

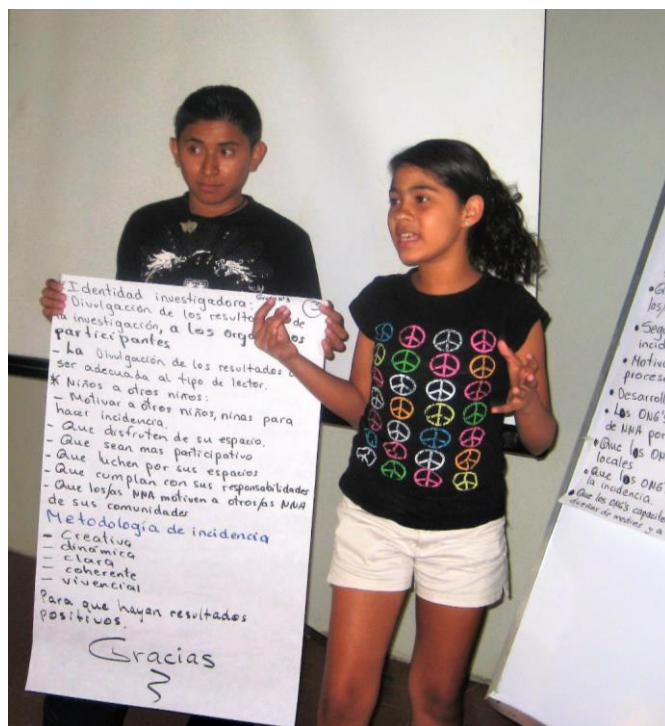


Participatory Research with Children

Dr Harry Shier

COVISION Project

UCD School of Nursing, Midwifery
and Health Systems



Overview

1. Research ON, ABOUT, WITH and BY children
2. Children as CO-RESEARCHERS
3. Children as RESEARCH ADVISERS
4. A tool to plan or evaluate research with children
5. A few ethical issues
6. A network for support and solidarity in participatory health research



Before I start: The problem of terminology

- 🌐 In the English-speaking world, “**children**” and “**young people**” have no generally agreed definitions and are **culturally-constructed conceptualisations** signifying various culturally-constructed notions.
- 🌐 In the Spanish-speaking world:
 - “**Niña/niño**” (child”) is 0-12 years.
 - “**Adolescente**” is 13-17 years.
 - “**Joven**” (young person) is 18+, i.e. a young adult.

These are **legal definitions**, which correspond to both **everyday language** and **academic discourse**.



- 🌐 In the children’s rights field, both academics and activists commonly follow the **UN Convention on the Rights of the Child** in classifying all under-18s as “**children**”.

3

1. Research ON, ABOUT, WITH and BY children



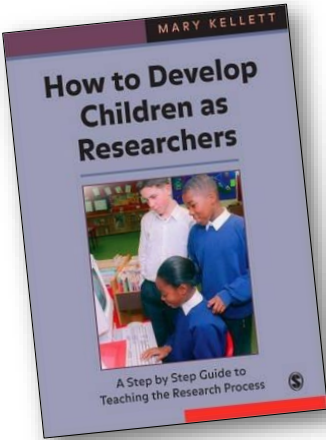
Mary Kellett was founder and Director of the Children’s Research Centre at the Open University in the UK. She identified four types of research involving children in the research literature:



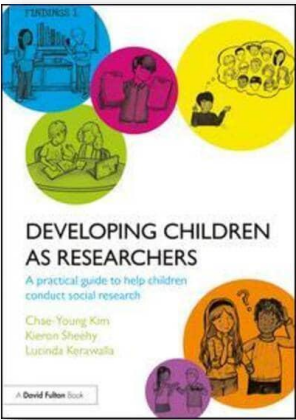
- ✂ Research **ON** children;
- ✂ Research **ABOUT** children;
- ✂ Research **WITH** children;
- ✂ Research **BY** children.



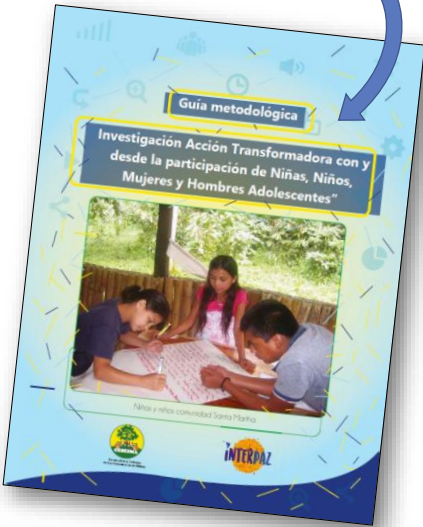
If you are interested in research **BY** children...



