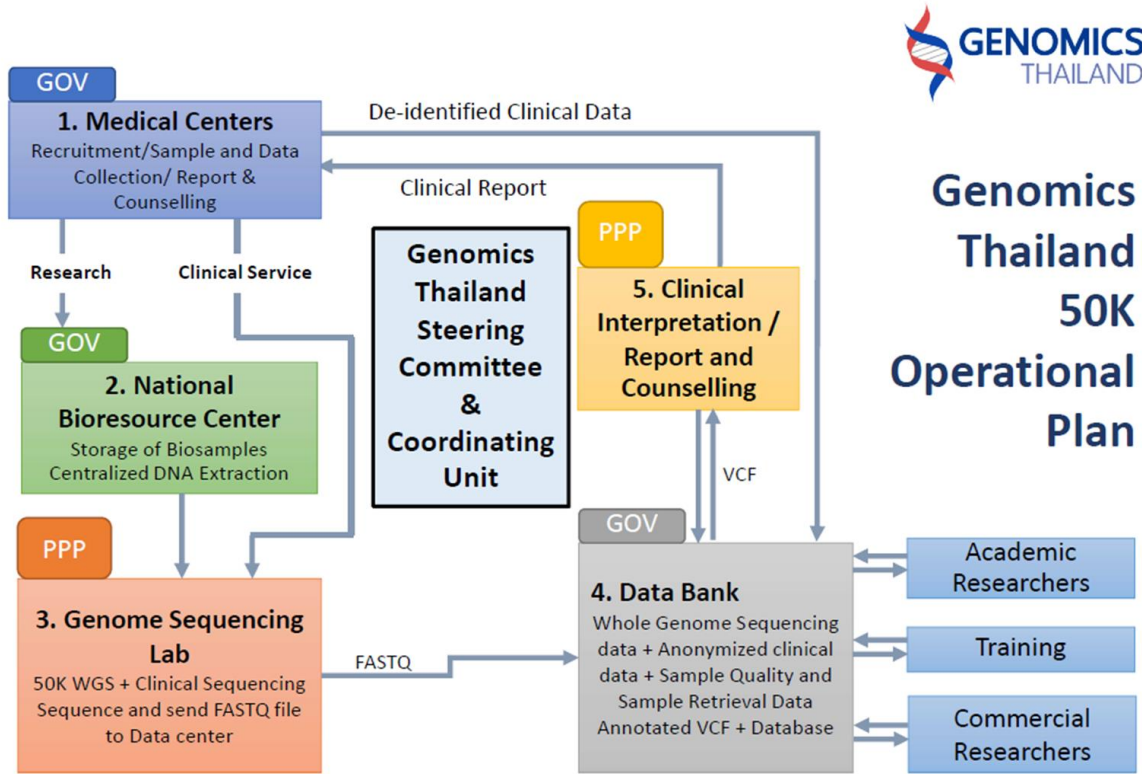


Figure 1. Map of Currently Active Government-Funded National Genomic-Medicine Initiatives

Ten years ago, Genomics England was formed to deliver the 100,000 Genomes Project.

The NHS is now the first healthcare system in the world to offer whole genome sequencing as part of routine care.

