

# COMMUNITY BASED RESEARCH ETHICS

## "NOTHING ABOUT US WITHOUT US"

"COMMUNITIES SHOULD BE PART OF DEFINING ETHICS"  
 TOWARDS A COMMUNITY-BASED RESEARCH ETHICS RESOURCE



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### WHY THIS RESOURCE?

Community groups and artists were at the heart of this resource from the beginning. The idea grew from conversations between Elaine Desmond, Siobhan O'Sullivan and Maggie O'Neill, on their participatory research experience and shared concerns about the uneven power dynamics between the university and community and the need for ethics guidance shaped by the very people so often asked to support or facilitate research. They were joined by Michael McLoughlin (TUS), Christine Backhouse (MTU), Ashling O'Sullivan, Fionn Woodhouse and Yvon Bonenfant.

Two workshops were organised at UCC where representatives from university, statutory and voluntary sector organisations, artists and community groups working to address social injustices and inequalities, collaborated and generously shared their experience and expertise. Together we have co-produced this resource with the support of Becky Hatchett, Artist. We worked together to develop a set of ethical guidelines, from the perspective of our shared experience, knowledge and understanding of working in collaborative, arts-based, and socially engaged ways.

### WHAT WE DID:

In the first workshop, we discussed what ethics means in our work and the ethical challenges we face. We shared learning and best practice using a world café dialogue approach.

In the second workshop, we built upon this foundation to drill down into the themes that emerged, looking at challenges, solutions, best practice, and examples of community-based research ethics. We used interactive theatre to develop scenarios based on our shared experiences. The scenarios were the basis for discussion and the development of the resource we present here.

These ethical guidelines are based on the perspectives of communities and community organisations, artists, and researchers to counter the experiences of 'extractive' research methods.

Four key ethical values emerged from our collaborative scenarios and discussions:

- Ethics as morality in action
- Ethics applied as moral values in practice, through engagement with communities
- Ethics of care
- Ethics in practice: respect, recognition, inclusion, active listening, attentiveness to power dynamics and genuine collaboration

In what follows in this resource, we share the themes and scenarios that formed the basis for visual research ethics guidance.

### THEME 1: ETHICAL ENGAGEMENT & COMMUNITY PARTNERSHIP

"Communities should be part of defining ethics"

Power dynamics, trust-building and consent

Scenario: A PhD student with external funding and ethics approval found that the community group she was due to work with were unwilling to participate in what they saw to be a top-down, 'extractive' project.

The funders pushed for the research to go ahead, but the community requested a collaborative, participatory approach based on an ethic of care. Eventually, everyone agreed.

The scenario highlights the importance of collaboration from the outset.



"IT IS NEVER TOO EARLY IN THE RESEARCH DESIGN TO RELY ON THE EXPERTISE OF THE COMMUNITY AND LEARN FROM THEM" (TVG).



### THEME 2: INCLUSIVE PRACTICE & REPRESENTATION

"Research should be for everyone"

Posing the problem of discrimination and misrecognition and the researcher's role in representation.

Scenario: A researcher studying a marginalised community finds that some participants misrepresented their addresses on official documents to avoid discrimination. Though relevant to her study, the researcher faces the ethical dilemma of whether to include this information since it could harm the community and she must decide how to best represent participants sensitively and collaboratively.

Rather than show a solution, this scenario aimed to stimulate discussion about ethical challenges, strengths and limitations of community research and working collaboratively.



POSING THE PROBLEM OF DISCRIMINATION AND MISRECOGNITION AND THE RESEARCHER'S ROLE IN REPRESENTATION



### THEME 3: ADAPTIVE APPROACHES & STAKEHOLDER INVOLVEMENT

"Research is relational"

Stakeholder relationships and collaborations

Scenario: A public body offers funding for research on public understanding of brown bins\*, proposing that school children photograph their family's bin use.

