

# Navigating Ethical Waters: Enhancing Research Ethics Committees Approaches in Child-Centred Research

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## 01. Introduction

- Research Ethics Committees (RECs) are responsible for protecting participants' rights and welfare.<sup>1</sup>
- REC members may not be closely connected to the research context or have experience working with certain populations, which leads to unrealistic demands, especially in research involving children.<sup>2</sup>
- For child-focused research, there is a need to balance protection with recognizing children's emerging autonomy and agency, but REC processes often exclude children's voices.<sup>3, 4</sup>
- Existing ethical guidelines are largely biomedically oriented, which challenges the evaluation of social research methodologies and may limit academic freedom.<sup>5</sup>

## 04. Results

Phase I: 8 studies met the criteria

Study	Summary	Country
<b>Theme 1: Composition &amp; traits of REC members</b>		
1 Taplin et al. (2022a)	Characteristics of REC Members	Australia
2 Norberg Wieslander et al. (2023)	Role of REC members in child research.	Sweden
3 Harger & Quintela (2017)	Social science researchers should serve on IRBs	N/A
<b>Theme 2: Required knowledge &amp; training needs</b>		
1 Taplin et al. (2022a)	Experience and expertise	Australia
2 Norberg Wieslander et al. (2023)	Experience of REC members in child research.	Sweden
<b>Theme 3: Process &amp; criteria used to review</b>		
1 Strode et al. (2018)	Different consent approaches and the legal liability of RECs of accepting these approaches	South Africa
2 Armijo & Willatt (2024)	The protectionist tendency of ethics committees.	Chile
3 Taplin et al. (2022a)	REC Activities and Assessments of Applications Involving Children	Australia
4 Parsons et al. (2015)	Challenge existing methods of informed consent and share information about REC and institutions practices with researchers and public.	UK
5 Taplin et al. (2022b)	Approval and denial process of paediatric research	Australia
6 Harger & Quintela (2017)	Reduce the widely different standards being used by different IRBs	N/A
7 Powell et al. (2020)	Building trust between researchers and REC to enhance children participation in research, and the factors affecting this participation.	Australia
8 Norberg Wieslander et al. (2023)	Criteria used to process child research	Sweden
<b>N/A: information is not available</b>		

## 02. Objective

**Phase I:** Conduct a rapid literature review on the composition, roles, and background training of REC members, as well as the complexities of the REC review process for social research involving children.

**Phase II:** Inventory available ethics training programs for REC members in Canada and internationally, identifying gaps in training specifically related to social research involving children.

## 03. Methodology

**Phase I:** Literature search for studies on the REC in child-focused non-clinical/biomedical research from January 2015 to January 2024.



**Phase II:** Online search of training programs offered to REC members in high-, middle-, and low-income countries

## Phase II:

- **Total Programs:** 23, from Canada, USA, Australia, UK, and others (Fig. 1).
- **Core Topics:** Focus on Human Research Ethics, Informed Consent, and Vulnerability.
- **Availability:** Most programs offered online and in English; some available in French, Spanish, and Korean. 13 programs were offered internationally, but 10 were only for the locale audience
- **Specialization:** 10 programs address vulnerable populations; only 3 do so comprehensively.
- **Formats:** Includes online modules, webinars, live sessions, and case studies.
- **Duration:** Ranges from 1.5 hours to several months, with longer training offered in low- to middle-income countries.

