Understanding **ETICAL 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.

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.

**AIM:**

**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

**SYSTEMATIC REVIEW**

- Study inclusion criteria:
  - Empiric studies formed the final sample 1-23
- A priori consult 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.

**REFERENCES**

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**DATA COLLECTION METHODS (Frequency)**

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<th>METHOD</th>
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<tr>
<td>2. Focus Groups</td>
<td>11%</td>
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<tr>
<td>3. Surveys</td>
<td>11%</td>
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<tr>
<td>4. Descriptive, Mixed Methods</td>
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**COUNTRIES STUDIES CONDUCTED**

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<td>Ireland</td>
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<tr>
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**STUDY METHODS**

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

**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.
- Assessments of risk is an ongoing process, beyond obtaining assent and / or consent.