

GFBR 2023: The Ethics of Health Research Priority Setting

Prioritizing Rare Inherited Diseases Research in Lower- and Middle-Income Countries: The Ethical Dilemmas of Cochrane Evidence Synthesis



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Rare Inherited Diseases (RID) in LMIC settings

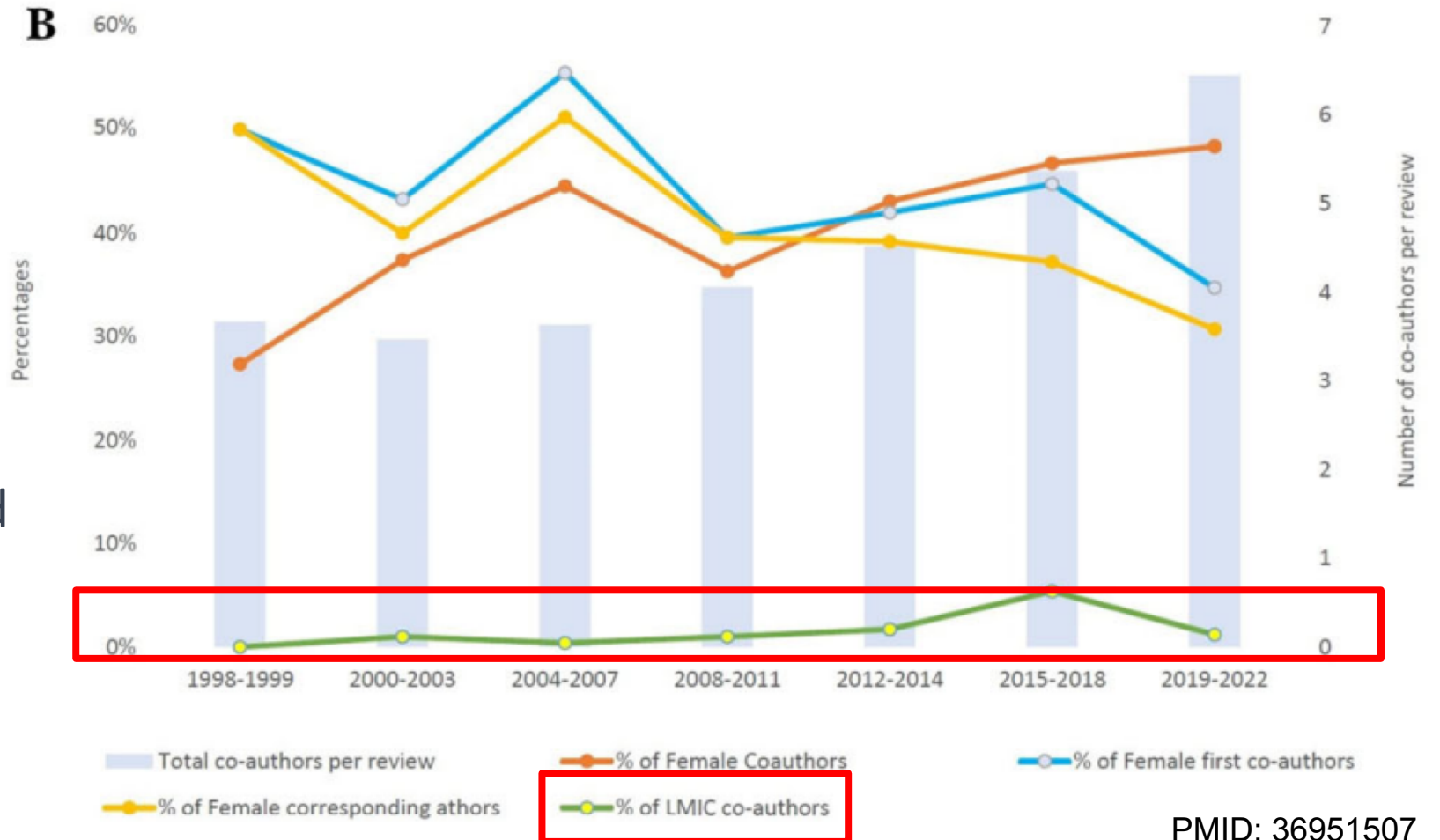
- RID are affecting ~300 million people worldwide and mostly from LMICs
- Challenges and limited resources
- Role of research in addressing gaps



