



Understanding **ETHICAL ISSUES** of Research Participation from the Perspective of Participating Children and Adolescents: A Systematic Review *

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BACKGROUND



- Society must balance the inherent vulnerability of children and adolescents with the necessity to research their unique needs and perspectives
- Historically, standards for ethical research arose from general ethical principles, without considering the heterogeneity of children and adolescents

AIM: To examine ethical issues inherent in research with children and adolescents from their perspective as participants, including: risk perception, assent and parental consent, impact of research participation, and incentives.

METHODS

- Systematic review conducted using Long et al. framework (2002)
- PubMed, CINAHL, and EBSCOhost were searched with terms 'research ethics' and 'child or pediatric or adolescent'
- Limitations: English language, Year of publication 2003–2014, Humans, Abstract available, and Age birth–18 years

DISCUSSION



RISK PERCEPTION

- Trust in researchers was a significant contributing factor to children's and adolescents' participation in research, and shaped their assessments of risk.

ASSENT AND PARENTAL CONSENT

- Even young children can understand essential elements of research, although individual variability exists in levels of understanding.



IMPACT OF RESEARCH PARTICIPATION

- Research participation was viewed as mainly beneficial by children and adolescents.

INCENTIVES

- Incentives were often viewed positively, although concerns of possible undue influence were expressed.



CONCLUSIONS

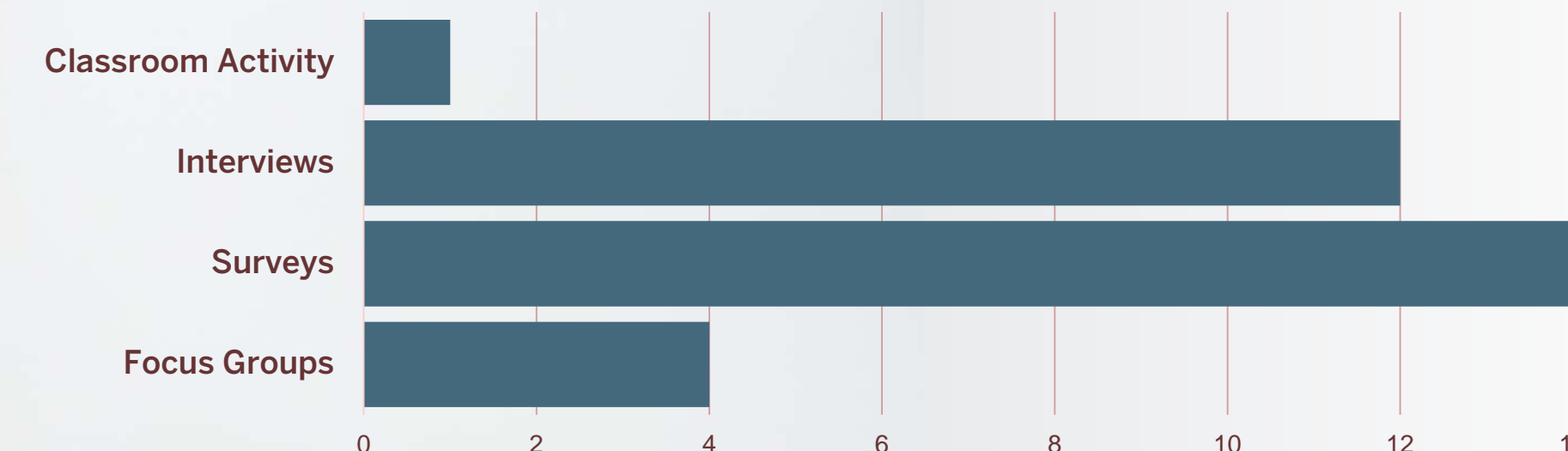
- Assent processes and instruments need to be created with input from child development specialists and piloted with children.
- A priori consultation with adolescents and parents can provide guidance for developing consent and assent procedures.
- All research with children and adolescents could include a short off-study interview or survey to gauge experiences in the study.
- An important gap in the literature is whether children and adolescents, beyond simply understanding their research rights, are capable of applying this knowledge and exerting their research rights.
- Age and vulnerability status needs to be considered when selecting incentives.
- Assessment of risk is an ongoing process, beyond obtaining assent and / or consent.