(Kellett, 2005)



(Kim et al, 2017)



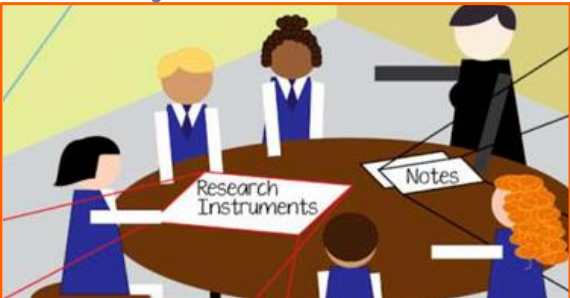
(Shier and Hernández Méndez, 2021)

Practice manual: Transformative Action-Research with and by children and adolescent girls and boys.

Back to research **WITH** children



Children as **DOERS** of research, working in collaboration with adult researchers (co-researchers)



Children as **RESEARCH ADVISERS**: Advising adult researchers on the doing of the research but not actually doing it themselves

2. Children as CO-RESEARCHERS

AN EXAMPLE FROM MY OWN
EXPERIENCE:

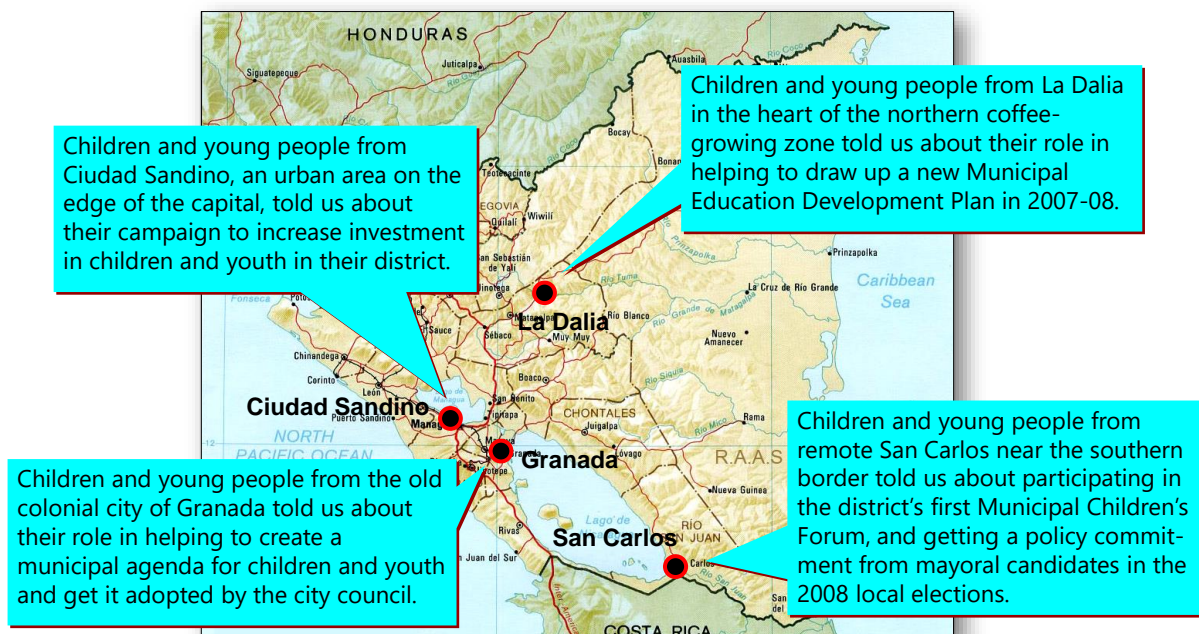
**How children and young
people influence public
policy in Nicaragua?**

*(CESESMA/University of the North of
Nicaragua 2010)*



Adults and children collaborated to analyse four case studies of experiences where children and young people's direct influence on public policy was clearly documented and attested by public officials.

We selected four contrasting case studies, from different parts of the country:



We investigated these four case studies through:

1. Interviewing at least one key decision-maker (e.g. town mayor, senior education ministry officials) in the four local authorities, in order to confirm beyond doubt that the authority's public policy decisions were influenced by the young people's proposals.
2. Focus groups with children and young people who had participated in the experience.
3. Focus groups with adult professionals who had helped facilitate the processes.

