

Instructions: Please do this!!!!

- Get the slides in 2 weeks before your presentation (ASAP)
 - Submit them at <https://webportal.systemdynamics.org>
 - Click on the name of the presentation
 - Click on upload files
 - Upload as a work in progress slide
 - The session chair will pull them together with other presentations.
 - If you make updates send the chair a note
 - Use the contact email on <https://isd2020.systemdynamics.org>
 - Follow the format and timing listed below
 - You may record your presentation and upload a link on the web portal under paper info (not files)
 - If you are not able to attend the session this will be used
 - If you do attend you can ask the chair to play this, or present live
- IMPORTANT: You have exactly 5:00 minutes for the presentation

No Disease Orphan: Technology, Economics and Policy for Providing Equitable Healthcare Amidst Extreme Inequality

Chintan Vaishnav, MIT

Vijay Chandru, IISc, OPFORD Foundation

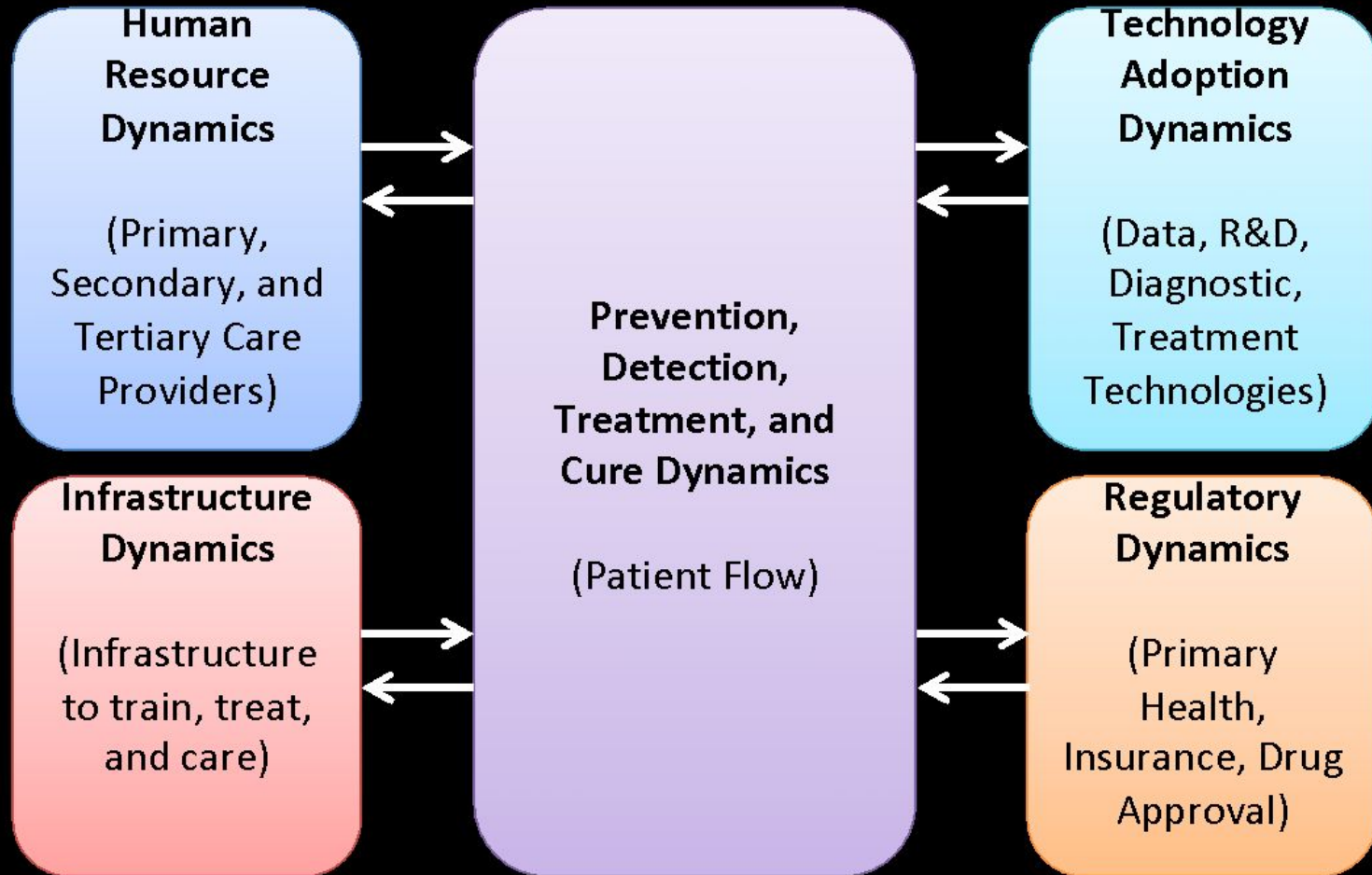
ISDC 2020, Bergen

Problem Statement

- **In developing economies, rare diseases have received little to no attention in policy as well as practice, making them orphan diseases**
 - Examples: rare cancers, hemophilia, hemoglobinopathies, ophthalmic, immunodeficiency, neuromuscular disorders, etc.
