Ethical Research with Children
International project led by
Childwatch International Research Network
and UNICEF Office of Research, Innocenti

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Presentation Overview

- Brief background to our ethics work
- International survey ‘headlines’
- The burgeoning ethics literature
- Draft Ethics Charter & Guidelines
- Relevance for research in relation to VAC?
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Aim of our ethics work?

To improve understandings of the ethical considerations in research with children in different international contexts

To identify relevant, respectful, robust, creative ways to respond to these issues and concerns

To develop initiatives that support researchers and other research stakeholders to improve their ethical understandings and practice
What have we done so far?

An online survey (2010) to identify ethical issues and challenges in undertaking research with/for children in different international contexts

A meeting of 17 child and youth research experts held in London (July 2011) to review the findings

A comprehensive literature review reporting on existing evidence about ethical considerations with child research (finalised 2012)
On line survey – 257 respondents across 46 countries

15% in 22 Majority world (L-M income) (N=39)

85% in 24 Minority world (H income) (N=213) (5 didn’t indicate country)

Females notably overrepresented (77%) – differed significantly across countries

Almost 80% aged between 30-60 years
The survey...

64% had 6 or more years experience in research

More Majority world (44%) than Minority world (34%) had < 6 years research experience

51% include children’s views in research ‘very often’ – similar across Majority & Minority countries
A ‘child’ is defined and widely recognised in most countries as under 18 years of age – although ‘child’ varies with social, cultural, legal and policy contexts.

Children’s views are included in research at least some of the time in most of the participating countries.

Different stakeholders are perceived to place differing importance on the inclusion of children’s views.

Researchers use a wide range of methods to gain children’s views.

Most researchers require both parental and child consent.
The three major influences on the way researchers do research with children are:

- researchers’ own ethical principles
- their previous research experience
- their institutional ethics requirements
Nearly one third of Majority world researchers are not aware of any national ethics standards, guidelines or requirements.

Almost half of Minority world researchers consider ethics standards/requirements to be a significant influence on the way they approach research with children.

The issues limiting researchers’ capacity to include children’s views in research were:

- concerns about anonymity;
- families/communities not wanting children to participate;
- confidentiality;
- risk-averse/ ‘overly protective’ ethical review processes;
- sensitive topics that may upset the child.
12% indicated no training at all for undertaking research concerning children

10% indicated they had extensive training

59% of researchers indicated a combination of formal and informal training for research with children

Participants in Majority world countries were significantly more likely to have extensive training (23%) than those in Minority world (9%)

Participants indicated a range of resources that are/would be helpful in improving their ethical understandings and practice
Children’s views are included in research at least some of the time in most of the participating countries.

Different stakeholders are perceived to place differing importance on the inclusion of children’s views.

Nearly one third of the Majority world researchers are not aware of any national ethics standards, guidelines or requirements.

Almost half of Minority world researchers consider ethics standards/requirements to be a significant influence on the way they approach research with children.
Researchers want more support with navigating concerns about anonymity; consent; confidentiality; approaching sensitive topics; payment; risk-averse/‘overly protective’ ethical review processes.

‘Training’ of researchers is ad hoc, ‘uneven’

Participants indicated a range of resources that are/would be helpful in improving their ethical understandings and practice.
Child research ethics is a complex and vexed issue

The increased emphasis on children’s participation in research needs to be translated into workable ethics

Considerable questioning of assumption that ‘ethics’ can be reduced to codified sets of principles

Importance of approaching ‘ethics’ as promoting the exploration and examination of ‘dilemmas’ rather than simply as rules about conduct and ‘tick box’ exercises

Methodology and ethics integrally linked

‘Ethics’ is ongoing throughout the research process

Need for more focus on issues of reflexivity and power
‘Headlines’ from lit review…

The key ethical issues widely documented in the literature relate particularly to:

• Informed consent
• Protection of children
• Anonymity and confidentiality
• Payment of research participants

Need to consider more closely how these are played out in different contexts…
What are we currently doing in response?

Joint project with UNICEF IRC & Childwatch International to:

Develop an *International Charter and Guidelines* for ethical research with children

Identify cost effective, flexible approaches to *training/capacity building*

Explore the feasibility of a *web-based repository* for sharing information, publications and resources
To date we have completed…

An email consultation with the international child research community via well-known Internet-based networks in December 2011 – 66 respondents

Collation, review and analysis of existing ethics systems, guidelines, practices and resources

Detailed mapping of existing Charters and Guidelines

Commissioned a review on relevant philosophical ethics and governance systems and practices

Convened an international expert project advisory group

Extensive consultation planned with researchers and other stakeholders in different international contexts
What are the key emphases in the draft Charter and Guidelines?

**Rights** – researchers have a responsibility to respect the rights, wellbeing and human dignity of children, regardless of context.

**Relationships** – with self, children, parents, community, other researchers, funders, policy makers etc.

**Reflexivity** – capacity to critically reflect on how assumptions, beliefs, values and attitudes impact on practice.
The draft ‘Charter’ commitments...

Ethics in research with children is everyone’s responsibility

Research with children must respect children and their views

Research with children must be just and equitable

Research with children must benefit children

Research with children must never harm children

Research with children must always seek children’s consent

Researchers must continually reflect on their practice
Ethical areas in the draft Guidelines

1. Harms and benefits
2. Child protection
3. Informed consent
4. Privacy and confidentiality
5. Payment and remuneration
Format of the draft Guidelines

Each of the five ethical areas is explored in relation to:

1. Key ethical considerations (including links to relevant CRC articles)
2. Existing guidance
3. Ethical challenges
   1. Case study ‘dilemmas’
   2. Questions to guide ethical research
   3. Practical ‘flashing light’ do’s and don’ts
Harms and Benefits

How are potential harm and benefits assessed in research with children?

How is harm minimised or eliminated in research with children?

How are children’s rights to protection and participation balanced?

What are researchers’ responsibilities if children show signs of harm or distress?
Child Protection

How do you protect children from potentially abusive researchers?

What if there are not appropriate follow up services to refer children or parents to?

What are the limits to confidentiality when there are child protection concerns?

What about preventing children disclosing care and protection issues?
Informed Consent

Are all children capable of providing consent?

How can researchers ensure that children are fully informed?

How can researchers ensure that children’s consent is freely given?

Is parental/adult consent always required in research with children?

What if researchers are unable to obtain parents’ consent?

Is it ethical to hide or disguise the purpose of the research?
Privacy and Confidentiality

Which location best supports privacy for children in research?

How does the presence of others impact on children’s privacy and information gathering?

How can privacy be provided for children if this is not the usual social/cultural practice?

What if children do not want to be anonymous in dissemination of research findings?

What are the challenges related to technological developments?

What are the limits to confidentiality in the light of safety concerns?
How can payment of research participants be addressed in locally specific ways?

What are the additional considerations related to payment in situations of acute poverty?

What are the implications within the community of payment to research participants?
Questions to Guide Ethical Research with Children…..

Considerations regarding the:

Children

Researcher

Always starting with…

Does this research need to be done?
How does the proposed research respect the human dignity of children?

In...

• Planning and Preparation
• Designing the Research
• Collection of Data
• Analysis, Writing and Dissemination
Considering particularly the VAC research context...

How are the needs of the research community working in the area of VAC best met regarding ethical guidance?

Could the draft Charter and Guidelines be useful in regard to research on VAC?

Is there scope for sector or issue-specific VAC guidelines to supplement the draft Charter and Guidelines?

Are there other means of supporting and improving understandings and practice in relation to ethical research on VAC that would be more useful?