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The Ethics of Engagement and Representation in Community-based Participatory Research

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ABSTRACT

This paper focuses on ethics in community-based participatory research (CBPR) from inception to post-publication. Central to CBPR is a collaborative, partnership approach that recognises the strengths of partners and engages their distinctive voice and knowledge in the research process. While the ethical complexities that arise in the course of research practice in CBPR can transcend individual projects, they are also grounded in the particularity of the project, community, and research partners. This paper reflects on the experiences of two participatory social policy research projects on housing in Ireland, conducted over the past three years. These projects involved collaborating with older people living in rural areas nationwide and with residents of small communities on offshore islands. The paper explores the ethics of engagement (regarding methods of involvement and access), and the ethics of representation (incorporating the depiction and sharing of research findings) and argues that researchers must pay attention to the specificity of each project and be alive to generating an organic research ethics in how research is set up, conducted, represented, and disseminated. In so doing, we can better foster agency and authenticity in the relationships developed throughout research processes and reflect on and meet shared values and responsibilities.

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Introduction

Community-based participatory research

Community-based participatory research (CBPR), a term particularly used in the field of health research, is also increasingly used to refer to research 'in a variety of fields that is 'community-based' and 'participatory'' (Banks et al. 2013, 264). This includes research in environmental justice, psychology, social science, social work and human rights. Similar to other forms of engaged and participatory research such as Participatory Action Research (PAR), central to CBPR is a collaborative, partnership approach that recognises the strengths of partners and engages their distinctive voice and ability in the research process. It is a collaboration between researchers and members of community

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groups with the purpose of creating new knowledge and developing understanding of issues, with the goal of bringing about change (Warwick-Booth, Bagnall, and Coan 2021, 7). CBPR and other participatory research methodologies often engage with members of marginalised groups and communities (Bergold and Thomas 2012), including people with disabilities (McDonald and Stack 2016), aboriginal and indigenous communities (Petrucka et al. 2012), children and young people (Jacquez, Vaughn, and Wagner 2013), older people (Donnelly, Raghallaigh, and Foreman 2019; O'Sullivan et al. 2022), refugees and internally displaced people (Hugman, Pittaway, and Bartolomei 2011; Pittaway, Bartolomei, and Hugman 2010), people living in poverty and areas of deprivation (Mosavel et al. 2005; Cullinane and O'Sullivan 2020), as well as with social movements (Cordner et al. 2012) and under-served communities (O'Sullivan and Desmond 2022). The benefits of community involvement in the design and process of research include a better understanding of an issue by bringing the everyday experiences and knowledge of participants into the research process (Campus Engage 2017, 49). The co-creation of research also helps to ensure it is relevant to people's lives and oriented to stimulating policy change (Goodson and Phillimore 2012, 11) and social action more broadly. Beneficial outcomes for participants include the development of new skills, knowledge and confidence (Banks et al. 2013, 264–265; Cullinane and O'Sullivan 2020, 53).

CBPR is embedded in the transformative research paradigm which has particular axiological standards regarding 'honouring the life experience of research participants, maintaining awareness of power differentials, and enhancing social justice' (Biddle and Schafft 2015, 329). Scholars in CBPR emphasise values of partnership, shared leadership and power, and co-learning (e.g. Banks et al. 2013, 264; Wallerstein 2020, 2) and highlight that research ought to involve people as 'active participants or co-researchers and not simply construct them as sources of information' (Hugman, Pittaway, and Bartolomei 2011, 1276). However, it also clear that there are different degrees or levels of community participation in CBPR which ranges from research that is controlled by professional researchers with greater or lesser degrees of community partnership, to co-production/equal partnership between researchers and community members, to community-driven and managed projects (Banks et al. 2013, 265). Overall, scholars recognise that CBPR approaches challenge the relationship between researchers and the researched and 'the traditional hierarchies of academics and community/practitioner stakeholders' (Wallerstein 2020, 2). Like other forms of university-community engagement, this transformative approach unsettles the expert model by emphasising multi-directional and shared expertise to generate and democratise knowledge (Reid and Brief 2009, 84) and mobilise for social justice and equality.

