



P 4 PLAY



# Children's Research Advisory Groups: 'Who else would you ask?'

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# Quotes from Youth Participants

‘When adults know what a young person’s view can be, is actually, *Wow! Like a young person knows what they’re talking about.* When you understand that, then you would always take it into account. You’d always like, think of asking young people. But a lot of adults just forget, and they forget what it was like to be a young person and they really need to know that.’

(Female, CYPF)

‘Who else would you ask?’

(Male, IMMERSE CYPAG)



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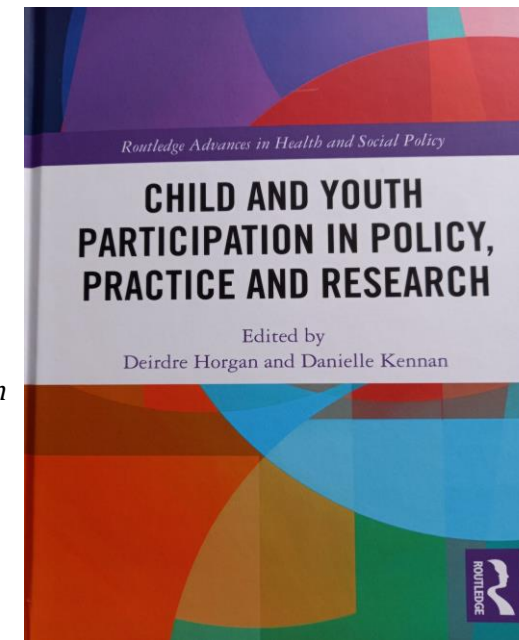
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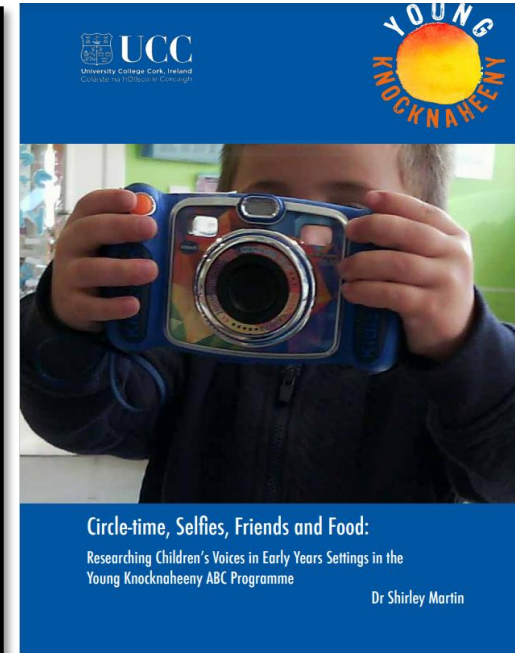
## 12 Children's research advisory groups

Moving from adult-research agendas to co-creation with children

Deirdre Horgan and Shirley Martin

### Introduction

Societal changes and political support for children's rights have coupled with theories on childhood to establish a new understanding of children as competent social actors (Broström, 2012). The importance of the child's perspective or 'voice' and the child as participant have been incorporated to a large extent into children's research (Horgan et al., 2017; Mercieca and Jones, 2018). Their inclusion in research can better influence practices and policies which are child-centred and appropriate to children's contemporary circumstances (Horgan, 2017a).

