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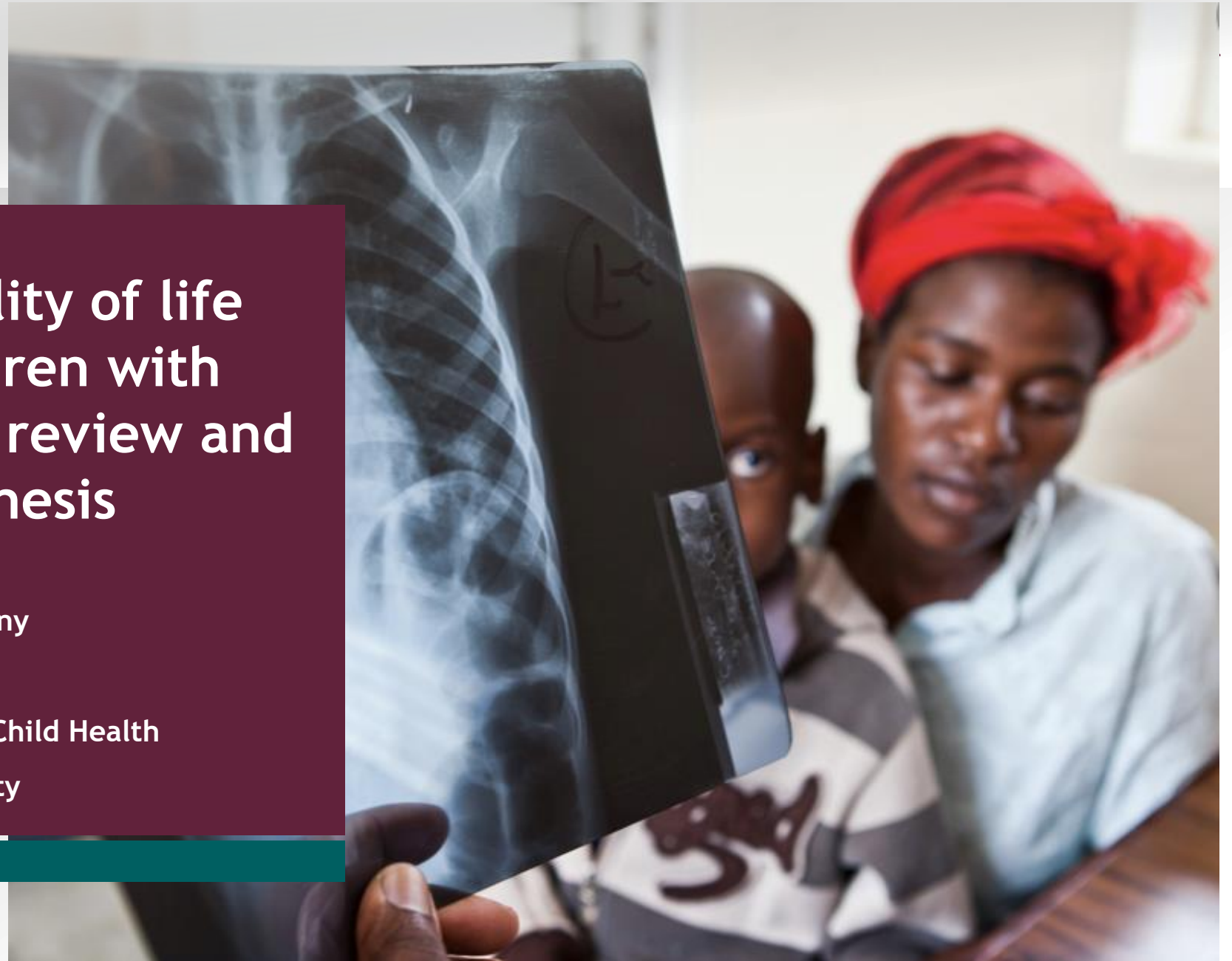
# Health-related quality of life measures for children with respiratory illnesses; review and evidence synthesis