Given the diverse groups of people that CBPR researchers collaborate with, the participatory and collaborative modes of engagement, and the changed dynamic between researchers and communities, there are specific ethical concerns that arise in CBPR. Increasing attention has been paid to understanding ethics in the practice of CBPR and this article aims to contribute to this examination by reflecting on the approach to ethics in the course of two CBPR projects on housing in Ireland through the lens of two features: the ethics of engagement and the ethics of representation. This article argues that researchers must pay attention to the specificity of each project in order to generate an organic research ethics in how research is set up, conducted, represented, and disseminated. This argument aligns with the understanding of situated ethics, relational and reflexive ethics that are documented and explored by other scholars in CBPR

as the next part of the article will explore. The article will then offer insights on ethics in CBPR by presenting vignettes on some key ethical moments related to the ethics of engagement and representation in CBPR that arose in the course of the two research projects, following the approach of van Zyl and Sabiescu (2020) and Banks et al. (2013). The term 'ethically important moments' is drawn from Guillermin and Gillian (2004, 265) who highlight that not all ethical issues that arise in the course of research are necessarily dilemmas but that there are instances where ethical concerns come to light that are important to document. The vignettes are descriptive and show how we set up and conducted the research to enable and ensure ethical practice. In the vignettes, we give examples of the research practices we employed to develop a situated, reflexive approach to the ethics of engagement and representation.

Ethics in CBPR

The understanding of ethics is an expansive one in CBPR, that extends beyond codified rules, guidelines and procedural ethics of institutions. While scholars recognise the important role of core principles, including: the 'baseline principle' of do no harm (Hugman, Pittaway, and Bartolomei 2011, 1272); respect for persons and their autonomy; informed consent; privacy; confidentiality and anonymity, and the procedures of academic/institutional research ethics boards, many scholars also critique research ethics boards for not considering the different nature of CBPR (e.g. van Zyl and Sabiescu 2020; Eikeland 2006). For example, CBPR projects are not predictable, which means it can be challenging to fit CBPR into procedures for institutional ethical review (Banks et al. 2013, 268). Furthermore, institutional ethics procedures tend to specifically focus on fieldwork, while in CBPR ethics is understood to be a continual consideration, not a 'stage' of research (Reid and Brief 2009, 83). Thus ethics is considered as Cordner et al. (2012, 164) state during

> 'the *identification* of research questions and motivation; the *engagement* with community actors, social movements, knowledge institutions and other publics; the *production* of knowledge; the *interpretation or analysis* of data; the *presentation and dissemination* of research results and the *use* of scientific knowledge.

As Pittaway, Bartolomei, and Hugman (2010, 241) state 'ethics is not simply a matter of following rules and procedures … but should inform all aspects of the discursive interactions between people'.

CBPR also 'presents new moments of ethical uncertainty' (Cordner et al. 2012, 162) due to dynamic relations and the uncertainty of research processes that engage directly with communities. Scholars therefore emphasise the importance of situated, relational/intersubjective and reflexive ethics rather than the 'pre-packaged ethics' that van Zyl and Sabiescu (2020, 304) describe as characterising institutional forms and procedures. This focus on ethics in practice (Guillemin and Gillam 2004, 269) is based on the understanding of research as a social endeavour with a 'community of inquiry' (Eikeland 2006, 43). This means that research ethics is understood to be an evolving process that dwells in relationships and dialogue among researchers and community members and is therefore 'an emerging, situated and negotiated enactment' according to van Zyl and Sabiescu (2020, 303). Thus, ethical issues are not just something to be 'designed prior to entering the field' but are 'interwoven with and carry implications for how research with communities is practiced' (2020, 310). For Banks et al. (2013, 266) the focus on ethics as regulation

and also ethics as decision-making (e.g. dilemmas and difficulties) in academic articles neglects the importance of 'everyday ethics', which they define as stressing 'the situated nature of ethics, with a focus on qualities of character and responsibilities attaching to particular relationships (as opposed to the articulation and implementation of abstract principles and rules)' (2013, 263).

