



# Ethics Consideration in Health Databases and Biobank

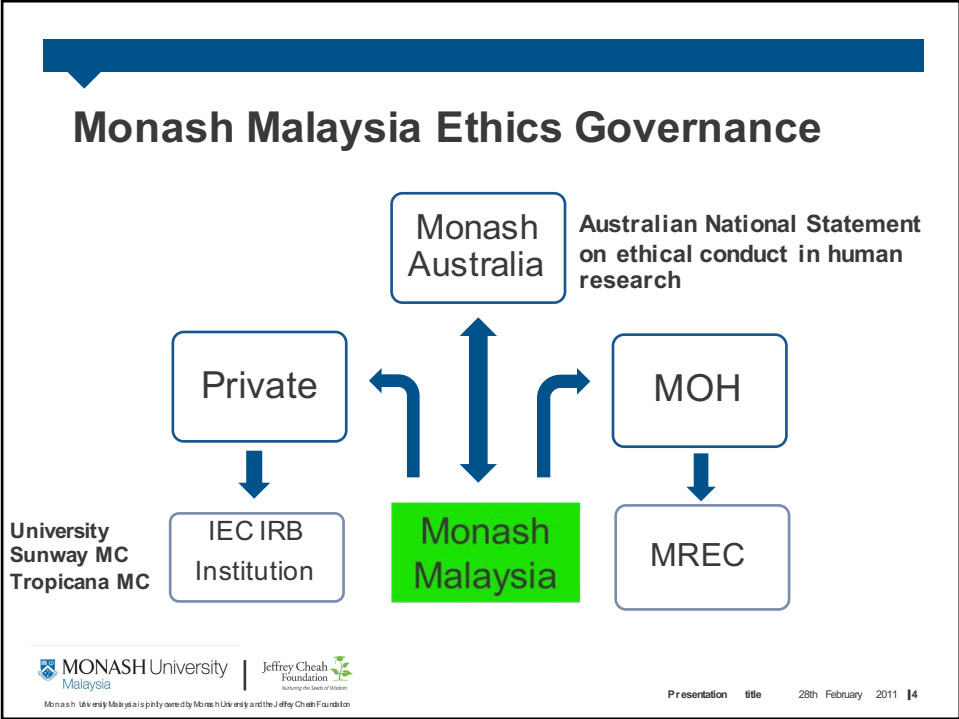
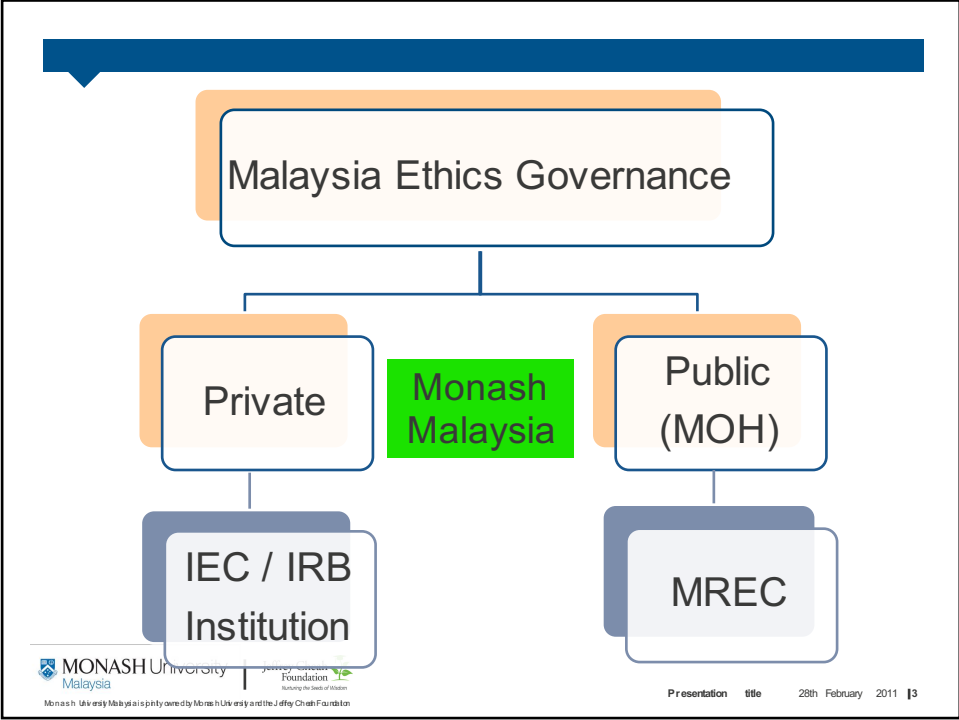
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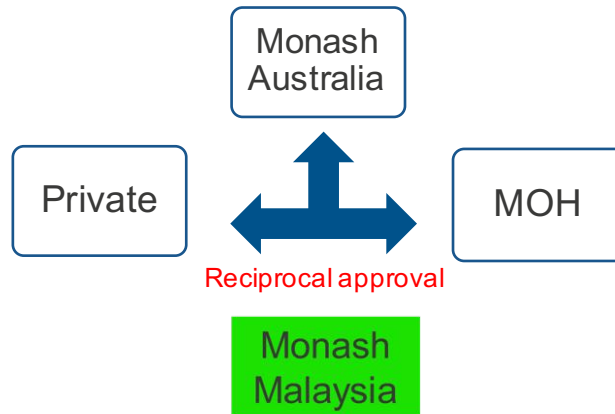
## Presentation