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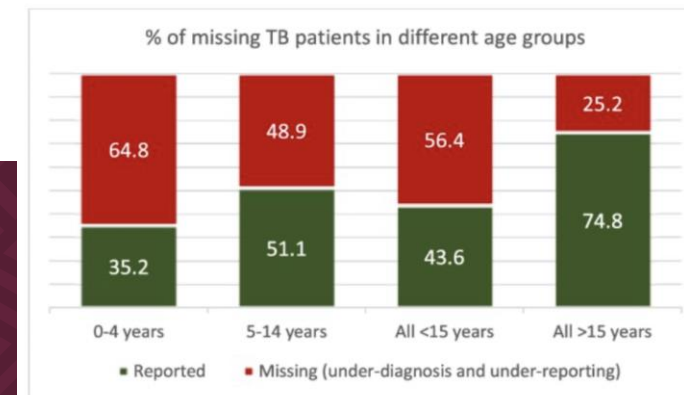
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# INTRODUCTION

- In 2022, an estimated 1.3 million children below 15 years developed TB worldwide
  - TB has been shown to have an impact on lung health in children, adolescents and adults
  - Effect of TB on HRQoL in adults' results in notable decline in both the physiological and psychological well-being
- However, our understanding of the impact of pulmonary TB (or other respiratory illnesses) in a high TB burden setting on the HRQoL of children is extremely limited



# LONG TERM IMPACT OF RESPIRATORY ILLNESSES

- Respiratory insults early in life (childhood) can lead to impaired lung function and respiratory diseases later on in life.
- The long-term outcome of childhood respiratory illnesses is well recognised in high-income countries (HICs)
- There is currently limited data available on the long-term impact of TB in children.
- Adult data shows that up to 50% experience respiratory sequelae after successful TB treatment

# WHAT IS HEALTH RELATED QUALITY OF LIFE?

- Health-related quality of life (HRQoL) is a useful indicator of overall health
- HRQoL instruments provide a holistic approach to quantifying and assess the burden of disease
- HRQoL measures are typically divided into two categories namely
  - Generic, and
  - Disease-specific measures

# WHY STUDY HEALTH RELATED QUALITY OF LIFE?

- Morbidity, “Local Social Value”, “Patient Reported Outcomes” - *essential* to policy impact
- In a recent review commissioned by the WHO, they found that TB has multiple negative impacts on adolescents that persist well beyond successful treatment outcomes
  - Improving quality of life for tuberculosis survivors has become a fourth pillar of WHO End Tuberculosis Strategy.
- No disease-specific measure for children and adolescents with TB living in LMICs has been developed.