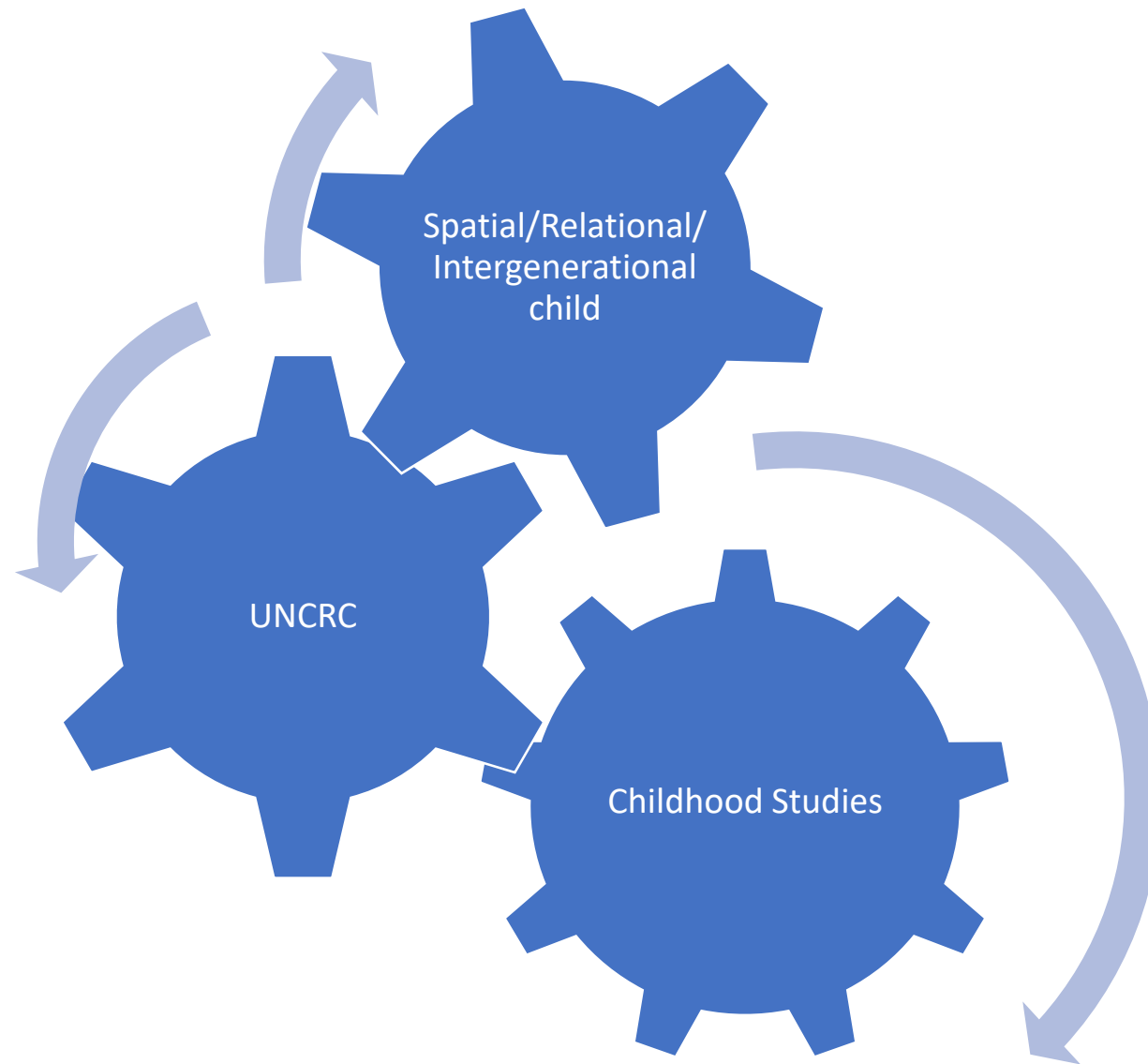


# Overview

- **Child participation – vision and policy context.**
- **Children impacting organisational, regional and national policy**
- **Children's participation in research**
- **PPI involving children**
- **Children's research advisory groups**
- **3 case studies**

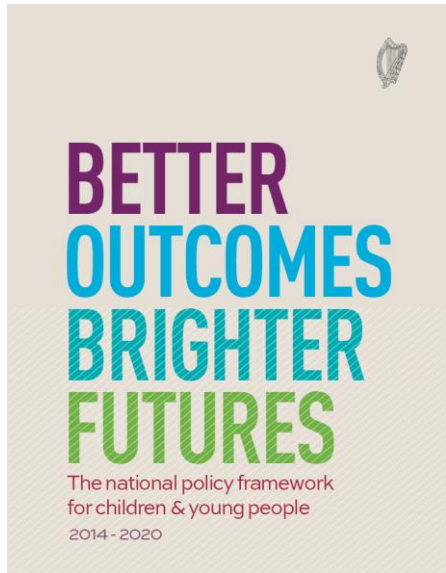


# Influences on Children's Participation





# Irish Policy context for Children's Participation



## *National Framework for Children and Young People (2014)*

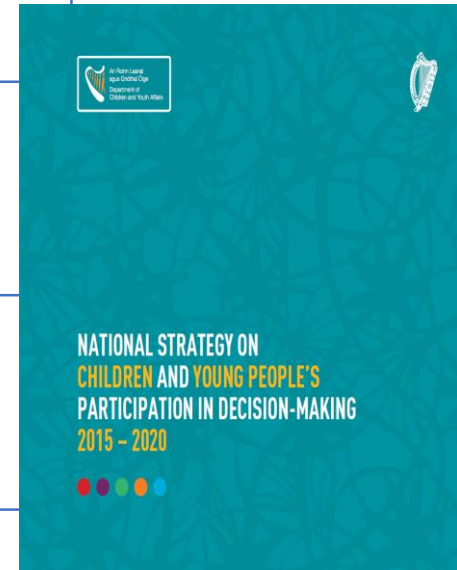
- **Outcome 5: Children are respected, connected and contributing**