- Two-day residential bringing together children and adults from all four areas to consider the findings and jointly formulate recommendations.



- Final “Validation Event” in the capital city: Representatives chosen by each group of children and young people presented their recommendations in a public arena with NGO leaders, public officials and media present ,

Note how the roles taken by the young people evolved as the research progressed: from focus group participants, to co-researchers, to a public role in presenting the findings and consolidating research impact.

We'll come back to the ethical implications of this later...





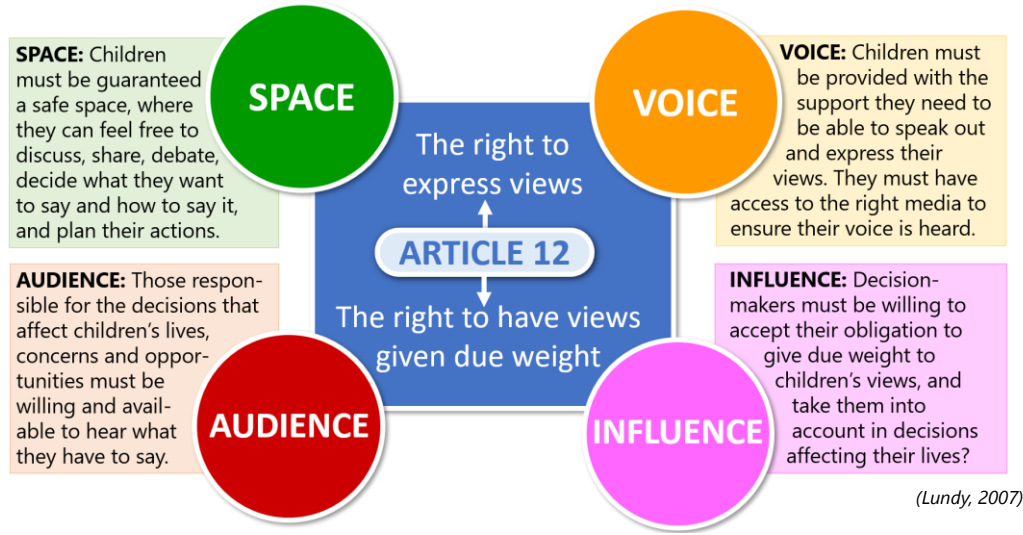
Final report

Child-friendly report



3. Children as Research Advisers

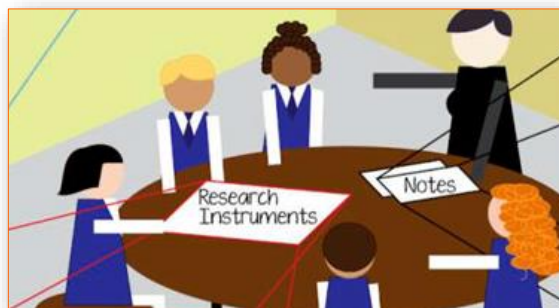
A child-rights-based approach based on Laura Lundy’s model of 4 key elements



Children's Research Advisory Groups (CRAGs)

- Every piece of research is supported by at least one Children's Research Advisory Group (CRAG).
- CRAG members are children and/or adolescents of roughly the same age-range as the research target group.
- CRAG members thus provide insight into the perspectives and perceptions of the target group, which guides the research process.
- CRAG members may advise adult researchers on:
 - formulation of research questions;
 - appropriateness of methods;
 - design of data-gathering instruments;
 - analysis and interpretation of findings;
 - design of dissemination materials and methods.

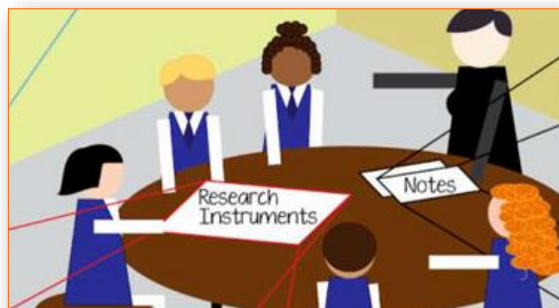
(Lundy and McEvoy, 2012)



15

CRAGs continued/...