Cordner et al. (2012, 162) propose a reflexive research ethics process that extends the static set of 'formal guidelines and pre-established professional codes of conduct to consider the relational nature of … research'. As a reflexive process, scrutiny, reflection and interrogation are not only directed to the gathering and interpretation of data but also to the backgrounds and values of the researchers and the community, the goals of the research, and the interpersonal aspects of the research. In their research, Mena and Hilhorst (2022, 309) develop an ethically-based risk assessment which includes the contemplation of power relations, the researchers' own positionality, and the potential harm that their actions and interactions could create or exacerbate. For the reflexive researcher, ethical practices are not viewed 'as static or detached from the universe in which they are developed, but rather as responsive, relational and often contextual' (Cordner et al. 2012, 171). Bergold and Thomas (2012) propose a reflexive approach to participatory research and Guillemin and Gillam (2004, 278) describe such reflection as a 'sensitizing notion' to enable both rigorous and ethical research practice. To produce reliable knowledge in CBPR requires that researchers are committed to professional scientific standards and are responsive to the interests and needs of individuals and communities (Cordner et al. 2012, 171). In the next two sections, the ethics of engagement and representation in CBPR will be explored and vignettes of our research approach in relation to these aspects shared.

The ethics of engagement

The ethics of engagement can be described as the ethical issues that arise regarding methods of access and involvement in research, including both the practicalities of conducting CBPR and the processes of relationship building with participants. Drawing on Banks et al. (2013, 267), this includes how partnerships are established, inclusion and exclusion in the research process, how power is distributed and the dynamics of power relations. The concept of authenticity is important to both the ethics of engagement and dissemination, which Reid and Brief (2009, 76) define as 'authentically involving community members in forming and responding to questions that are relevant to them.'

In the first instance, the ethics of engagement requires attention to *who is engaged with and how the engagement is enabled and structured*. Who is involved depends on the focus and aims of the research and as Bergold and Thomas (2012) state 'it is generally argued that those persons, groups, and institutions who are affected by the research theme and the expected outcomes must be involved'. This may go beyond local participants to include wider stakeholders and Bergold and Thomas (2012) argue that there is a need for a systematic approach to involve those who are affected by the research problem. This requires consideration of modes of communication to reach community members and stakeholders, structures for establishing partnerships, and facilitating participation through training (Pittaway, Bartolomei, and Hugman 2010, 244). Structures of engagement include the establishment of advisory groups as explored by Wallerstein (2020, 3) who argue that 'a fully participatory approach requires a structured mechanism, such as community advisory

boards, community research teams, or community scientific research committees, so that academic researchers can work in ongoing partnerships with other stakeholders'. However, how community is defined, who represents the community, and how to take account of conflict in the community are key concerns in CBPR, raising 'complex matters relating to democracy and community relations' (Banks et al. 2013, 267). Scholars in CBPR recognise that, as Cordner et al. (2012, 169) state, 'community groups may not be synonymous with or fully representative of the communities in which they work'. They emphasise that 'ethical research also involves being attentive to the heterogeneity of interests, needs and demographics within a particular movement, group or community' (Cordner et al., 2012, 169). As Reid and Brief (2009, 77) highlight, CBPR requires embracing diverse voices and experiences and welcoming meaningful reflection and revision.