## *National Strategy on children and young people's participation in decision-making (2015)*

- **Objective 7: mainstreaming the participation of children and young people in the development of policy, legislation and research.**

## *National Framework for Children and Young People's Participation in Decision-making (2021)*

- **Vision: Participation with purpose**



## An Evaluation of the Operation and Impact of The Ark Children's Council Executive Summary

Dr. Deirdre Horgan, Dr. Shirley Martin,  
Dr. Annie Cummins-McNamara  
UNIVERSITY COLLEGE CORK | MARCH 2019



# Children impacting policy in an organisation

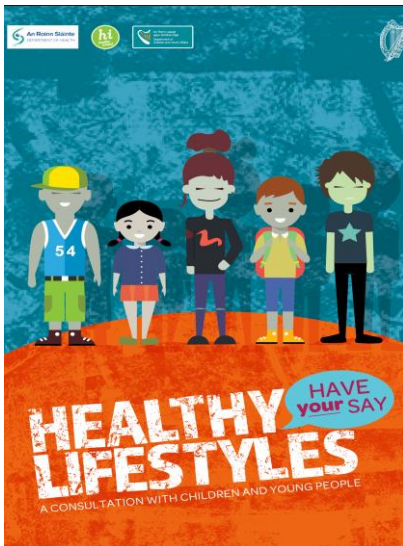
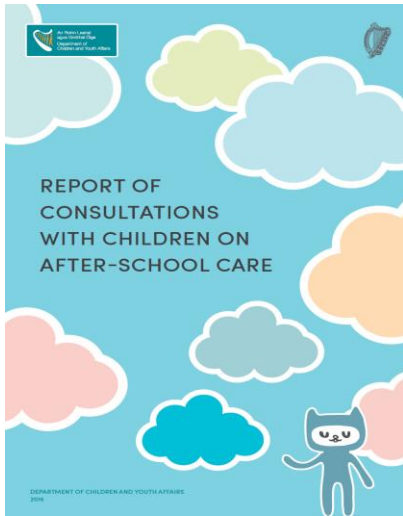
- pilot project to create ongoing participation practice in arts and culture for a diverse group of children to inform artistic programming for The Ark's child audience and overall institutional decision making.
- Gathered experiences of current and past participants of The Ark Children's Council (CC),
- Findings: positive impact of their participation on the children themselves, on The Ark's artistic programming and decision-making, on the wider arts community and government policy.

# Children impacting national policy

- Children contribute to the development of national policy in areas which affect them –  
housing, transport, health, education, play & recreation, the care system.

- Daíl na nÓg
- DCYA Inclusion programme
- National consultations

- Increasingly, government is conducting consultations with children and young people to inform policy impacting on their lives.
- Generally conducted by the DCEIDY and childhood researchers using child friendly participatory methods.





# Children's Participation in Research

- The need to understand how children experience the world (Winstone et al., 2014).
- Recognition of the value of child participatory research utilising **creative research methods** and the expansion of such research is well documented (Christensen and James, 2008; Kellett, 2010).
- **Methods** of participatory research are believed to enable young people to speak openly about their lives in unthreatening contexts (Ansell et al., 2012)
- As well as the methods it is the **social relations** involved in the co-production of knowledge which makes the research participatory (Gallagher, 2008).
- The **process** of child participatory research is complex, fluid and multi-layered (Horgan, 2017)



# Child Participatory research approaches

Generally, **group** activities.

Verbal communication is often superseded by **activities** - drawing, mapping, and tours - to elicit children's views.

Optimises their abilities and helps them to set the agenda, have **greater control** and participate on their own terms.

**But**, it raises questions about how capable adults are of interpreting & writing about children's lives.

# PPI with Children

Coyne & Martins (2021) highlight that children continue to encounter obstacles to being heard, receive limited information and generally occupy a marginal role in the decision-making process regarding their healthcare.

Preston et al (2022) - listening to, and acting on, the voices of children and families during clinical research and innovation is fundamental to ensuring enhanced paediatric health care, medicines development, and technological advances.

While often discussed as an important step in ensuring patient-centred care, involving children and families across the life cycle of clinical research is not currently routine.

Menzies et al (2016) highlight the challenges – children are often too sick to discuss being involved in a study and parents are too upset about their child to think about taking part.