- As advisers, CRAG members are expressly excluded from the category of research subjects. They do not provide data for the research.
- This allows children to be engaged in every stage of the research, as appropriate to the circumstances, with a considerable amount of flexibility.
- Time-consuming and complex work such as data-gathering and statistical analysis can be left to appropriately-qualified adult researchers.
- If the circumstances are appropriate, CRAG members can go on to engage with duty-bearers in advocacy activities relating to the research.



16

The COVISION CRAGs

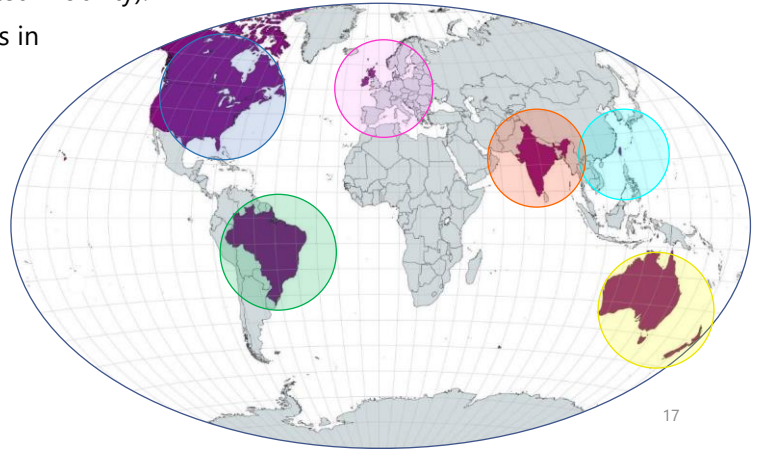


■ Challenges:

- **COVID restrictions:** All interaction has to be online.
- **Risk of excluding those not online** (though working online can also bring unprecedented INCLUSION for those with limited mobility).
- **Global reach:** Multiple partners in incompatible time-zones.

■ Proposal: Regional CRAGs:

- Shared language and similar time-zones.
- CRAGs can collaborate, share, combine, synergise as the project develops.



Learn more about global online CRAGs in practice at the ...

COVISION Webinar series

Wednesday 13 October 2021 (13:00-14:00 Irish time)

Dr Michelle Templeton,

Research Project Coordinator, Centre for Children's Rights,
Queen's University Belfast



Working with CRAGs in international research in the post-COVID digital age

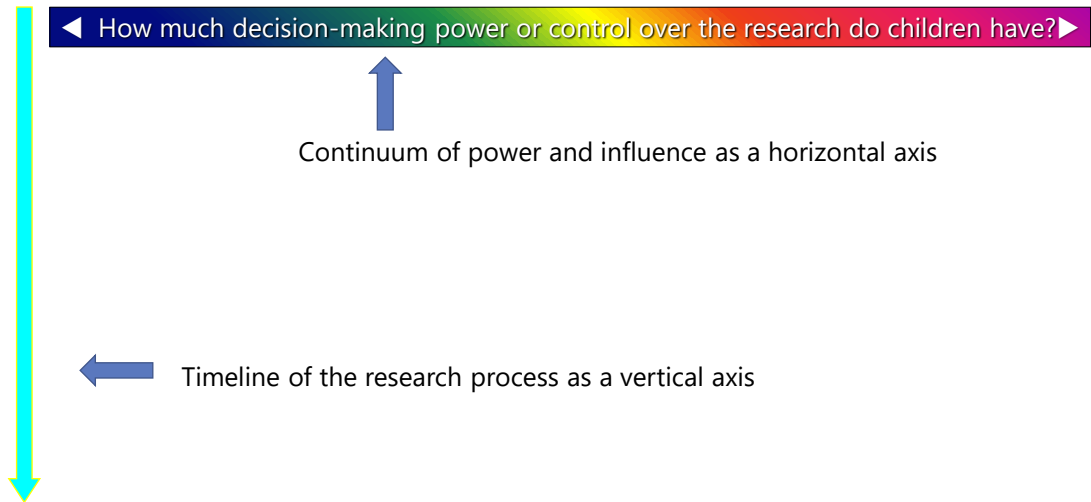
- Focus on youth participation in the **"#COVIDUnder19"** study, a global initiative to involve children in responses to the pandemic.
- Based on the Children's Research Advisory Group (CRAG) approach, working with the young people at all stages of the research.
- Challenges, limitations and opportunities for working online with a diverse international group of young co-researchers from 28 countries during the pandemic.

18



4. A tool to plan or evaluate research with children

BUILDING A MATRIX



FOR THE HORIZONTAL AXIS: LANSDOWN'S SIMPLIFIED TYPOLOGY OF PARTICIPATION

Consultation:

Is when adults ask children for their views, and children are not involved beyond this.