Important ethical issues also arise in CBPR regarding the *conditions of engagement*. CBPR is a time-consuming process, and the timeframe and duration of researchers' commitment can be extensive, both for professional and community researchers. Therefore, Kara (2018, 109) argues that in some cases 'it may be more ethical to offer a flexible approach to participation, with options for participants to move through different levels of involvement at different times to suit their needs'. There is also the issue of remuneration since in participatory research, community partners are treated as co-researchers rather than 'objects of research' (Bergold and Thomas 2012). In many cases, co-researchers receive little if any remuneration, often due to the limits of funding. As Bergold and Thomas (2012) outline, in cases where co-researchers have limited material resources at their disposal, direct remuneration is recognised as important. Where this is challenging due to limits of funding, other benefits can be provided, including training and formal recognition of people's engagement. For example, in a previous participatory survey with fifteen residents in a social housing estate in Cork City, Ireland, the co-researchers gained credit through a specially devised module (equivalent to 5 credits in the standardised European Credit Transfer system) on 'Research in the Community' and also received a small stipend in recognition of their research work (Cullinane and O'Sullivan 2020, 48). Of increasing concern is also the remuneration and working conditions of professional academic researchers whose contracts are often precarious and short term, and whose salaries are often low. This is linked to growing casualisation of university staff within the academy documented by Courtois and O'Keefe (2015, 48). Although the impact of precarity on staff in CBPR and engaged research is under-explored, Barrett and Rose (2022, S167–168) highlight how these conditions can impact the well-being of researchers and the building of community partnerships. Increased funding aligned with longer timelines are therefore critical for improving the conditions of engagement so that engaged research is not undermined by poor working conditions, thereby enabling more ethical practice in CBPR.

As highlighted earlier, it is the *relations of engagement* that the literature on ethics in CBPR particularly emphasises. Instead of 'parachute research' i.e. dropping in to collect data without engaging the community or sharing the data (Cordner et al. 2012, 167), the development and sustaining of collaborative relationships is critical in CBPR. For Banks et al. (2013, 266), ethics 'is present in' the relationships in research and in 'ways of being' and acting. They propose (2013, 266) that key qualities of researchers include 'relational virtues, such as trustworthiness (reliability and not letting others down)'. While all researchers need to ensure rigour and honesty, researchers in CBPR are not detached; they often stay involved with communities, having gotten to know them and seek to make an

impact through a focus on social justice outcomes of research. Banks et al. (2013, 274) argue that an ethics of care and 'relationship-based ethics' are as important as principle-based ethics and that the process of community-based research requires paying attention to 'building relationships, generating trust and negotiating power'. Instituting an ethics of mutual respect, open communication and the recognition of knowledge, expertise and resource capacities of all partners is highlighted by Cordner et al. (2012, 165). Essential to this is creating a safe space because, as Bergold and Thomas (2012) outline:

> [p]articipatory research requires a great willingness on the part of participants to disclose their personal views of the situation, their own opinions and experiences. In everyday life, such openness is displayed towards good and trusted friends, but hardly in institutional settings or towards strangers.

Throughout the stages and phases of the research process, Bergold and Thomas (2012) argue that 'such communicative space must be produced anew' and that 'negotiation processes must be continually engaged in'. In so doing, a symbolic space is produced 'in which, in the best case, the participants can trust each other [and the researchers] and, thus, express their views on the subject under study' (2012). The ethics of engagement also requires paying attention to the 'fluid and unpredictable nuances of the field' (van Zyl and Sabiescu 2020, 320) which can arise in collaborative research. Mertens (2007, 216) argues for the need for an 'interactive link between the researcher and participants in the definition of the problem, methods should be adjusted to accommodate cultural complexity, power issues should be explicitly addressed, and issues of discrimination and oppression should be recognised'. This requires that the researchers 'constantly bear in mind the group dynamics of the research team, its inclusiveness and barriers to participation' (Banks et al. 2013, 274), which may require naming or giving voice to power issues that arise, developing conflict resolution skills and active listening, and creating an environment where everyone can speak. Through the engagement structures and building of relationships in CBPR, power imbalances can be moderated, and the researchers and community members can work together to identify research questions, co-develop the research design and methods, and decide how to collect, interpret and disseminate data and advocate for action and social change (Wallerstein 2020, p. 3).