- Malaysia Ethics Governance
- Monash Ethics Governance
- Challenges in Health Data
- IT revolution in Healthcare
- Malaysia Initiatives
- Ethical issues encountered
- Discussion

**Heavy in health databases**



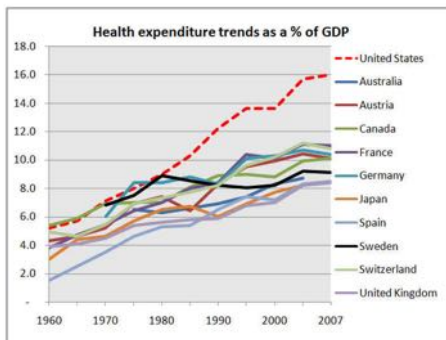
## Monash Malaysia Ethics set up



## Problems

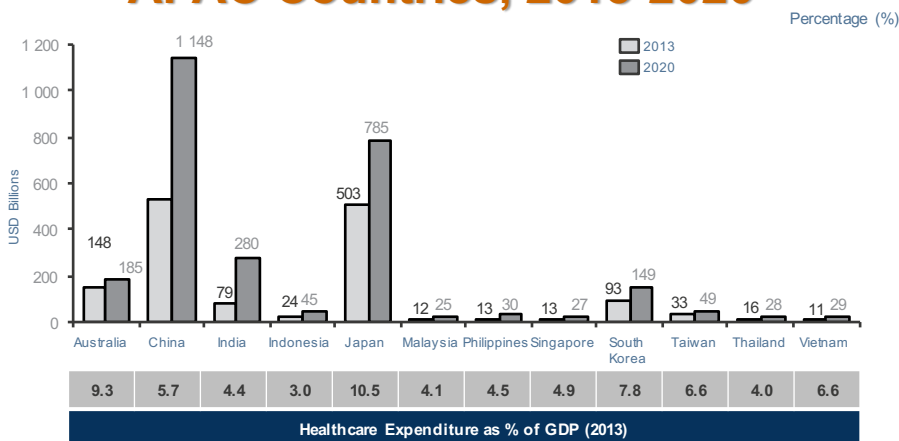
- **Healthcare cost and sustainability**
  - Population explosion
  - Aging population