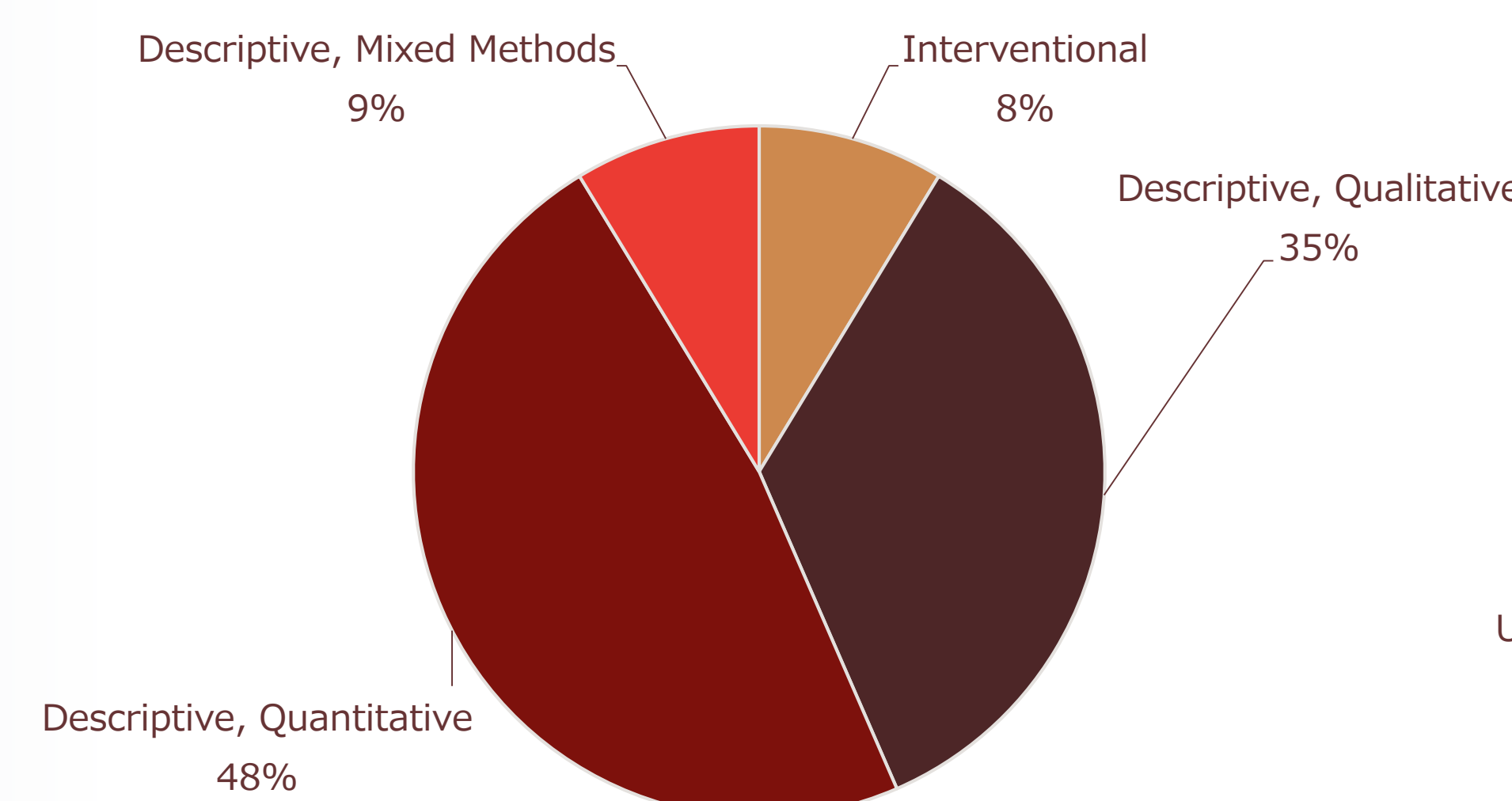
SAMPLE

- Initial searches identified 5,681 articles; 1,372 articles remained after limitations applied; all were screened
- **23** empiric studies formed the final sample 1-23

