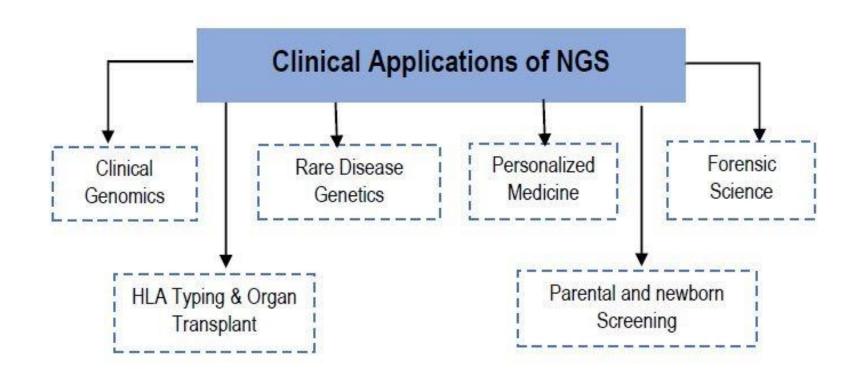
Ethical Challenges In Integrating Genomics Information For Health Care.

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Applications of Genomic Sequencing in Health Care



Rasheed M. Next Generation Sequencing as an Emerging Technology in Rare Disease Genetics. J Islamabad Med Dental Coll. 2020; 9(1):1-3. Doi: 10.35787/jimdc.v9i1.521

Some Government Genomics Projects

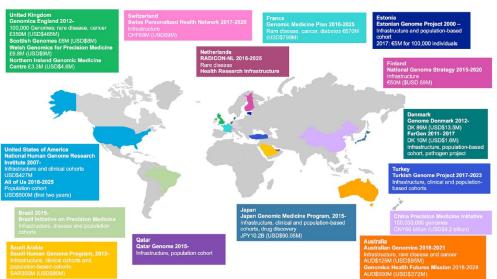


Figure 1. Map of Currently Active Government-Funded National Genomic-Medicine Initiatives

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.

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



413,350+Survey
Responses



337,500+Physical
Measurements



312,900+Genotyping Arrays



287,000+ Electronic Health Records



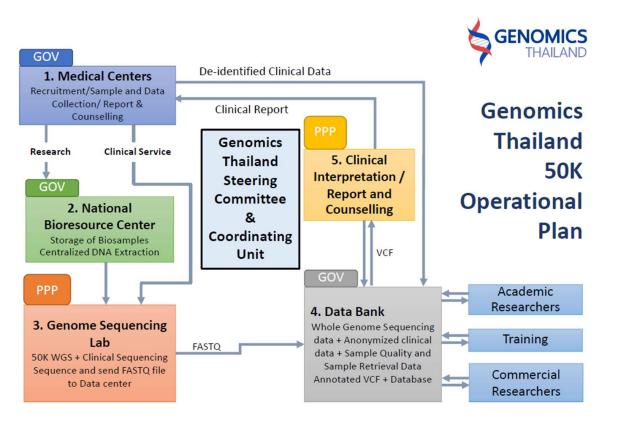
245,350+ Whole Genome Sequences

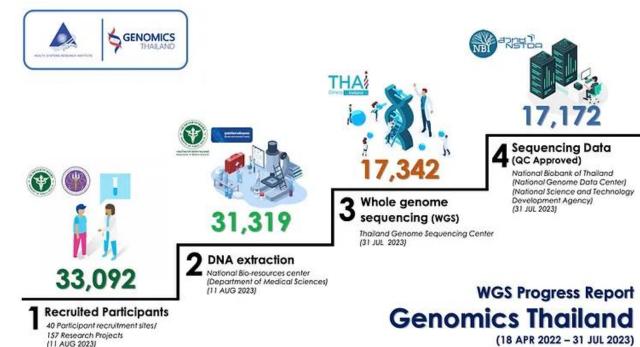


15,600+ Fitbit Records



Genomics Thailand





Genomics Thailand Steering Committee Genomics Thailand **Genomics Thailand** Genomics Thailand Eastern Economic Research Working Group **ELSI Working Group Data Committee Corridor Office** 6. Genomics Thailand 5. Clinical Interpretation, 1. Medical Centers Coordinating Unit Report and Counselling **Faculty of Medicine Hospitals** HSRI, MOPH Private Enterprise /Specialized Institutes / Coordinate between Develop Clinical Interpretation Tertiary hospitals units/centers/committees/WGs and report Tools Collect samples/Clinical data Funds allocation Provide Genetic Counselling and de-identify samples Report to GT Steering Service Storage of original specimen Committee Monitor progress and deliverables 2. National Bioresource 4. Data Bank Center 3. Genome Sequencing Lab NSTDA/National Biobank of DMSc, MOPH Thailand Centralized Specimen Private Enterprise Central Data storage Management Centralized Whole Genome Central Secondary analysis Centralized DNA Extraction Sequencing 50K Develop and provide analysis Long- and Short-term storage of Clinical Sequencing tools both original and DNA samples Central protocol + ISO15189 Aggregated data analysis certified for clinical seq. Curate and manage Thai Perform Primary Analysis Genome Database Deliver FASTQ to data center

ภาพประกอบที่ 43 : บทบาทและความรับผิดซอบซองผู้ที่มีส่วนได้ส่วนเสีย ในเครือซ่ายจีโนมิกส์ประเทศไทย*

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.