Growing up in research: children’s involvement in longitudinal research.

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Aims

To consider

- The value of children's longitudinal research
- The current practices in children’s longitudinal research reported in literature
- The conceptual challenges of “growing up” in research
Involve to evolve: registry and database of children’s palliative care needs

https://mds-web.bham.ac.uk/involvetoevolve

Increasing number of registries/ databases/ biobanks $^{1,2}$ Producing new insights$^{1,3}$

Recognition of children and young people as social actors in research$^{4}$
Literature review: Method

- Electronic database search (EMBASE, Ovid Medline (R), and PsycINFO) plus snowballing references

- Inclusion:
  - 2000- November 2011
  - Written in English
  - Relevant primary data reports in peer reviewed journals

- Exclusion
  - Over 18’s
  - Cross sectional research
  - Opinion or non evaluation papers
PRISMA phases of the systematic review adapted from Moher et al ⁵

**Identification**
- Records identified through electronic database search = 1090
- Additional records = 1 (from reference lists)
- Records after duplicates removed = 898

**Screening**
- Records screened = 898
- Records excluded = 734

**Eligibility**
- Full text papers assessed for eligibility = 164
- Full text papers excluded = 149
  - Rationale
    - Not primary research
    - Not relevant to research question
    - Cross sectional studies
    - Adult populations not child 0-18

**Included**
- Studies included = 15

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CASP Qualitative evaluation

- CASP Qualitative questionnaire\(^6\) used although some studies included quasi/Quantitative methodology
- Methods and methodologies variable
- Hard to reach groups possibly under represented
- Researcher's role and relationships often not defined
- Data analysis often poorly or not described at all
Themes

- Acceptability
- Motivation to participate
- Consent and confidentiality practices
- Negotiating parental rights and child autonomy
- Clinical Priorities
Acceptability and Motivation to participate

- **Acceptability**
  Low refusal rates (0.57-10%\textsuperscript{8}) if transparent specific consent and kept informed how data is used

- **Motivation to participate**
  Children and carers showed both individual and altruistic motivation. Clinicians recognised the power of data collected over time
Consent and confidentiality practices and Negotiating parental rights and child autonomy

- Similar challenges but variable solutions
- Variable practice consent, re identification and managing negative findings (increased risk)
- Age of child consent/assent variable (8-10)
- No consistent view on parental rights/responsibilities and child autonomy/rights
Clinical Priorities

- Perhaps biggest threat to collecting data - engaging clinicians
- Loss data opportunities 15-56.5%\textsuperscript{7,11}
- Barriers to consent \textsuperscript{12}:
  - 80% timing of approach
  - 63% availability of trained staff
  - 46% sensitivity of the issue
  - 38% difficulty managing consent process
  - 27% maintenance of paper trail
Challenges of “growing up” in research

- Maturing cognition
- Recognition of agency\textsuperscript{13} vs risk of “losing” data
- Withdrawal of data (which may have been proxy consented) already used over many years\textsuperscript{9,14}?
- Rights regarding negative findings/increased risks\textsuperscript{9}
Challenges of “growing up” in research: Who “owns” the research child?

- Parental rights and responsibilities
  - Gatekeeping
  - Managing negative findings/increased risks
- Children’s rights
  - A child’s voice?
  - Their body, their health
- State responsibilities
  - Data to deliver services/UN convention rights of the child
  - Nudge towards self reliant citizens?
Conclusions

- Child health registries, databases and bio banks are increasing in number and have potential to reveal new insights into children’s health.

- There is no evidence based consensus as to when children can or should consent/assent to research participation nor on how to negotiate parental rights and child rights.

- Research practices in children’s longitudinal studies are variable.

- Further research should aim to build consensus on how to manage “growing up” in research.

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References


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