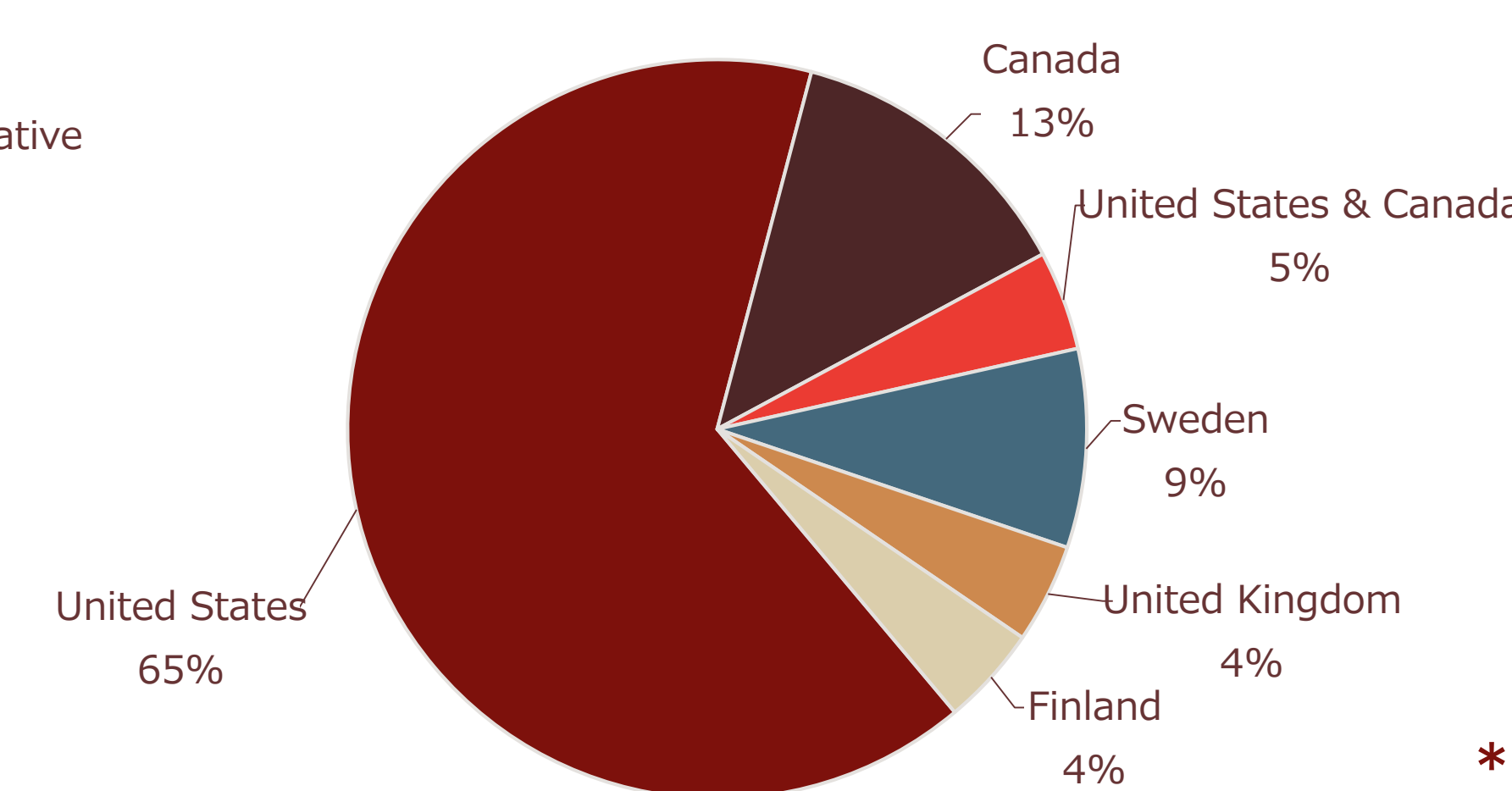
DATA COLLECTION METHODS (Frequency)



STUDY METHODS



COUNTRIES STUDIES CONDUCTED



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* Crane, S. & Broome, M. (in press). Understanding ethical issues of research participation from the perspective of participating children and adolescents: A systematic review. *Worldviews on Evidence-Based Nursing*.

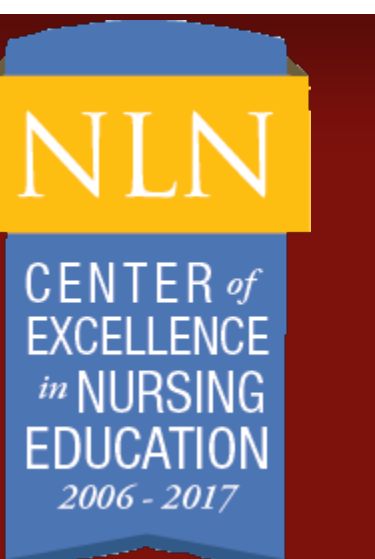
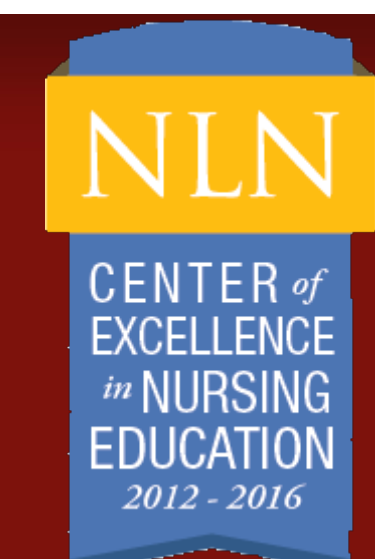


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