# Healthcare expenditure



Source: OECDHealthData\_FrequentlyRequestedData.xls

# Healthcare Expenditure APAC Countries, 2013-2020





# Problems

- Healthcare cost
- Current healthcare ecosystem

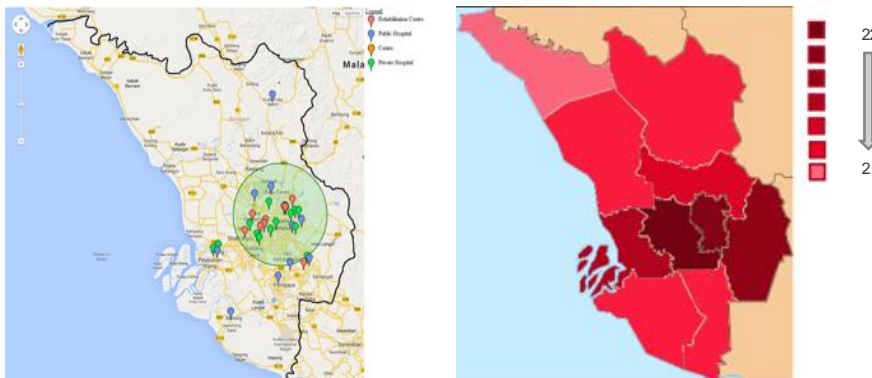
# Current healthcare ecosystem



# Problems

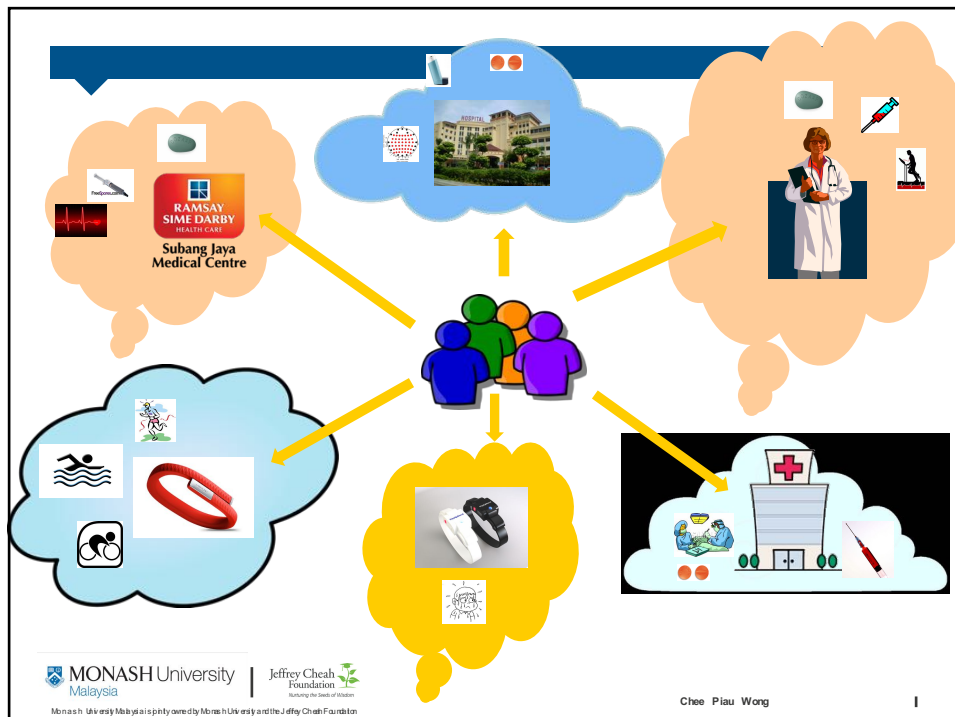
- Healthcare cost
- Current health care ecosystem
- Accessibility and availability

## Demand for and supply of rehabilitation services for children with head injury within Selangor and Wilayah Persekutuan Kuala Lumpur