Open communication is also important when discussing expectations of the research, including the commitment expected of researchers, what benefits may be gained or risks experienced, and what the research outcomes may or may not achieve. Scholars in CBPR critique the focus in research ethics on individual harm minimisation as insufficient. Pittaway, Bartolomei, and Hugman (2010, 247) propose the notion of reciprocal benefit as an ethical base, while Cordner et al. (2012, 163) argue that community engaged research must consider community harm and benefit, not only individual harm and benefit. The need for tangible benefits to the community is likewise explored in Brugge and Kole (2003, 490). However, few university research ethics boards ask about community or societal level benefits and risks according to Reid and Brief (2009, 84). Benefits identified by participants engaged in CBPR include bringing additional resources to a community, providing 'the community with data that it needs to advocate for itself' (Brugge and Kole, 2003, 490), and training (Pittaway, Bartolomei, and Hugman 2010, 234). In the course of CBPR, trusting relationships are key should any mismatches arise in the research process on what the research is expected to accomplish and how it is being conducted.

This is crucial to ensure that harm does not result from research that raises participant expectations that cannot be fulfilled (2010).

Several writers in the ethics of CBPR also argue that the co-development of research requires 'jointly shaped and agreed ethical protocols and any associated tools and forms' (van Zyl and Sabiescu 2020, 304), since intersubjective ethics views ethics as 'anchored in process, … emergent, and … co-created and shared in a research site' (2020, 304). However, the joint shaping of ethical protocols is challenging in many university contexts as research ethics boards often have pre-set and codified requirements (Cordner et al. 2012, 168). Eikeland (2006, 42) depicts this framing of the protection of research subjects as a 'condescending attitude' as the discourse takes place between the researchers, not the researchers and their participants, which has 'othering-effects'. This is also highlighted in Reid and Brief (2009, 76) who consider how 'the construction of ethical decision making is one of the powerful (i.e. the academic researcher) protecting the powerless (i.e. the research subject)'. In contrast, in engaged research as Hugman, Pittaway, and Bartolomei (2011, 1278) explore, informed consent should be 'seen as a process rather than an event' with the risks and implications of the research clearly and simply explained and discussed throughout the project. This can help to mitigate power differentials and people consenting because they are desperate for any form of assistance (2011) or because they feel compelled to do so due to requests from figures of authority in the community (Mena and Hilhorst 2022, 310).

Due to the diverse and ongoing ethical aspects that arise in CBPR, Reid and Brief (2009, 83) suggest that specific CBPR research ethics boards could be established or collaborative relationships between community-based researchers and research ethics boards could be built to provide ongoing support during research. Community-led ethics review boards have also been established in some countries, including in India by the NGO Praxis – the Institute for Participatory Practices – due to the concern that 'communities are not represented in the forums in which the ethics of research is debated, such as institutional research ethics review processes' (CSJCA & NCCPE 2022). These can complement academic research ethics boards to ensure that 'the voices of communities of place, identity or interest … count in defining the ethics that govern research with those communities' (CSJCA & NCCPE 2022, 020) or can provide support to organisations and individual researchers who do not have access to institutionally based research ethics boards (such as the Community Research Ethics Office, Canada).

Vignette 1: The ethics of engagement

The two CBPR projects drawn on in the vignettes focused on social policy and housing and were conducted between 2020 and 2022. The first project with Age Action, Ireland's leading advocacy organisation for older people and aging, focused on aging in place in rural areas to explore where older people choose to age, and the enablers and barriers they face for remaining in their homes or moving into new homes. We collaborated with residents across rural Ireland to build a survey to establish the preferences of older adults in rural Ireland. The second project involved partnership with six community sector organisations (CSOs) on the West Cork islands, Ireland, to document the role of housing in sustaining island communities. This project involved collaboration with residents of the islands to co-construct a survey on the availability,