# WHY DO WE STUDY HEALTH RELATED QUALITY OF LIFE?

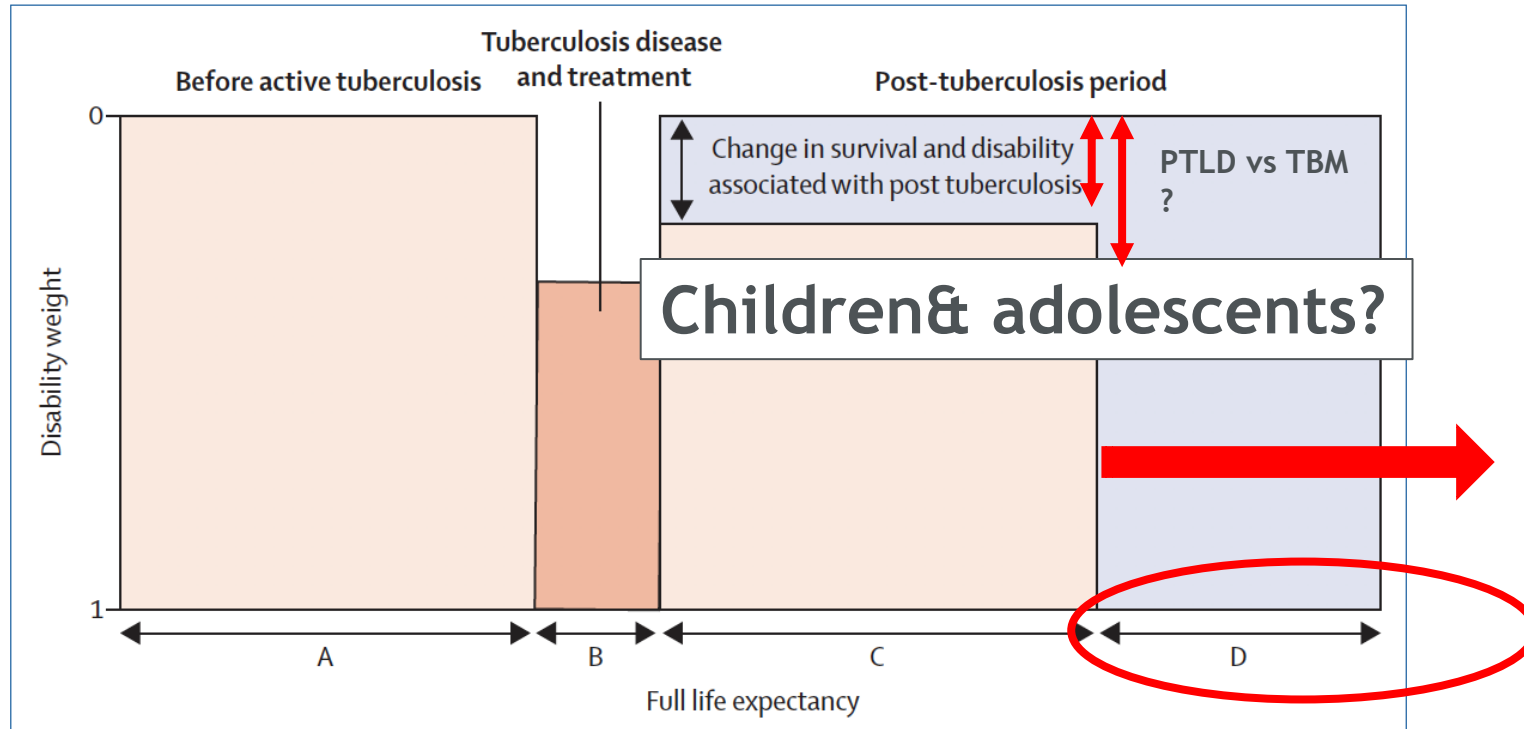


Figure: Illustration of post-tuberculosis DALY loss for a typical survivor of pulmonary tuberculosis treatment in India without HIV infection

# THE AIM AND PURPOSE OF THE STUDY

## Aim

- To chart the available generic and disease-specific HRQoL measures for children 0-18-years-old.

## Purpose

- To identify key components of these measures to inform the development of a novel HRQoL tool for young children with respiratory illnesses, including TB, living in LMICs

# METHODS

- Search strategy
  - Databases: PubMed, EBSCOhost and PsycArticles
  - Grey literature: Google (limited to first 10 pages)
  - Screening, selection of articles, and data extraction by 2 independent reviewers