Lack of measurement of impact.



transition information for young people,  
with long-term illnesses, moving to  
adult health care services



# Limitations of PPI model in children's research



**Increasingly funding bodies require evidence of research involvement by users of services.**

Given the complex and demanding funding mechanisms and time constraints in research, the tendency for parachuting in and out of children's worlds in order to quickly 'collect data' and analyse data (Spyrou, 2011: 157) may be exacerbated.



**We can attempt to mitigate these through participatory research methods, working with Children's Research Advisory Groups, and training youth as researchers.**



# \*Childrens Research Advisory Groups

- children are both informants and researchers but not research subjects (Jones, 2004).
- a space for *thinking about research* (Mercieca and Jones, 2018: 256)
- an expert group, to reflect on the experiences of children in general (Lundy & McEvoy, 2012)
- the potential to contribute to deeper participation (Horgan & Martin, 2021).



# Child and Youth Spaces or shared Intergenerational Spaces

- Case Study 1:  
Children/Youth and  
Adult Research Steering  
Groups

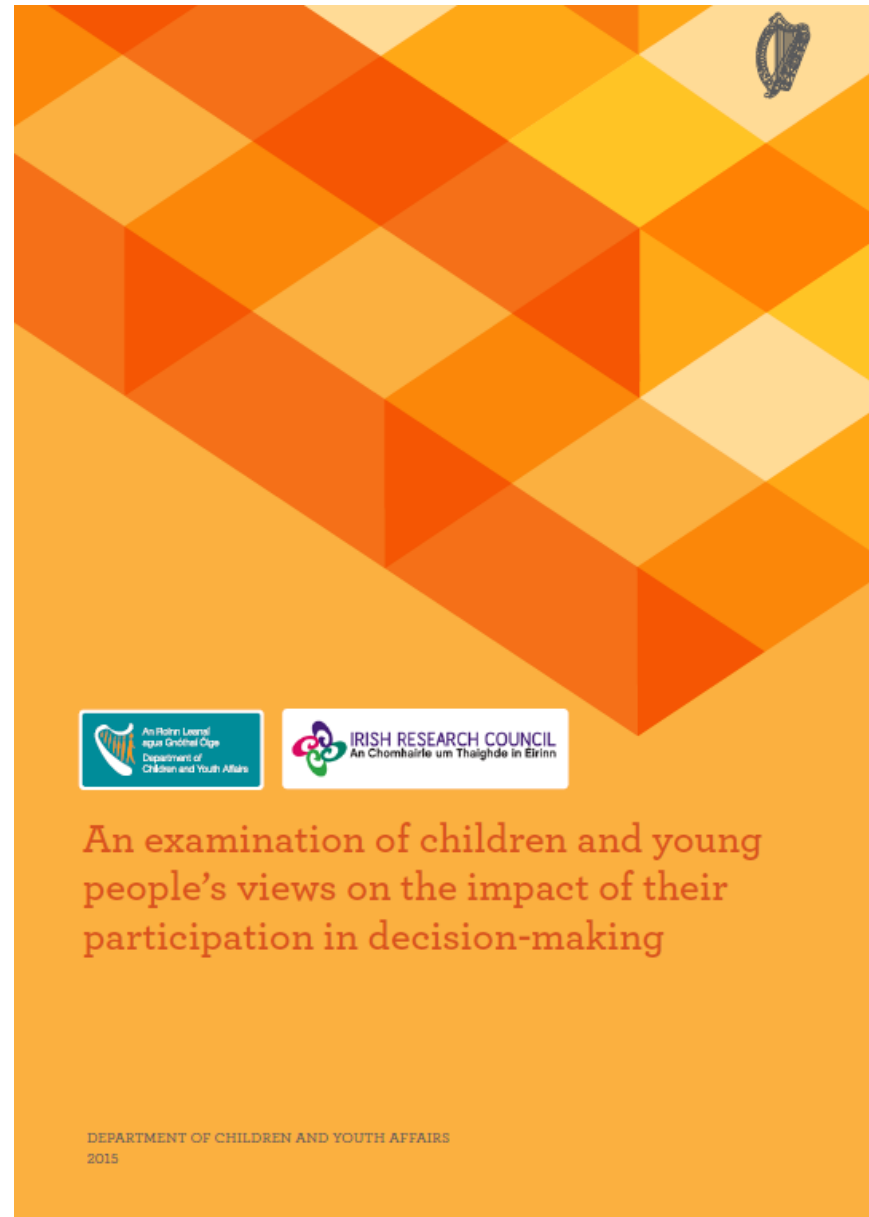
- Case Study 2 and 3: Separate  
Children and Young People's  
Research Advisory Groups

# Case Study 1



**Irish Research Council/DCYA-funded study**

Authors: Shirley Martin, Catherine Forde,  
Audrey Dunn Galvin and Angela O'Connell.