affordability and quality of housing. In both projects, the collaborative surveys were followed up by in-depth focus groups. More information on these projects is available in the project reports – O'Sullivan et al. (2022) and O'Sullivan and Desmond (2022).We developed a number of steps in the projects to cultivate ethical practice on engagement. At the outset, we developed a systematic approach through which engagement was structured by developing two forums: a research advisory group and a participatory research group. In the research advisory group, academic researchers collaborated with members of community organisations and other stakeholders (which included a statutory agency, the Health Service Executive, in the research with Age Action) to shape and oversee the study design and focus, recruitment and methods, collection and interpretation of data, and dissemination. Meetings took place at least monthly and continued for more than a year on each project. In both projects, the research focus was co-designed with the stakeholders at funding application stage. While it is more challenging to involve participants at this stage (Bergold and Thomas 2012), the model of the Irish Research Council New Foundations grant, which funded the projects, requires demonstration of engagement at application level. This brought community partners into the research design from the outset.

In each project, a systematic approach was then developed to reach and involve community members, utilising a range of modes of communication. The community organisations widely distributed a call to their public (the members of Age Action and island residents in West Cork) for expressions of interest to take part in the participatory process. We held information meetings online, liaised individually with each person interested in participating, and then established the participatory research groups. Everyone who was interested in taking part got to do so – 11 people participated in the aging in place project and 16 in the West Cork Islands project. The participatory research groups embraced diverse voices and experiences – they had a range of genders, ages, and geographical spread, although they were more similar in terms of socio-economic status (SES) with the majority of the participants homeowners, indicating a generally higher SES among participants.

The projects were conducted during the COVID-19 pandemic and all engagement was conducted online in 2021, with the exception of the report launches which were held in person in 2022. Working online brought particular concerns around digital literacy and accessibility of broadband in rural and island communities. While confidence in computer technology was high (and in the aging in place project, Age Action provided a Get Started kit on working online), we checked with each participant that they were comfortable with the technology. Furthermore, due to the unequal access to broadband or poor connections that several participants experienced, and one person's disability that hampered synchronous participation online, we also enabled other modes of communication and engagement through emails, letters and phone calls throughout the projects and two participants' engagement was solely through those means.

In the participatory research groups, we collaborated with the co-researchers to develop the research focus and methods, which entailed the co-construction of a survey. Each participatory research group began with training on social science research methods and survey design, a benefit identified by participants in other studies on CBPR as explored above. As the funding grants were small, there was no funding to provide remuneration to the co-researchers – hence

the commitment of the co-researchers was kept discrete to four meetings in each project, aligning with Kara's (2018, 109) argument that researchers 'have an ethical responsibility to know when and how to offer involvement or participation'. Some of these workshops were quite lengthy, however, and the co-researchers gave considerable time to the project. An open agenda was distributed in advance of each workshop that participants could add to or alter, and we stayed in contact between meetings. Given the size of the group of 16 in the West Cork islands study, the two researchers each worked with a group of 8 and then all met together at the final workshop. Once the research methods were finalised, the community sector organisations widely distributed links to the online/postal surveys, which included a call for participation in follow-up focus groups.

We engaged closely with university ethics procedures. There is no specific CBPR ethics research board in our university. Given the nature of the projects, we applied for ethics approval twice in each project to the UCC Social Research and Ethics Committee (SREC) – once to establish the participatory research group and, at a later date, for undertaking the research that was determined in the collaborative process (Approval Logs 2020-158; 2021-045 & 2021-045A1; 2021-143; 2021-209). We also worked with the research advisory groups on the language used in the project information and consent forms, thereby ensuring ethical tools were jointly shaped.

Throughout the projects, we aimed to integrate a relational, reflexive ethics of care. This required paying explicit attention to how we related to each other and developing a safe, welcoming communicative space to enable trust and collaboration. Unexpectedly, the challenges of COVID-19 assisted with the building of connections as we all opened up about how hard things were and everyone shared their feelings and struggles during that time. We were also attentive to power relations and their impact upon the research process, having flexibility in the methods to respond to the interests and wishes of the participants, while also ensuring rigour in the research.