- In India, a policy for Treatment of Rare Diseases was released in 2017 and revised and published as the National Policy for Rare Diseases 2020 by the Ministry of Health and Family Welfare, India.
 - Disease burden in India ~50-70 Million children and adults
- **How can we size the response in policy and practice when gaining the system level understanding of Equitable Access, Accurate Diagnostic, and Affordable Treatment remain illusive?**
 - Total afflicted population
 - Prevalence
 - Frequency of occurrence

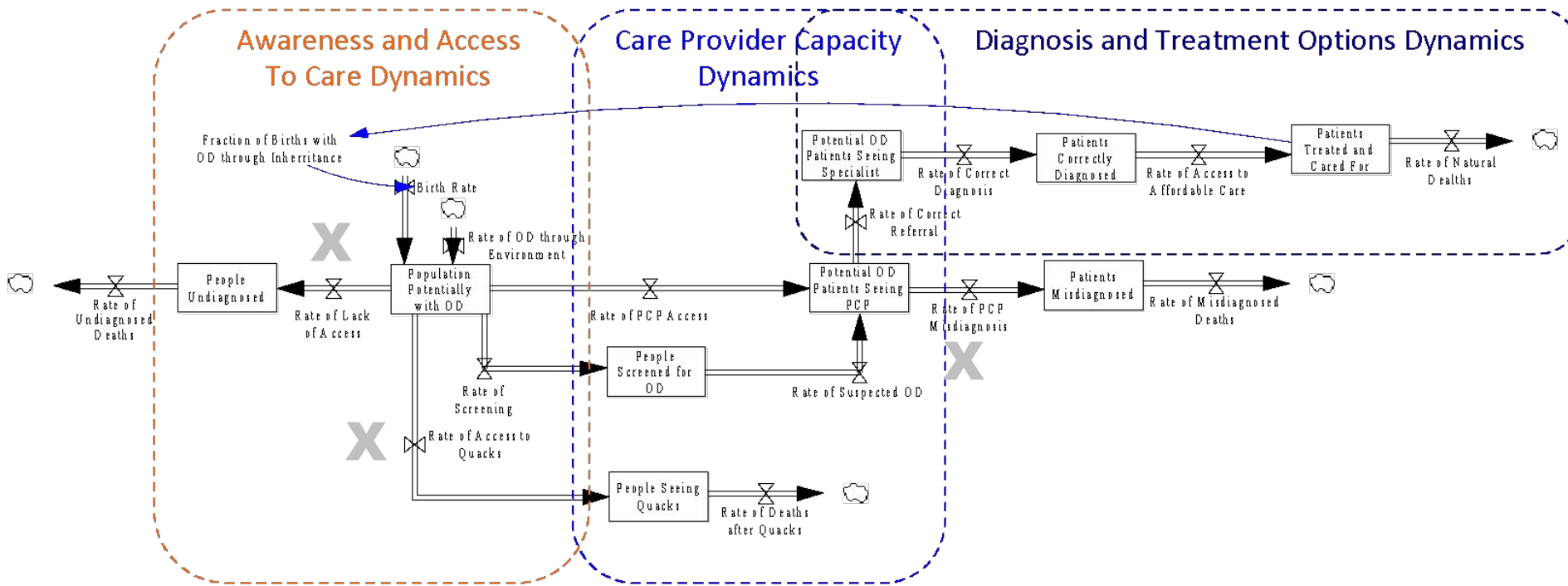
Approach or Dynamic Hypothesis

Backdrop: Economic Efficiency, Equity, Empowerment, Environmental Soundness



Emergent Understanding: OD Health, Cost of Care, Tech/Policy Levers

Progress, Insights and Questions



- **Three Foci**
 - Equitable Access
 - Accurate Diagnosis
 - Affordable Treatment
- **OPFORD Foundation**
 - Focus on haematological genetic disorders
 - Patient centred digital platforms

- What is the payor model for orphan diseases in your health system – for diagnosis, maintenance, cures by genomic medicine?
- **Has Hardy-Weinberg Equilibrium been reached in genotype frequencies in your system or do evolutionary influences still have a role to play?**