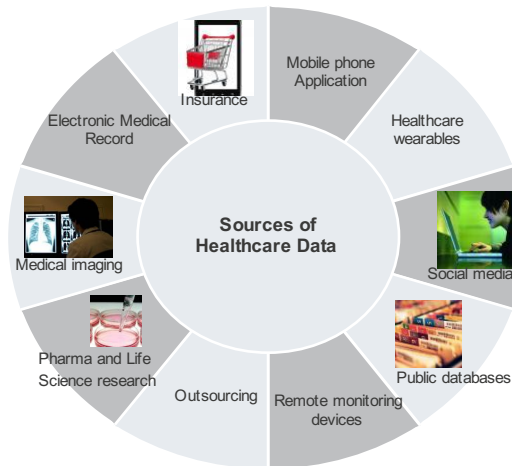


# Problems

- Healthcare cost
- Current health care ecosystem
- Accessibility and availability
- **Scattering of medical information**



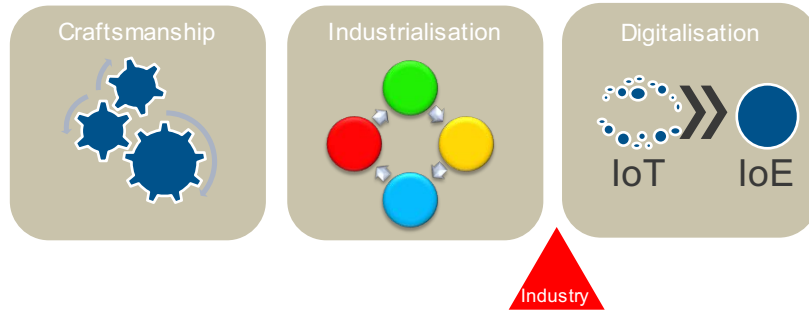
# Sources of health data



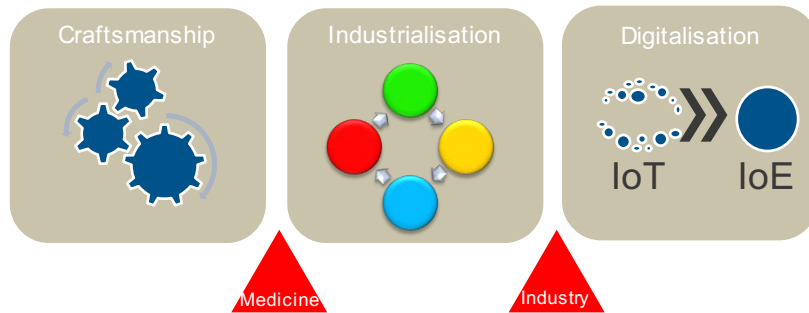
# Problems

- Healthcare cost
- Current healthcare model
- Accessibility and availability
- Scattering of medical information
- IT lag