Collaboration:

Is when adults and children work together, sharing roles and responsibilities in planning and carrying out an activity.



Pro-activism (child-led):

Activities initiated, organised or run by children and young people themselves (adults may still provide support, though not always necessary).



Taken from "Every child's right to be heard" (Lansdown 2010): A user guide to UN CRC General Comment 12

THE VERTICAL DIMENSION: PHASES OF THE RESEARCH PROCESS AS A TIMELINE

(Based on Kumar, 2014)

-
1. Identify a research question: problem analysis, consultation.

▼

2. Develop research design, select (or develop) methodology, draw up a plan (find funding, resources)

▼

3. Design instruments, seek ethical approval.

▼

4. Identify and recruit participants, obtain consent.

▼

5. Generate data

▼

6. Data analysis: findings, conclusions, recommendations.

▼

7. Produce a report

▼

8. Dissemination of findings: formal publication, wider publicity, media engagement.

▼

9. Advocacy, public mobilisation, campaigning, policy impact, action for social change.



21

COMBINED IN THE MATRIX...

Phases of research process

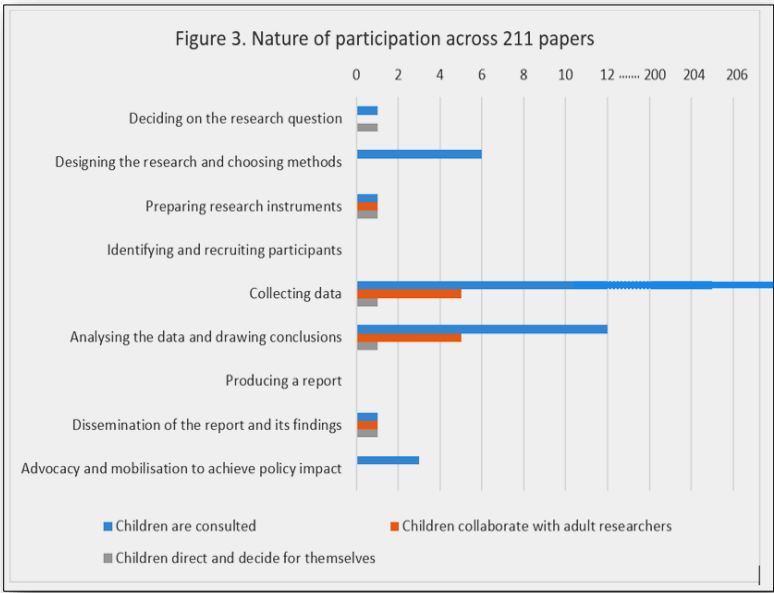
	◀ How much decision-making power or control over the research do children have? ▶			
	Children are not involved	Consulted	Collaborate with adult researchers	Child initiated or directed
Deciding on the research question		Children asked about problems that concern them.	Children and adults jointly define research question.	Children choose their own research question.
Designing the research and choosing methods		Children consulted on what research methodology to use.	Children and adults deliberate and jointly decide on the methodology to use.	Children decide what methodology they want to use.
Preparing research instruments		Children consulted on (and perhaps test) research instruments before use.	Children and adults work together on design of research instruments.	Children create their own research instruments.
Identifying and recruiting participants		Children asked to advise on recruiting participants.	Children and adults jointly identify and recruit participants.	Children identify and recruit research participants.
Collecting the data		Research involves adults interviewing children or surveying their opinions.	Children and adults collaborate on data-gathering activity.	Children organise and carry out data collection activities.
Analysing the data, drawing conclusions		Adults show preliminary findings to children and ask for feedback.	Children and adults work together to analyse data and determine conclusions.	Children analyse data and draw their own conclusions.
Producing a report		Adults consult children on aspects of the final report.	Children and adults work together to produce a report.	Children produce their own report in their own words.
Dissemination of the report and its findings		Adults consult children on how to disseminate findings.	Children and adults collaborate on dissemination and awareness-raising activities.	Children undertake activities to disseminate their findings.
Advocacy and mobilisation to achieve policy impact		Children consulted about possible advocacy actions.	Children and adults work together on plans for advocacy and mobilisation.	Children develop and implement an action plan for advocacy and mobilisation.