# Role of Young People in the Project

Members of the Steering Group alongside adults and involved in research design, data collection and analysis (Consensus Workshop)

Research Training sessions and ongoing engagement with UCC research team. Ongoing support and capacity building from DCYA and Youth Workers for the young people involved

Considerable time and resources to allow for in-depth consultation and reflection from design stage (Sinclair, 2004, p. 113)





# Case Study 2

- **Irish Research Council/DCYA-funded study**
- **Authors: Horgan, D., Forde, C., Martin, S., Mages, L. and Parkes, A. (2015)**



# Role of children in the project

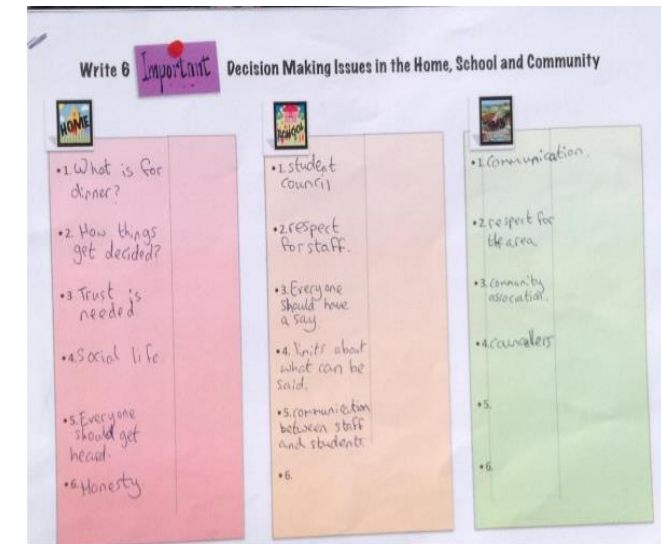
2 CRAGs:

- children aged 7-12 years (n= 8 )
- young people aged 12-18 years (n= 5).

Identifying research themes – deciding on key questions to be explored

Developing and trialling research materials

Initial data analysis to ensure representation of participants voice



# Case Study 3: IMMERSE

Horizon 2020 European Research Project: IMMERSE – to measure the socio-educational integration of migrant and refugee children in Europe

**Spain, Italy, Greece, Belgium, Germany, Ireland**

## Outputs

- dashboard of 30 integration indicators
- survey of thousands of children in the partner countries
- online data and resource hub for educators and policy-makers
- policy recommendations



11

PARTNERS

6

COUNTRIES

€3M

TOTAL BUDGET

4

YEARS



immerse

INTEGRATION MAPPING OF REFUGEE  
AND MIGRANT CHILDREN

# Role of the children

Children and young people aged 9-16 years (n = 18) of migrant and refugee backgrounds resident in Ireland.

- providing input into themes for qualitative data collection

developing, validating and piloting research materials

data analysis

dissemination of data through online blogs, podcasts and videos

IMMERSE Questionnaire 6-9 YEAR OLDS

20. How many best friends do you have?

\_\_\_\_\_

21. Do you feel like this?

21a. My friends really try to help me.

Never or almost never ☐ Sometimes ☐ Always or almost always ☐

21b. I can talk with my friends about what makes me happy and sad.

Never or almost never ☐ Sometimes ☐ Always or almost always ☐





# Reflections

- Adult–youth partnerships go beyond consultation to provide a greater measure of intergenerational involvement in which parties may be equal or unequal in their levels of participation. If both parties share interpersonal and institutional power, they take a step toward quality participation. If the power remains largely in adult hands, however, they do not (Arnstein, 1969; Hart, 1997).
- Competing tensions between the need for academic research outputs and allowing children to have control over the research process.
- Training is one way of equalising power between adult researchers and young researchers.
- There are clear benefits in working with established groups
- Need ongoing updates, for example, an online platform.
- Challenge of having multiple steering groups – who is mediating youth voices?

# reading

- Preston, J. et al (2022) Developing a More Tailored Approach to Patient and Public Involvement with Children and Families in Paediatric Clinical Research: Lessons Learned. *Therapeutic Innovation & Regulatory Science*. <https://doi.org/10.1007/s43441-022-00382-4>
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- Rouncefield-Swales A, Harris J, Carter B, Bray L, Bewley T, Martin R (2021) Children and young people's contributions to public involvement and engagement activities in health-related research: A scoping review. *PLoS ONE* 16(6): e0252774. <https://doi.org/10.1371/journal.pone.0252774>
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