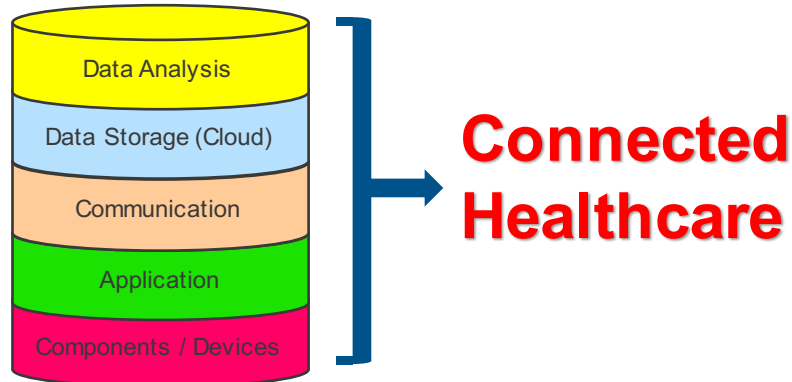
# IT Revolution



# IT Revolution



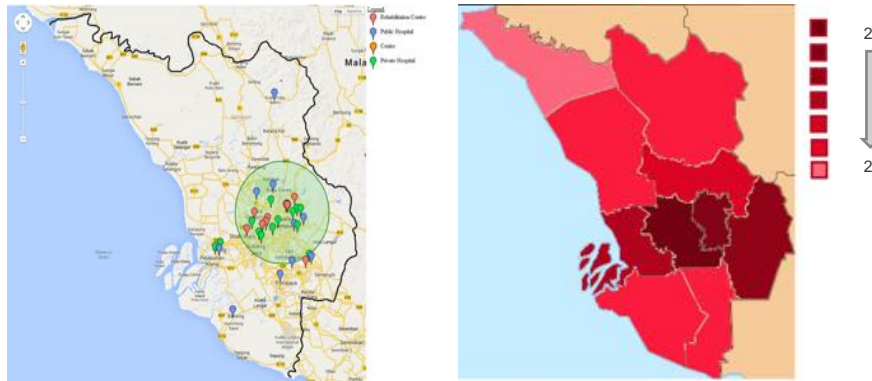
## Progression in IoT



## Problems

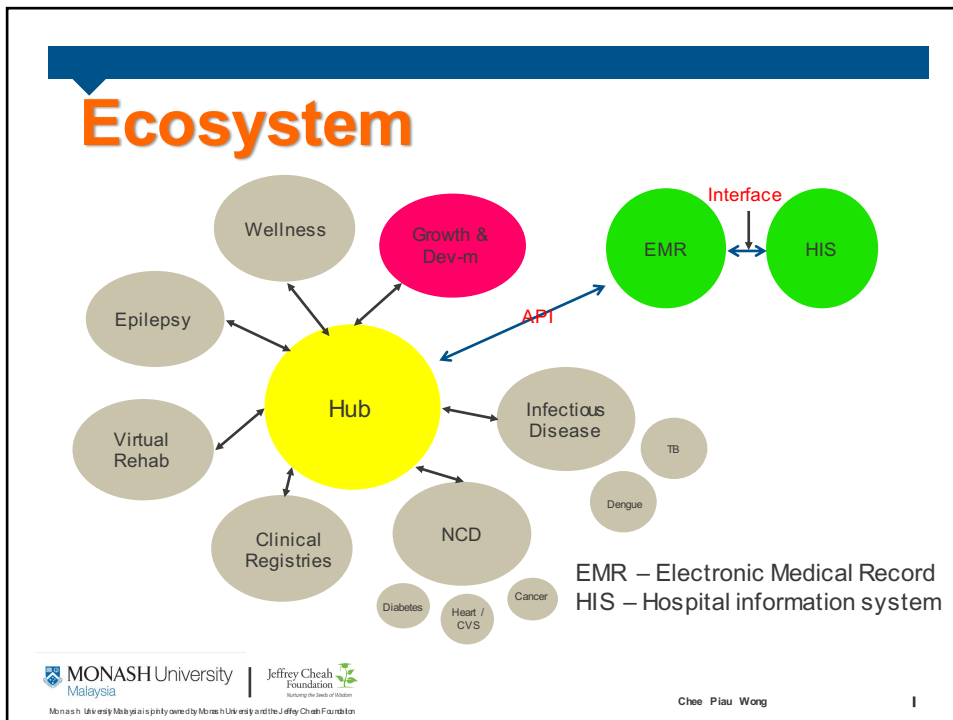
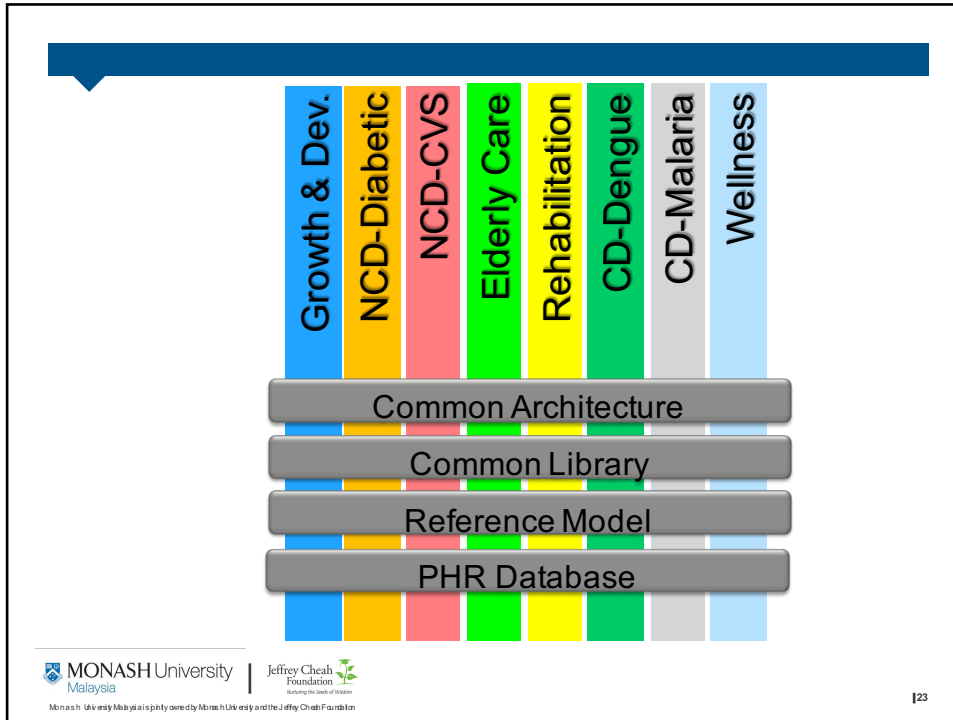
- Healthcare cost
- Current healthcare model
- Accessibility and availability
- Scattering of medical information
- **Predictive analysis**