Using the matrix to appraise a research process (example 1)

- Applying the matrix to the Nicaraguan research project presented earlier

	◀ How much decision-making power or control over the research do children have? ▶			
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IN 2019 A SCOPING REVIEW LOOKED AT METHODS OF PARTICIPATORY RESEARCH WITH CHILDREN IN AUSTRALIA



In the vast majority of studies reviewed, children were not involved at all outside of the data-collection phase.

Grace et al, "Where are the silences? A scoping review of child participatory research literature in Australia". (Children Australia, 44: 172-186)

Using the matrix to appraise a research process (example 2)

- Applying the matrix to the Nicaraguan research project presented earlier
- The typical experience of children engaging in research (at least in Australia)

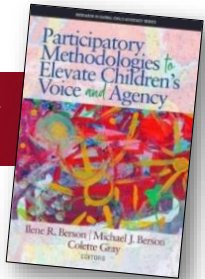
Phases of research process

	◀ How much decision-making power or control over the research do children have? ▶			
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Advocacy and mobilisation to achieve policy impact	✗	Children consulted about possible advocacy actions.	Children and adults work together on plans for advocacy and mobilisation.	Children develop and implement an action plan for advocacy and mobilisation.

THE MATRIX TOOL IS AVAILABLE IN...

Berson, Berson and Gray (2019) "Participatory Methodologies to Elevate Children's Voice and Agency".

Also at www.harryshier.net



- ✗ DO use it as a tool for planning research projects involving children.
- ✗ DO use it as a tool for reviewing and evaluating research projects involving children.
- ✗ DO use it as a check-list to be sure you are not excluding children through narrow thinking.
- ✗ DON'T use it to make judgments about whether any particular approach is right or wrong; it just helps you ask good questions.
- ✗ DON'T be fooled into thinking some kinds of participation are "better" than others. Use the matrix to think about what might work well in a particular situation.

5. Ethical Issues

ETHICAL ISSUE 1: Gatekeeping versus autonomy

- There can be tension between ethical frameworks based on **protection** and the **participation rights** established in the UNCRC (Skelton 2008).
- For example, ethical guidelines may require that children be approached via an adult **“gatekeeper”** such as a school head.
- Children themselves may not want this person to control their access to a research opportunity.

GAGGING THE “VULNERABLE”

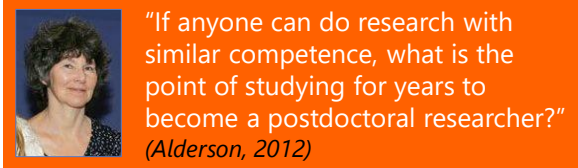
The greatest resistance to the participation of ‘disadvantaged’ children and young people comes, not from the young people themselves, but from professional adults acting as gatekeepers...

By the trick of labelling these young people as ‘vulnerable’, the adult gatekeepers can deny them their right to be heard, by claiming it is in their own best interests. No evidence is needed; the magic word ‘vulnerable’ is sufficient to act as a gag. The same trick is also regularly played on young people with disabilities by their supposedly well-intentioned adult gatekeepers.

Shier, in Corney et al (2020), drawing on the experience of the ReSPECT project at Western Sydney University

27

ETHICAL ISSUE 2: “Academic rigour” versus child participation



Responses to this:

- Providing appropriate training and preparation for child researchers (e.g. Kellett 2005).
- Giving children advisory rather than researcher roles (e.g. Lundy and McEvoy, 2012).
- Developing a more effective model for facilitation and the role of facilitator (e.g. Shier and Hernández Méndez, 2021).