# Genomics Thailand



**1 Recruited Participants**  
40 Participant recruitment sites/  
157 Research Projects  
(11 AUG 2023)



**2 DNA extraction**  
National Bio-resources center  
(Department of Medical Sciences)  
(11 AUG 2023)



**3 Whole genome sequencing (WGS)**  
Thailand Genome Sequencing Center  
(31 JUL 2023)

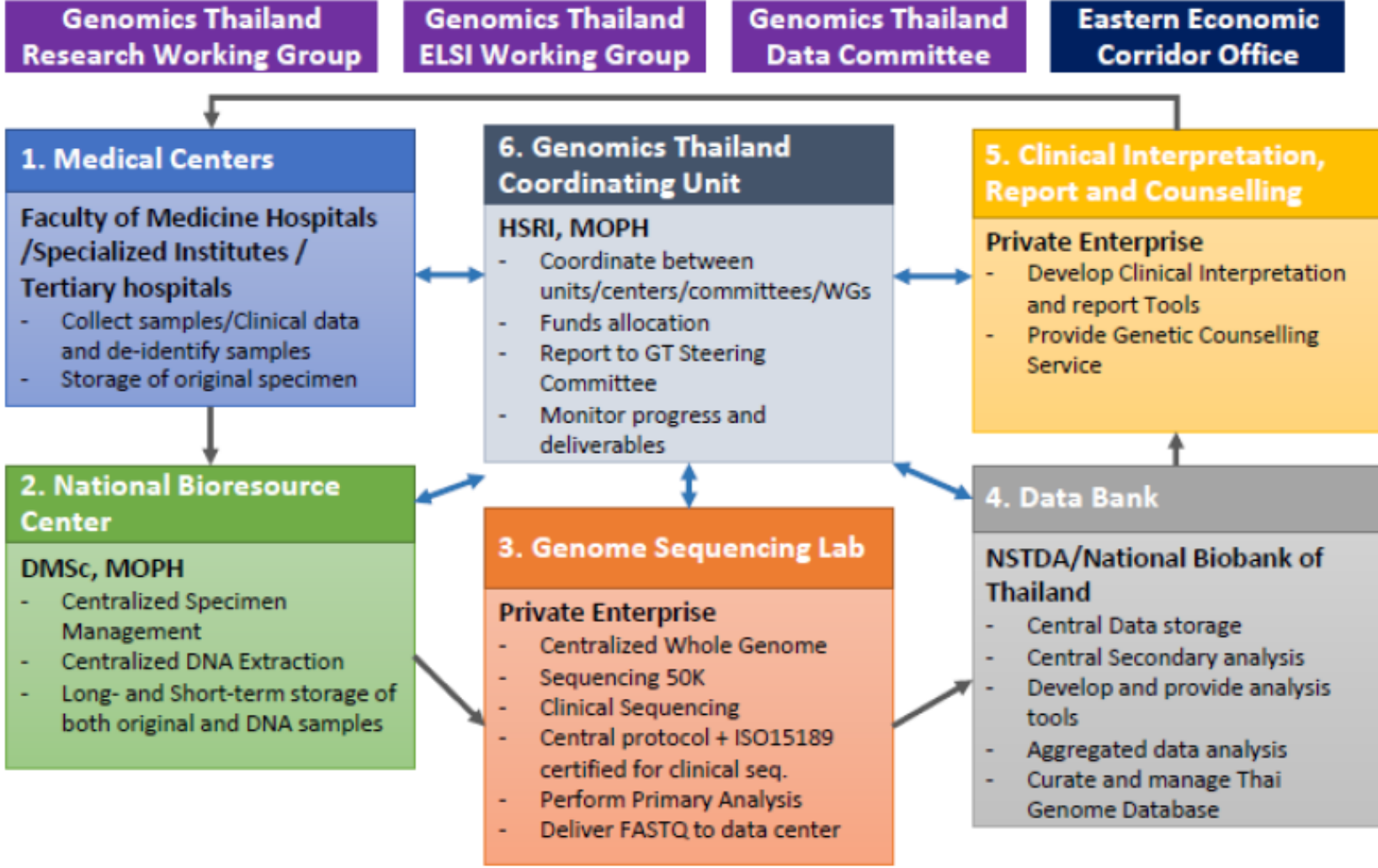


**4 Sequencing Data (QC Approved)**  
National Biobank of Thailand  
(National Genome Data Center)  
(National Science and Technology Development Agency)  
(31 JUL 2023)

**WGS Progress Report**  
**Genomics Thailand**  
(18 APR 2022 – 31 JUL 2023)



# Genomics Thailand Steering Committee



ภาพประกอบที่ 43 : บทบาทและความรับผิดชอบของผู้ที่มีส่วนได้ส่วนเสีย  
ในเครือข่ายจีโนมิกส์ประเทศไทย\*

# Genomics Data Management

- Genomic data are big.
  - Raw sequence short reads >100 GB/sample
  - Total SNPs (single nucleotide variants) > 5 million/person
  - Structural variant data
- Genomic data are potentially identifiable.
- Data Security is of prime importance: data processing needs to be done in a secure environment.

# Ethical Issues Related to Genomic Data

- Privacy

- Data to be stored in a central secure server.
- Only analyzed results are reported back.
- Only aggregated information (such as frequency of each SNPs) is made publicly available.
- Privacy is a hurdle for changing WGS from research to service

- Property Right

- Donors own their own genomic data.
- Donors retain the right to get the data.
- Donors retain the right to withdraw their raw data from the data bank. However, the aggregated information will not be updated for each withdrawal.

# Ethical Issues Related to Genomic Data

- Discrimination
  - Universal health coverage schemes in Thailand prohibits discrimination.
  - Special programs for ethnic minority.
  - Health insurance industry.
- Stigmatization
  - Results are informed to the consenting physicians who inform donors when
    - The findings are actionable.
    - With pre-consent from the donor that they would like to get the information. They can choose not to know.
- \*Process to re-informing donors when there is new knowledge relating to previously harmless SNPs.
  - Significance of a SNP becomes known.
  - Previous conditions become actionable.



# Conclusion

- **Genomics medicine is a future.**
- **Universal health coverage helps alleviating several ethical issues, particularly regarding discrimination and stigmatization.**
- **Data management is a key agenda for future scaling up to health care.**
- **Raising public awareness of benefits and ethical risks, and massive training of related personnel are required.**