### Demand for and supply of rehabilitation services for children with head injury within Selangor and Wilayah Persekutuan Kuala Lumpur



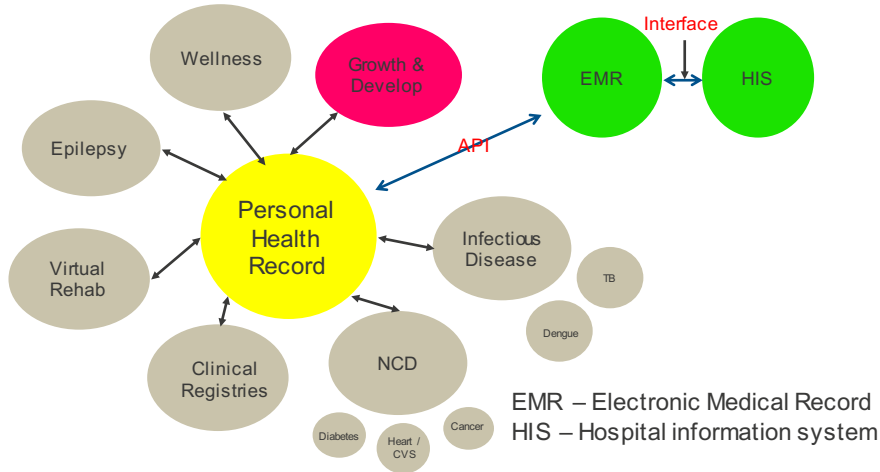
## Malaysia Initiatives

- Data warehousing
- Information Exchange
- Centralised PHR (Patient centred)
- Lifetime health record
- Industry – Academia partnership
- Example
  - Centralised Online telemedicine system
  - Child Growth and Surveillance
  - Virtual rehabilitation
  - Cardiovascular disease