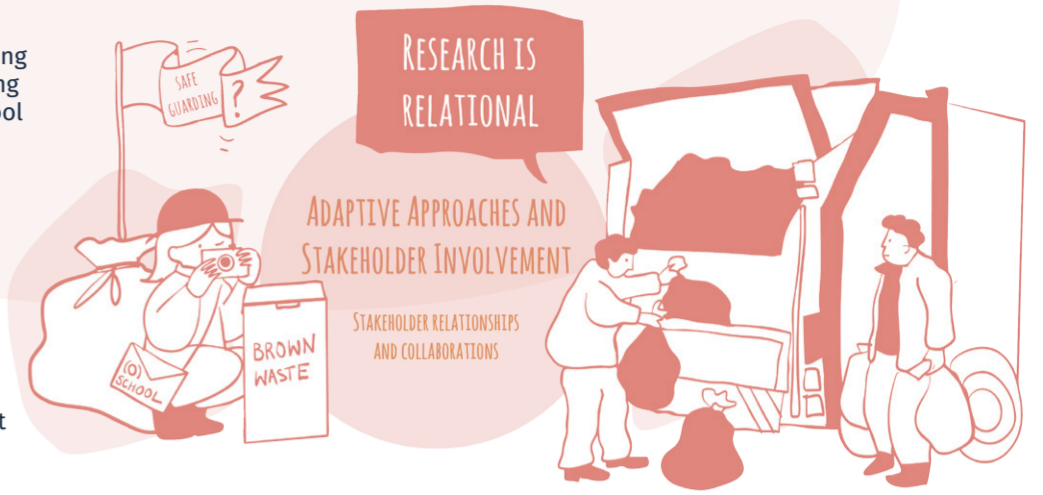
However neither the children, their parents, nor local advocates are consulted, and potential child protection risks in the photography are not acknowledged.

Instead of imposing research, this scenario shows how the project needs to ensure all participants' involvement and safety.

\*Brown bins are used for the disposal of compostable food and garden waste.



RESEARCHERS MET WITH STAKEHOLDERS TO DISCUSS RESEARCH AIMS AND ADAPT AN APPROACH REFLECTIVE OF THE PARTICIPANTS' NEEDS.



### THEME 4: CHALLENGES & CONSIDERATIONS IN RESEARCH



"Care as a grounding principle"

Stakeholder relationships and collaborations

Scenario: A community member is tired of being the subject of research that brings no change and shows little interest when a new researcher arrives with funding and consent forms.

A community development worker steps in, listens, and urges the researcher and funder to do the same.

The scenario focused on a solution where the project is reshaped so that themes are co-developed with the community, aiming for meaningful change.



FUNDERS' NEEDS, RESEARCHERS' AIMS, WHO IS LISTENING - BUILDING GENUINE COMMUNITY CONNECTIONS.

### THEME 5: ETHICS OF RESEARCH OUTCOMES & REPRESENTATION

"All are co-learners and co-owners of research"

Advocacy, data sharing and implementation

Scenario: In a top-down project that did not seek community input, research expectations between the community, a local NGO, and a national research company are not aligned, and there is pressure for timely results.

The process feels intrusive to the NGO, who decides they cannot stand over the findings, use, or share them. The scenario highlights that ethics is not phase-specific but is interlinked throughout the research process.



COMMUNITY BASED PARTICIPANTS WONDER "WHAT ARE YOU ASKING ME? HAVE YOU THOUGHT ABOUT THE IMPACT OF THIS QUESTION?"



### THANK YOU TO ALL OUR COLLABORATORS:

Age Action, Cork Alliance Centre, Cork City Council, Cork Healthy Cities, Cork Learning Neighbourhoods, Cork Migrant Centre, Cork Prison, ETB Prison Education Service, Frameworks Films, HSE, Let's Grow Together! Infant & Childhood

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Health, Department of Sociology and Criminology, Social Research Ethics Committee (SREC), Department of Theatre, and The Glucksman.