PMID: 36339196

Cochrane Contribution in Building Research Evidence Base

- Cochrane's role as the gold standard for evidence synthesis
- Systematic reviews and clinical studies
- Imbalance between HICs and LMICs in review production



Cochrane's Transformation

- Impact of reduced resources due to the pandemic
- Plans to establish evidence synthesis units (ESUs) in LMICs
- Ensuring continued support for RID research. “Cystic Fibrosis and Genetic Disorders” Group transformed into “Cystic Fibrosis” Group

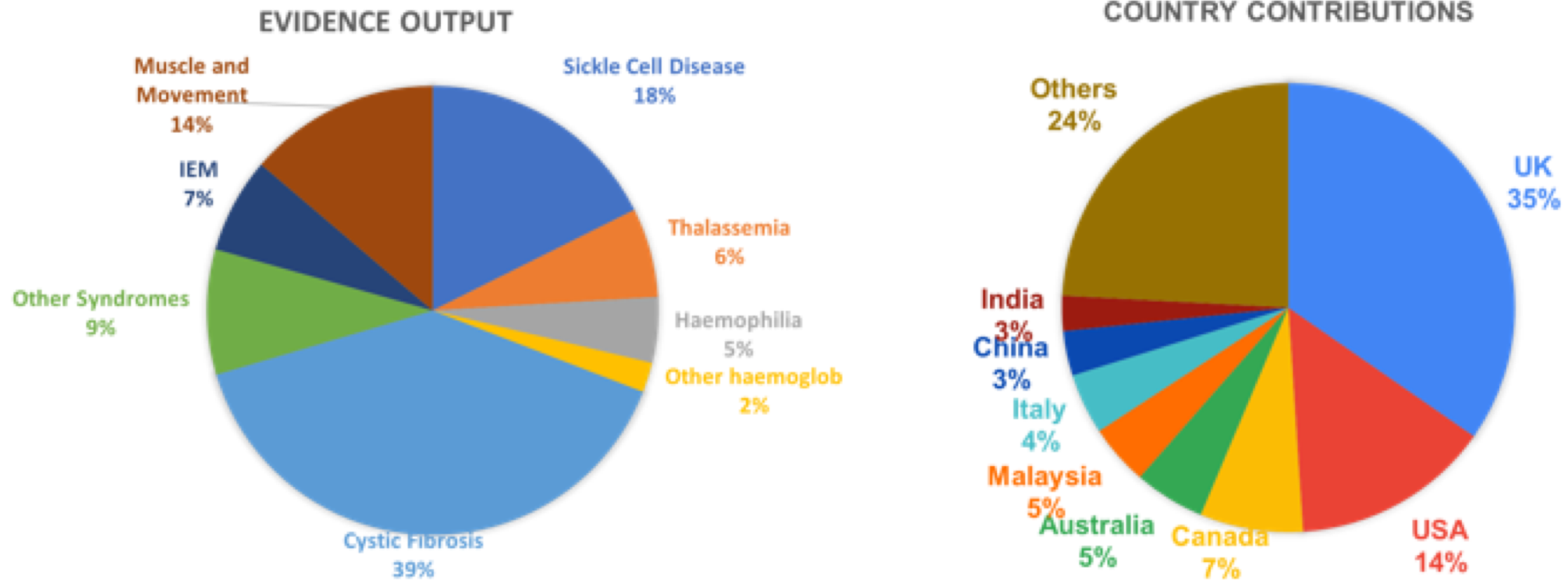
COCHRANE HAS CHANGED.