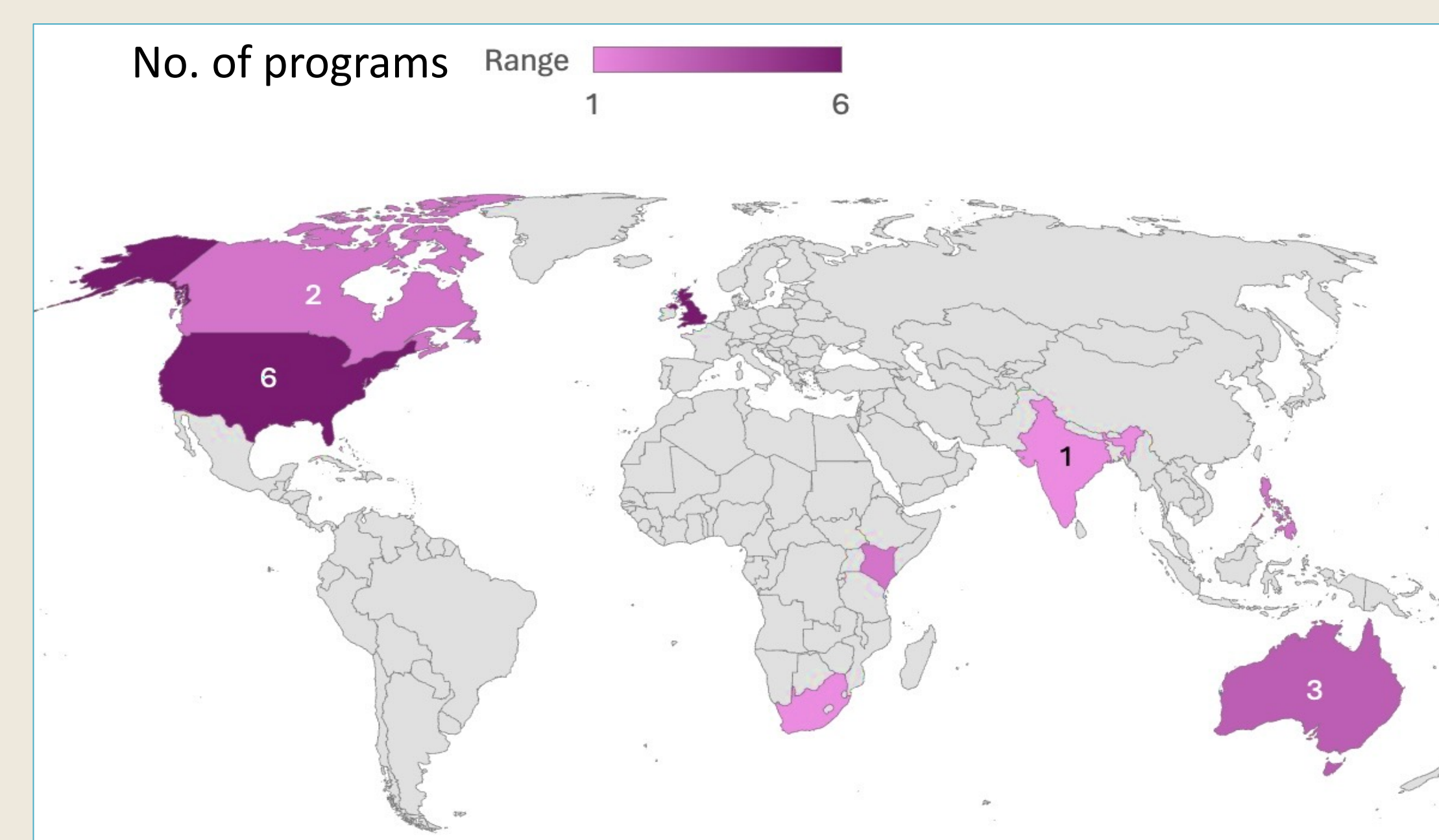


Fig.1 Geographic distribution of training programs for REC members

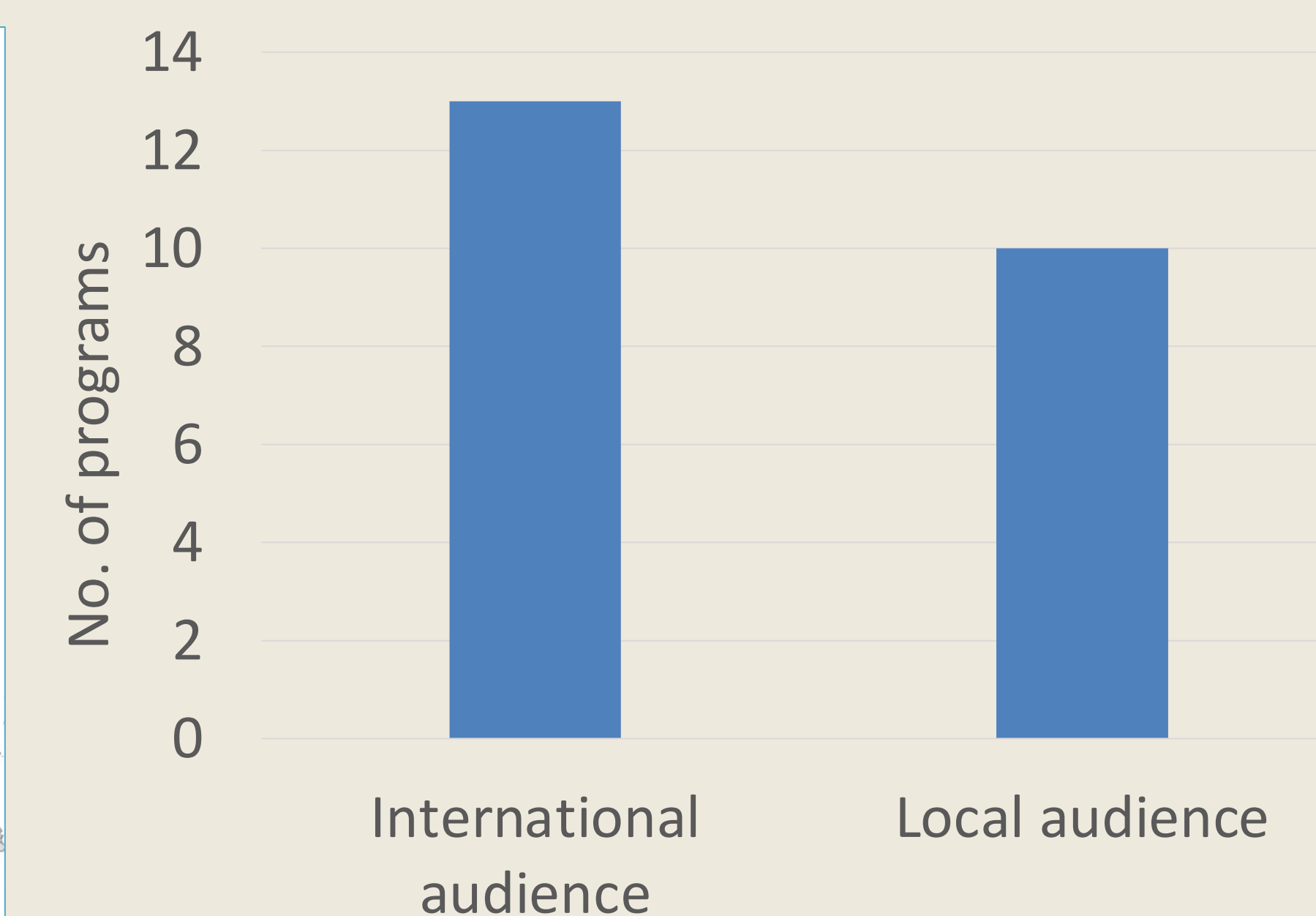


Fig. 2 Program availability by type of audience

## References

1. Tsan, 2021
2. Nichols, 2015
3. Hibbin et al., 2018)
4. Harger & Quintela, 2017
5. Davies, 2020

## 05. Conclusion

- There is a critical need for specialized training programs for REC members.
- Enhancing REC members' competencies can lead to more contextually appropriate ethical reviews.
- There is an urgent need for more comprehensive data on REC practices and their impact on child-centred research.

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