

Who is sitting on the research ethics committee table of child-focused research?



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Introduction

Research involving human subjects, particularly children, requires careful ethical consideration. Research Ethics Committees (RECs), also known as Institutional Review Boards (IRBs), are the ethical gatekeepers of the research world. Their rule is to protect participants' rights and welfare.^{1,2} This scrutiny intensifies for child-focused research due to the perceived heightened vulnerability of children who, legally and ethically, require additional protection to ensure their rights are prioritized and their voices heard. The REC's task is two-fold: to protect the child while respecting their emerging autonomy and agency in research participation.³

The composition and expertise of REC members are pivotal, as they bring their professional and personal experiences to the decision table. However, despite their critical role, RECs are often not closely connected to the research settings. This distance from the research site makes RECs evaluate research proposals without considering the study context and approving or rejecting a project based on the RECs' experience and ethics guidelines.⁴ This is particularly the case in research involving children, where their voices are usually absent and not heard. In addition, RECs often consider all children to be vulnerable since, in many contexts, children cannot provide consent or protect their rights, so RECs try to protect children by excluding them from research.

Health and biomedical disciplines have primarily influenced the establishment of regulatory frameworks. To the point that social science and other research are evaluated against the same ethical standards despite variances in research methodologies and analytical approaches.⁵ This has occasionally resulted in a skewed focus on consent processes rather than a comprehensive risk-benefit analysis tailored to the unique contexts of children's research.

Objectives and Methods

This paper summarizes a literature review regarding the composition, roles, and background training of REC members and the complexities of the REC review process, particularly as they pertain to research involving child participants.

A literature search of Psych Info and Scopus databases was conducted for articles published between January 2015 and January 2024. Only studies relevant to social sciences (i.e., anthropology, sociology, social work, psychology, and childhood studies) were included. Clinical and biomedical studies were excluded. Subject headings and terms used included research ethics, committee, ethics review, ethics committee, institutional review board, ethics review, competence, performance, roles, child, pediatric, adolescent, and youth.

Discussion

Composition and traits of REC members

- Most REC members received and were available to receive ethics training. However, specialized training and guidelines in child-led research were rare.
- Even when a public representative is among the REC to ensure transparency and that children or public perspectives are present during the process of decision-making, the law does not enforce that their voices be heard and implemented at the decision table.
- The diverse backgrounds at the decision table were seen as an asset and enriched the REC experience.

Required knowledge and training needs

- Researchers highlighted the importance of ethics competence and training among REC members.
- Although the law and the guidelines are the basis for approving or rejecting research, REC members still need to work on having close perspectives and definitions when interpreting, translating, and applying the law and guidelines for child research, for example, the definition of vulnerability. They argue that specific skills and competencies are required.

Conclusion and next steps

- REC detachment from research contexts and a predominant biomedical influence have led to calls for more contextually informed guidelines.
- This paper emphasizes the need for specific training for REC members, focused on child psychology, development, and legal frameworks to navigate the balance between protection and participation.
- A consistent challenge remains in defining and applying the concept of vulnerability. This paper advocates for a paradigm shift towards a more inclusive understanding of vulnerability, one that recognizes children's capacities and the varying degrees of risk within different research settings.
- By enhancing the competency of REC members, the research community can better serve children's interests and contribute to an ethically sound and robust body of knowledge.
- The limited available research highlights an urgent need for more comprehensive data on REC practices and their impact on child-focused research.
- Next, we will identify and review the curriculum of training resources available for REC members focused on social science research around Canada and internationally.

References

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Results

A total of 1808 publications were identified. An Endnote database was created with all relevant sources. After full-text screening, 8 sources were retained and thematically analyzed manually to extract characteristics of REC members, review processes, and knowledge gaps (Table 1):

Table 1: Included studies by theme		
Study	Summary	Country
Theme 1: Composition and traits of REC members		
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
Theme 2: Required knowledge and training needs		
1 Taplin et al. (2022a)	Experience and expertise	Australia
2 Norberg Wieslander et al. (2023)	Experience of REC members in child research.	Sweden
Theme 3: Process and criteria used to review		
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. REC Activities and Assessments of Applications Involving Children	Chile
3 Taplin et al. (2022a)	Challenge existing methods of informed consent and share information about REC and institutions practices with researchers and public.	Australia
4 Parsons et al. (2015)	Approval and denial process of paediatric research	UK
5 Taplin et al. (2022b)	Reduce the widely different standards being used by different IRBs	Australia
6 Harger & Quintela (2017)	Building trust between researchers and REC to enhance children participation in research, and the factors affecting this participation.	N/A
7 Powell et al. (2020)	Criteria used to process child research	Australia
8 Norberg Wieslander et al. (2023)		Sweden
N/A: information is not available		

Process and criteria used to review

- Vulnerability is under-defined.
- There is a common challenge between protection and participation.
- REC tends to choose to be protectionist, believing that all children are vulnerable.
- It is recommended that social science researchers be involved in the REC, which can bring the missing perspective to light and acknowledge the differences between vulnerability in social science and biomedical research.
- There is limited information describing the guidelines and processes employed by RECs to evaluate child research and the accessibility of this information by the public.
- Child-focused research is often considered potentially high-risk and, hence, more susceptible to full ethical review, even when the study was considered low-risk by researchers. The full revision process for child-focused research is more common when REC members have less experience in research with child participants, while more experienced REC have more confidence to conduct delegated review.

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