Future Cochrane: a new model for delivering global evidence



SCROLL

Ethical Issues (1) - Inclusion and Fair Processes

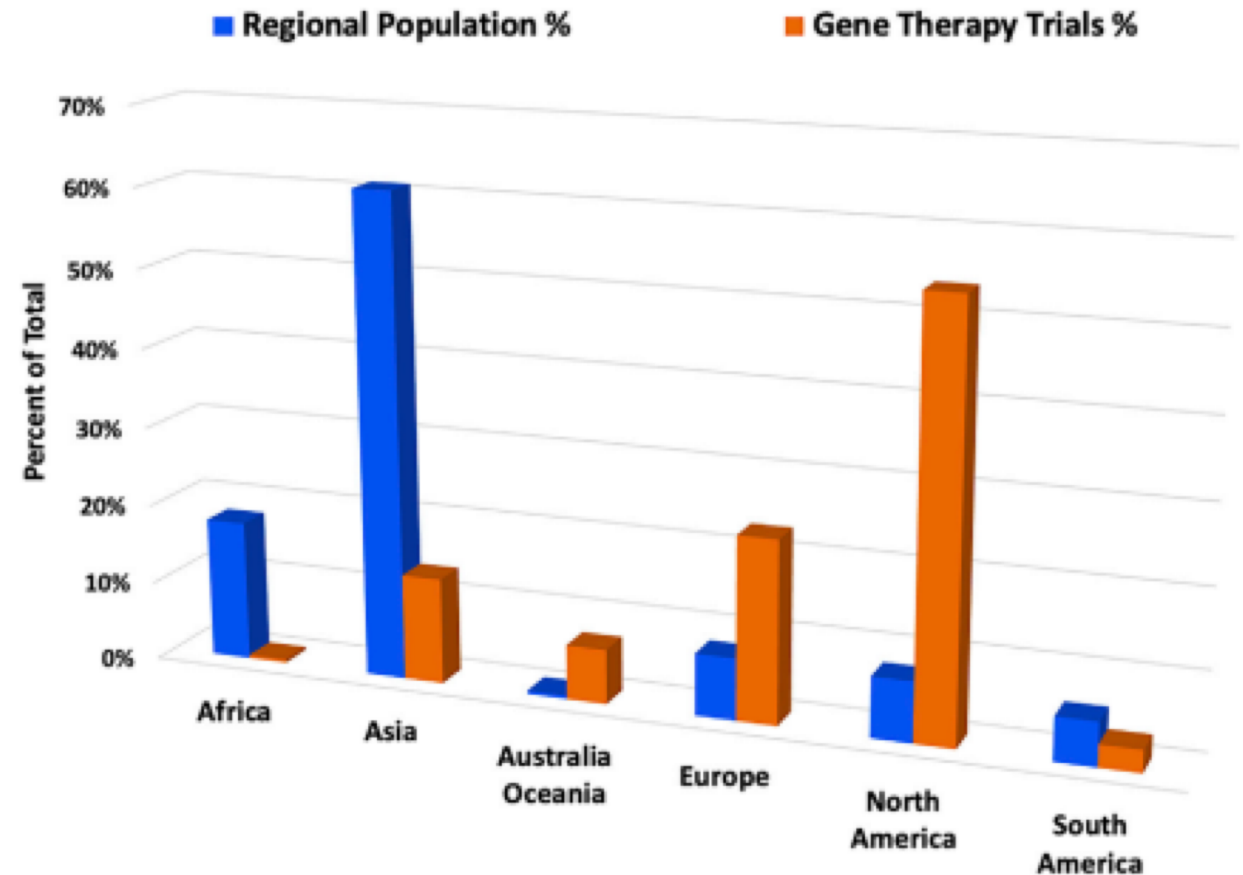


January 2003 – May 2020

Cochrane on Rare Diseases – Evidence Output and Country
(331 review documents)