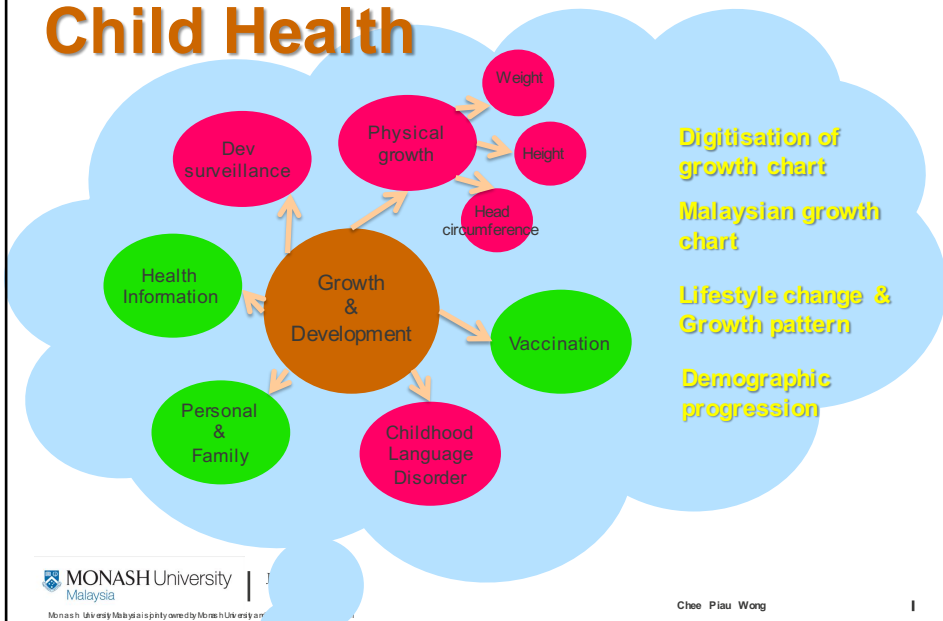




# Ecosystem



# Child Health



## Issues encountered (additional)

- Hardware issue
  - Patient centred
  - mHealth ? Mobile phone
- Funding
  - public service vs research vs commercial
  - Conflict of interest?
  - Different interests of various stakeholders
- Legislation vs common sense
  - Autonomy, empowerment
  - Patient's ability to safeguard their own interest
    - Confidentiality, security
  - Medical Insurance
- Balance between Individual and community

## Genetic in Paediatric Epilepsy

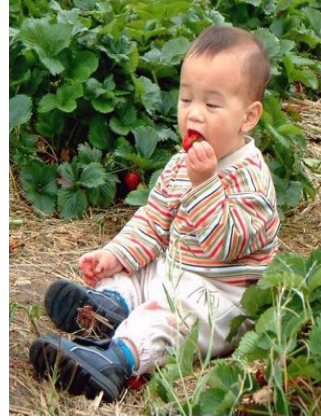
- Future classification and diagnosis of epilepsy?
  - Each gene accounts for several epilepsy or epilepsy syndrome
  - Each epilepsy or epilepsy syndrome has several different genetic abnormalities
  - Disease may manifest only later.
- Need for re-identification
  - Non-identification will reduce the usefulness of the databases
- Ethical hurdle
  - Prediction of malignant condition – to inform or not to inform
  - Medical insurance

## Telemedicine Development Group

- Inclusive group
  - Medical practitioners, Researchers, Academics
  - Industry, funders, Regulators, policy maker
- Facilitator
  - Conference, innovation challenge, policy guidance
- Provide guidance and direction
- Governance structure
  - Steering committee
  - Director General of Ministry of Health
  - Under the Prime Minister Department

## Summary

- Increase emphasis on primary prevention and wellness
- Shift from remedial to wellness & preventive healthcare
- Telemedicine / Telehealth increasingly prominent
- Embracing “Digitisation” lead to data generation
- Big Data and Predictive analysis the future norm
- Balance between individuals and society
- Re-strategise ethical consideration



**Thank you**