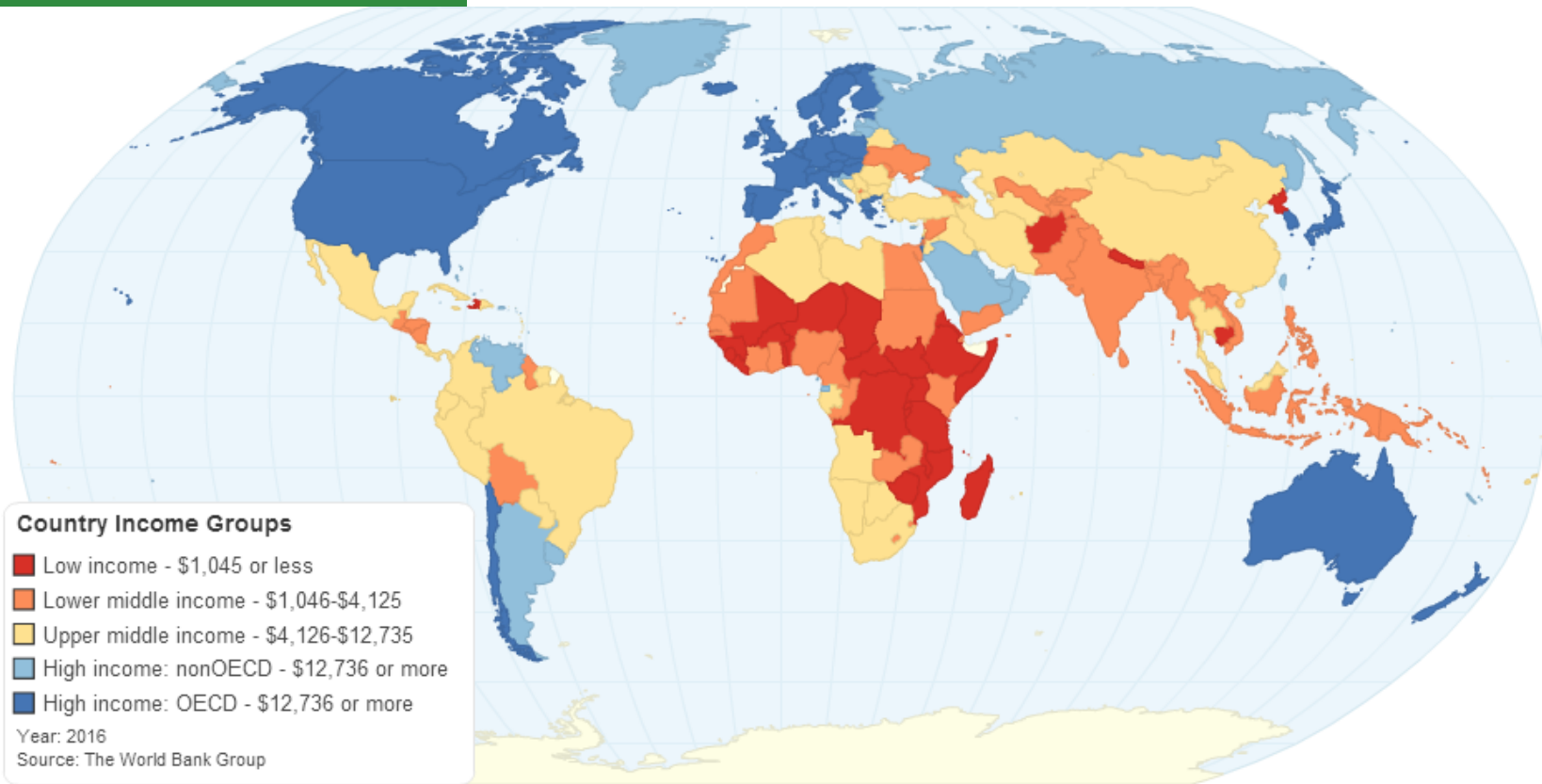# Flagship Project
Genomic Medicine Clinics for Rare Genetic Disorders
Promoting Implementation of Genomic Medicine in Low Middle Income Countries

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Country Income Groups

- 🟥 Low income - $1,045 or less
- 🟧 Lower middle income - $1,046-$4,125
- 🟨 Upper middle income - $4,126-$12,735
- 🔵 High income: nonOECD - $12,736 or more
- 🔵 High income: OECD - $12,736 or more

Year: 2016
Source: The World Bank Group

Outline

- **Overall Objective**
- **Objectives**
- **Specific Objectives**
- **Breakout Discussion Points**

Overall Objective

To enable LMICs around the world to implement genome and exome sequencing in children with rare undiagnosed genetic disorders.

By establishing a network of clinics in hospitals in LMICs.

Specific Objectives

1. To train local clinicians in genomic medicine in the genetic evaluation, result interpretation, and pre and post-test counselling;

2. To implement a research pilot program in which exome sequencing is performed in eligible patients for molecular diagnosis; and

3. To evaluate clinical outcomes, provider and patient satisfaction, ethical, social and legal implications, and cost-effectiveness of the intervention.

Breakout Discussion Points

- Prior Experience - Regeneron Genomic Center's Global Collaboration
- Selection of Clinical Sites
- Co-ordinating Center
- IRB Approval
- Government Engagement/Regulatory Issues
- Exome Sequencing, Bioinformatics Analysis, Validation of Results, Return of Results
- Wider collaboration with the rare disorders research community – Undiagnosed Diseases Network International (UNDI)

Next Steps

- Expression of interest from LMIC teams [36 prior to meeting + 2 now]
- Selection of local PIs and Teams at Implementation Sites
- Establishment of a Project PI & Steering Committee
- Development of a high-level Project Proposal
- Discussion with a funding agency followed by funding application
- LMIC government engagement
- Development of a detailed project proposal
- Obtain IRB approval from a Central IRB and Local IRBs
- Train project Implementation Teams
- Upgrade facilities in the clinics
- Project Implementation with monitoring and evaluation by the steering committee

Timeline

- Monthly progress review meetings starting in June 2020
- Launch the project at the 6th G2MC Meeting