Ethical Issues (2) - Criteria and Goals

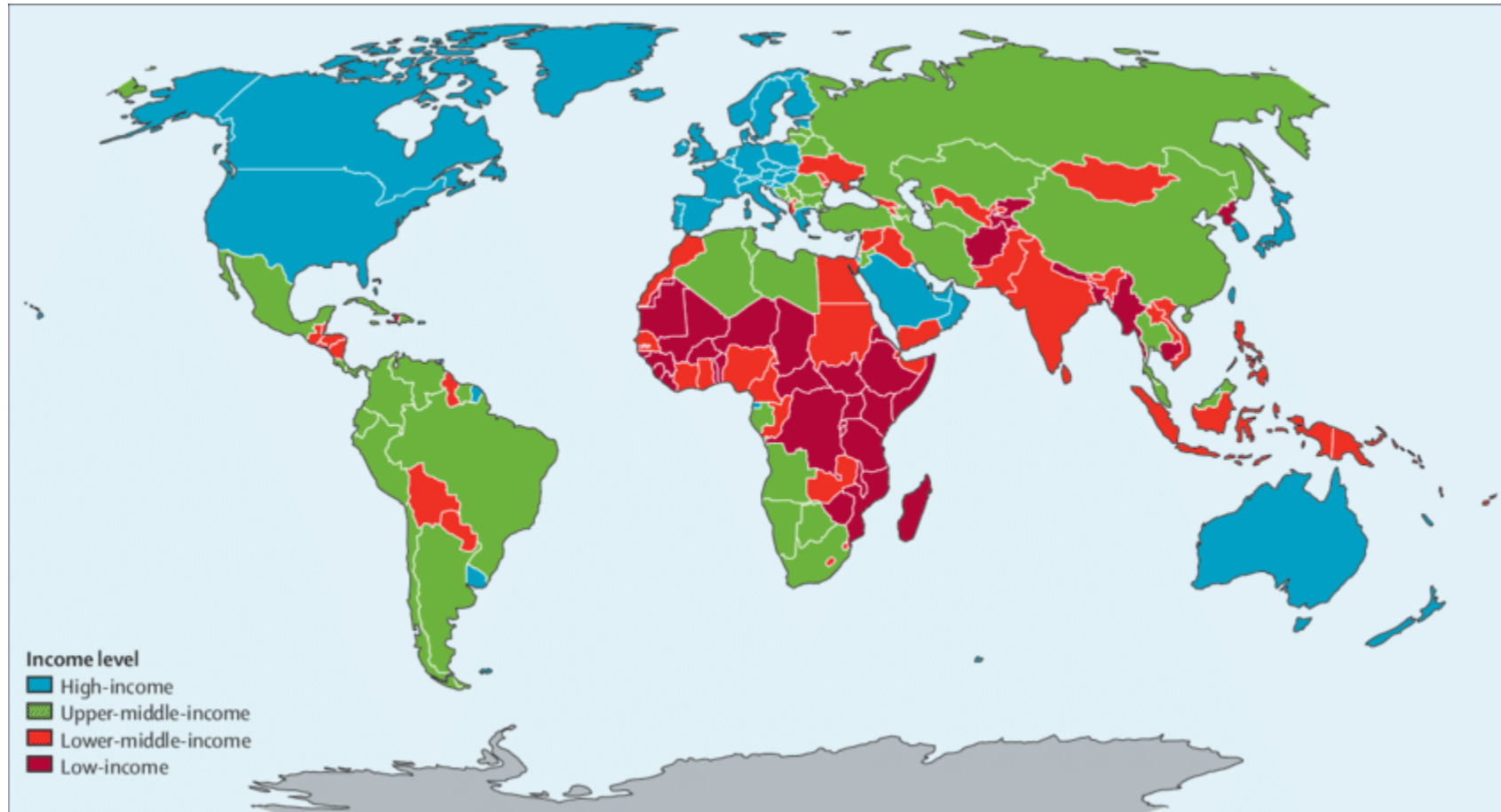
- Balancing limited resources and ethical considerations
- Prioritizing affordable treatments in LMICs
- Ethical implications in resource-constrained settings



PMID: 35390542

Ethical Issues (3) - Global and Local Settings

- Aligning research questions with LMIC priorities
- Bridging the gap between global and local needs
- Cultural appropriateness and local contexts



Ethical Issues (4) - Cochrane's Roles

- Reflecting on Cochrane's roles in LMIC disease topics
- Challenges in establishing LMIC-based ESUs
- The need for locally sourced funding and engagement



Challenges Summarized

- Ensuring inclusiveness in process
 - Selecting research questions
 - Global vs Local setting of where priorities are developed
 - Capacity building
 - Allocating scarce resources
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Recommendation 1 - Ensure Inclusivity

- Review groups to reflect on diversity of stakeholders
- Capacity building for local LMIC expertise
- Involve local communities in development of research questions



Recommendation 2 - LMIC-Sensitive Questions

- Considering ethical implications and cultural appropriateness
- Impact on local communities and cultures

Research Questions



Slide 12: Implementation Challenges

- Resource constraints LMIC setting (e.g. funding and trained personnel)
- Diverse context of LMIC; no one-size-fits-all concept for all LMICs
- Bureaucratic resistance



