



MEDICAL PANEL: Definition & Challenges in Rare Disease Management

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- Size: 7.19 square km
- Population : 5.54 million
- Annual number of newborns: 42,185 (2015)



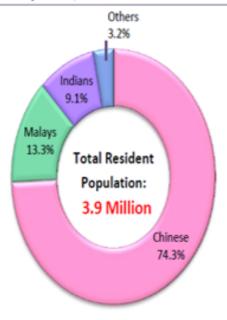








Ethnic Composition of the Resident Population, 2015





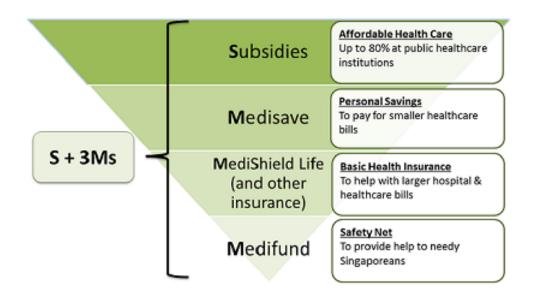


- Primary healthcare
- 8 public hospitals
- 2 clinical genetics department





Healthcare funding







Definition of rare disease

- Orphan Drugs exemption order (1991)
- Rare disease is defined as a life-threatening and severely debilitating illness affecting less than 20,000 persons





Challenges in definition

- No local data
- Not linked to subsidies or support



Challenges in management

Clinical suspicion



Diagnosis



Management

- Too many specialists
- Fragmented care

- Improve access to testing
- Knowledge
- Funding

- Access to drugs/trials
- Poor outpatient funding
- Educational / therapy support





Next steps for Singapore

- Local data genetics registry and rare disease impact study
- Increase public awareness patient groups
- ? Expand newborn screening panel
- Compulsory Education Act for special education (2019)

Thank you very much