## Variation of the keywords used

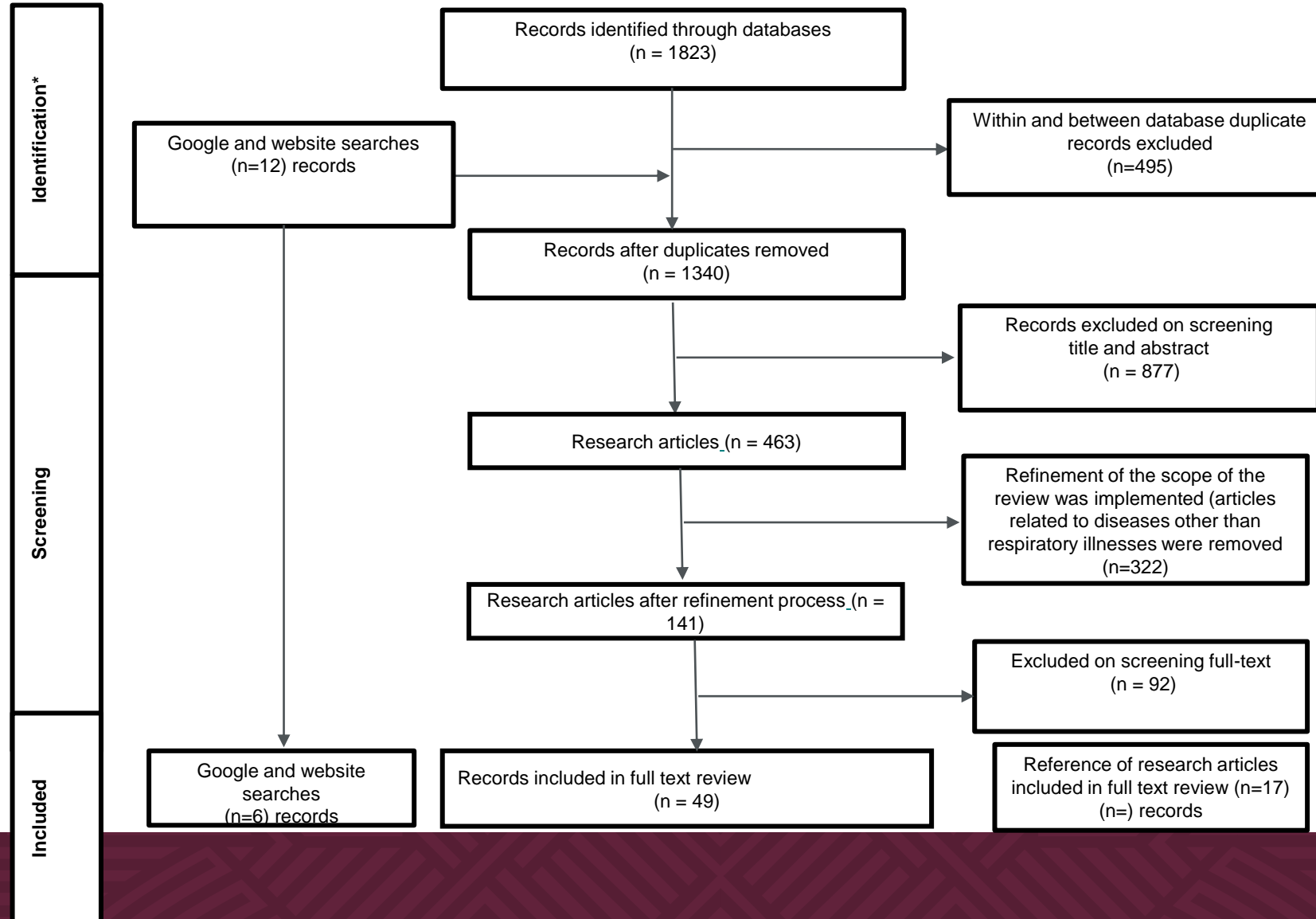
‘quality of life’, ‘health-related quality of life’, ‘wellbeing’,  
‘questionnaire’, ‘instrument’, ‘measure’, ‘children’,  
‘toddler’, ‘paediatric’, ‘child\*’, ‘develop’ or ‘validation’



# METHODS

- **Selection of studies**
  - Studies about the development of a HRQoL measure
  - Studies about the validation of HRQoL measure
  - Studies about development and/or validation of respiratory illnesses and generic measure
- **Study designs**
  - Qualitative and quantitative

# IDENTIFICATION OF STUDIES VIA DATABASES



# FINDINGS

- **Age range**

- Of the 20 generic HRQoL measures, four measures were for children aged 0-5-years-old.
- Of the 21 disease-specific HRQoL measures, Only one of the disease-specific measures was designed specifically for children aged 0-5-years.

- **HRQOL Domains**

- The most measured domains for children aged 0-5-years-old included physical, emotional, cognitive, and social functioning.
- Other, less common domains, for children aged 0-5-years- old included communication and sleeping.

# FINDINGS

- **Respondents**

- All five measures applicable to 0-5- years-old , and they were all by were designed for parent proxy reporter respondents.

- **Country of origin**

- We found one generic measure that was developed within an LMIC context (TANDI) while another (EQ-5D-Y) was validated/translated in an LMIC context.
- We found that none of the disease-specific measures of HRQoL has been developed within an LMIC context.

# LESSONS LEARNED

Age ranges in the available measures do not align well with children 0-5-years-old

HRQoL tools encompass a broad range of domains and items, with inconsistent definitions and criteria.

Considerable overlap among the domains and items

Developmental appropriateness of measures is not adequately considered

The responses from parents/caregivers lack standardisation.

Difficulties arise in translating HRQoL measures.

# CONCLUSION

- We confirmed that there is currently no disease-specific HRQoL tool specifically designed for children with respiratory illnesses, including TB and PTLD, in LMICs.
- An urgent need for an HRQoL tool in young children with respiratory illnesses in high TB burden settings.
- This new measure should consider essential aspects such as childhood development milestones, extended social networks, changes in behaviour, and other observable changes that are significant in LMICs.

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EDCTP



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QUESTIONS?

**THANK YOU**

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