Future Prospects

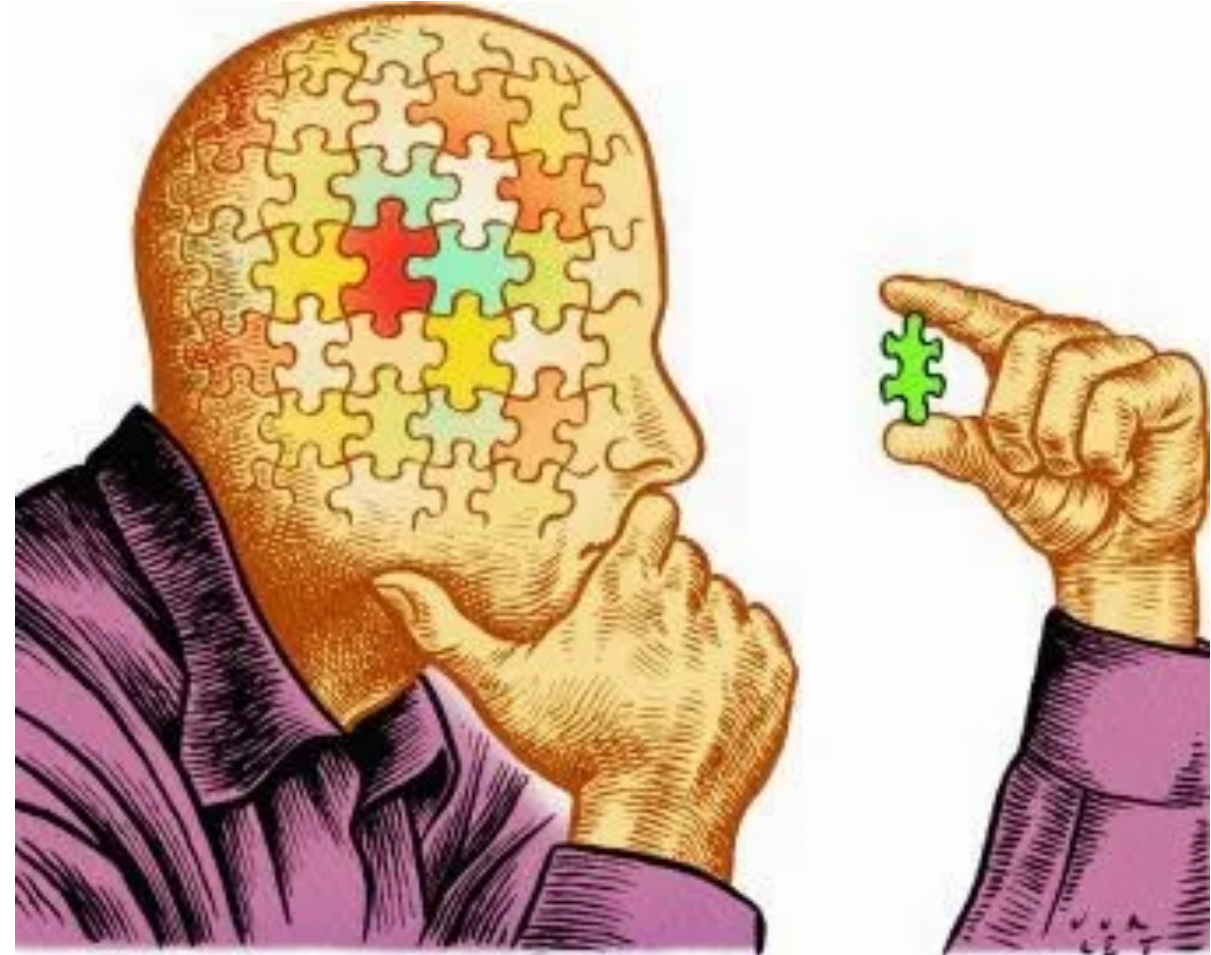
- Global collaboration and knowledge exchange
- Capacity building and empowerment
- Advancements in funding models

Be Optimistic



Closing Thoughts

- Embracing diversity for inclusive research
- Ethical imperative in RID research
- Collective action for global health equity



Thank You

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