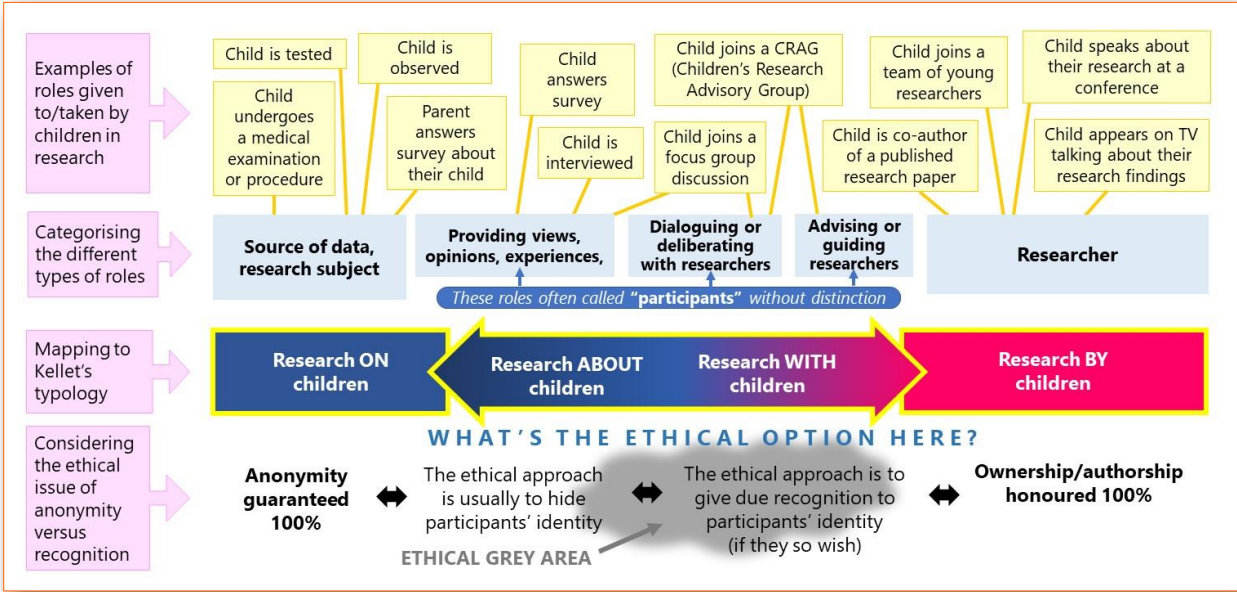
28

ETHICAL ISSUE 3: Anonymity or recognition?

How can we harmonise the dissonance between the guarantee of anonymity we are required to give those children who engage in our research, and children's desire to be seen, heard, identified, recognised and valued for what they contribute?



29



(from Shier, 2021)

30



ETHICAL ISSUE 4: How do we use images?

CESESMA's practice in Nicaragua was to photograph the children's research activities and use the photos (with consent) to document the work, disseminate learning and enhance impact.

But not everyone agrees with this practice...

Learn more about ethical use of images at the **COVISION Webinar series**

Wednesday 16 September 2021 (14:00-15:00 Irish time)

Professor Kay Tisdall and colleagues
University of Edinburgh



Ethical issues in using images of children online in the context of participatory research projects

- Join a conversation on the ethics of using images of children, within and from participatory research.
- Explore questions around ownership, consent, and the legacy of images, particularly when shared through the internet and social media.
- We will share current dilemmas in relation to how we use images of children, seeking to take our debates further and seek to identify ways forward.

31

ETHICAL ISSUE 5: Payment and reward?

Questions to ask...

1. Are you getting children to help you do YOUR research and achieve YOUR goals?

OR

Are you acting as supporter and facilitator to help them do THEIR research and achieve THEIR goals?

2. How would an adult participant be paid or rewarded in a similar situation?
3. Does expecting a voluntary commitment bias the kind of people who are likely to show an interest?
4. Does the offer of payment bias the kind of people who are likely to show an interest (will it attract participants who are more in need of the cash than interested in the research)?
5. Is there a standard way of doing things regarded as "best practice" in your sector/organisation?



Wider benefits of participating in research

What are the benefits of being a CRAG member?

Joining a CRAG is not a paid job. It is a voluntary commitment.

However, there could be all kinds of other benefits for you if you decide to join the CRAG:

- You will learn a lot about the topic of the research;
- You will have a good experience of working with others on an important project, and learn new skills for working with others...;
- You will meet new people and might make new friends – it could be fun;
- You will know you have made a real contribution to helping other children, families and communities face pandemics and disasters in the future;
- This would be an achievement you (and your family) could feel proud of;
- All this could boost your confidence for new projects in the future.

We will give you a Certificate of Achievement as a CRAG member, outlining what you have done.

*Extract from the
Participant Information
Leaflet (PIL) for the
COVISION project
online CRAG
(McAneney et al, 2021)*

33

6. KIDS IN ACTION: A network for support and solidarity in participatory health research

"Kids in Action" is an international network that is part of the:



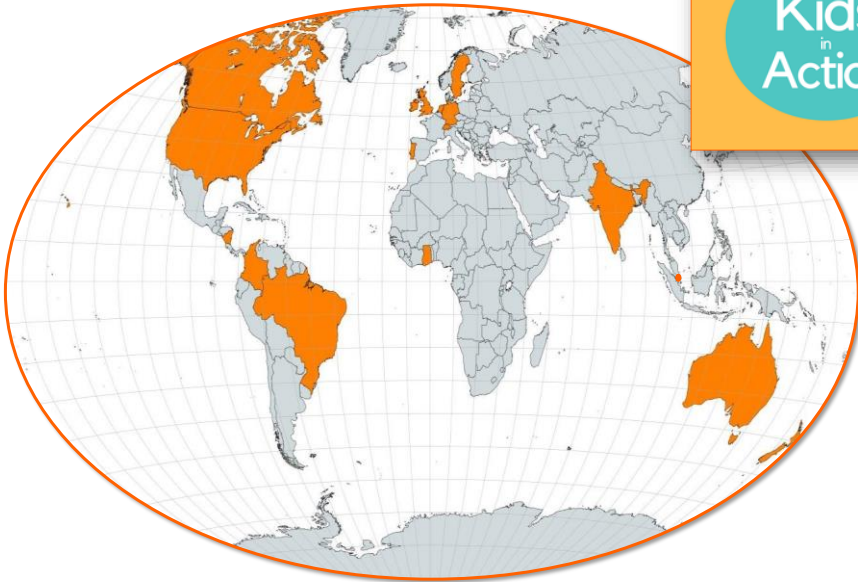
Coordinated out of Melbourne Australia

<http://www.icphr.org/>

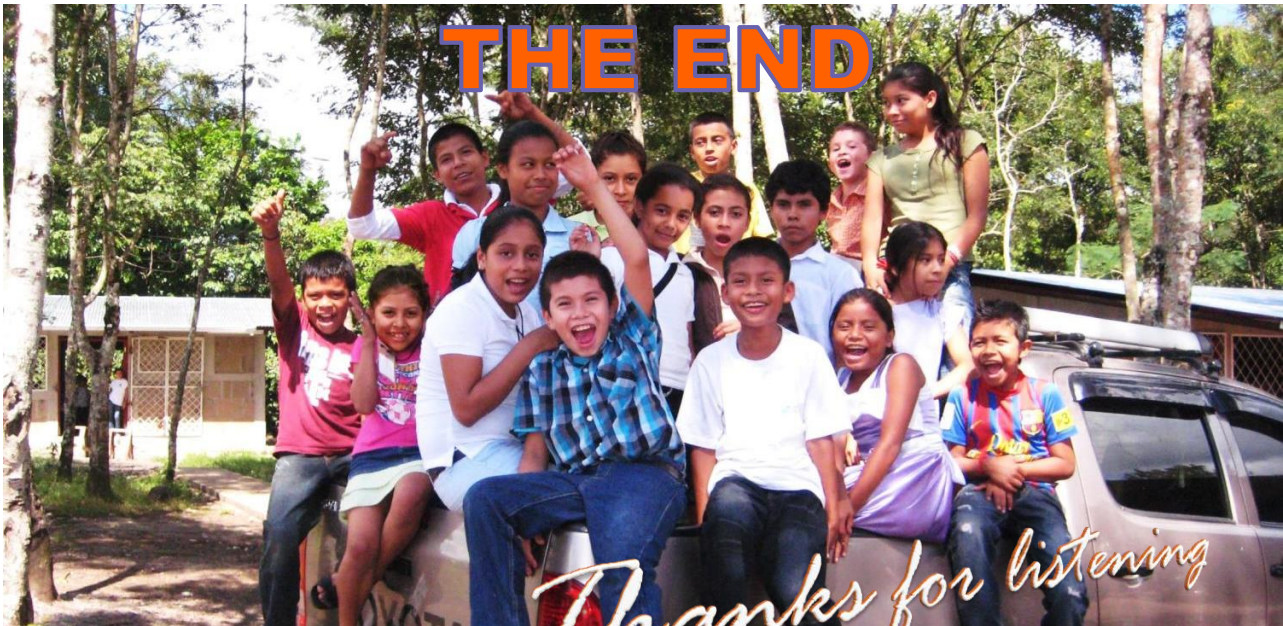


Lisa Gibbs, KiA co-ordinator, speaking at UCD Children's Day Conference in November 2019 (just before COVID-19)





- Kids in Action meets on-line 4 times a year.
- Annual meeting coincides with ICPHR annual meeting: chance to meet face-to-face if conditions allow.
- Joint projects and workshops.
- New digital Hub created: Collating worldwide experiences of children and young people responding positively to the COVID pandemic.



www.covision.ie



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37