Open communication was also essential when discussing participant expectations of the research. All participants in the research were highly motivated; they wanted to have a say and to be heard by the government. The participants in the aging in place research (including members of the participatory research group and focus group participants) expressed how they felt disempowered as both older people and rural residents and that they felt empowered by the research process. For the island residents, there was also a high degree of motivation. However, some expressed research fatigue as, although no academic research had been conducted on housing in the area, CSOs had conducted studies and consultations and there was a perception of insufficient action by the government. In both projects, participants were hopeful that, while the issues were widely known and action to address them was slow, gathering an evidence base with the involvement of a respected, impartial research institution would add to the pressure on government to act. Participants felt that having professional researchers on board would provide tangible benefits to the community and give their concerns legitimacy due to the rigour of the approach and standing of the academics. They felt that what they had been saying or knew anecdotally or from their own research was likely to be taken more seriously with a university involved.

However, as researchers, we were concerned that the expectations about what the research could achieve might not be met and that the specific purpose of bringing about political change could be

slow to occur, if at all. As Pittaway, Bartolomei, and Hugman (2010, 234) state, it is important in CBPR to ensure that harm does not occur where expectations are raised that cannot be achieved. We were frank about not knowing what the outcomes might be and that the extent to which the government would respond, given the crises of the times, was not within the project's control. We spoke of our past experience, both positive and negative, on the achievements of CBPR and aimed to stay cognisant of the tension in the research between the sense of empowerment and recognition engendered by the process and a concern that, given political realities, change might be slow to occur, if it happened at all. Hence, we had to be careful about making promises about the benefits for the community from participating in the research, while not falling into apathy and disillusion. The CSOs also had a key role in this in highlighting the advocacy that they would be engaging in following the findings, explored further below in the ethics of representation.

The ethics of representation

The ethics of representation can be described as the ethics related to the depiction and dissemination (the use and sharing) of research. As already explored, while formal university ethics procedures tend to focus primarily on data collection, Pickering and Kara (2017, 300) stress that ethical conduct in social scientific research is a process which extends to data analysis, writing and beyond and they highlight that the presentation of research is always embedded in relations of power (2017, 303). Usually, in social research it is the 'researcher who has jurisdiction over the data, results and the dissemination plan' (Reid and Brief 2009, 76). CBPR aims to transform this.

The ethics of representation reflects on *how the findings, participants, and communities are represented*. As Pickering and Kara (2017, 300) state, representation in research is 'a deeply ethical arena' that requires of researchers 'reflection, consideration and the weighing up of multiple – often conflicting – goods in order to represent others ethically'. These competing goods include 'participant control over what is presented and how, researchers' 'interpretive authority', and how to represent participants' speech' (2017, 299). Like the ethics of engagement, a critical concept is authenticity, which necessitates exploring with participants how they will be represented, discussing with participants the analytical approach, creating space for reflection and discussing issues in community advisory boards. This can enable co-construction of findings and enhance scientific practice by producing more accurate and nuanced interpretation of findings (Cordner et al. 2012, 170).

Circulating drafts to participants to allow comment on content can also assuage power differentials whereby researchers often have the final say about the content of a research report (Brugge and Kole 2003, 487). It can also assist in tackling any concerns about the identifiability of participants in the findings (such as from surveys, focus groups and interviews), especially where CBPR is conducted with small communities. The 'thick descriptions' that add to the richness of data may be limited in these cases to ensure there is no breach of confidentiality during the data analysis and reporting stages (Damianakis and Woodford 2012, 711). Ellis (2007, 24) speaks about first writing an uncensored draft and then attending to '*the ethics of what to tell*'. This can be seen as a form of representational consent, embedded in relational ethics. Discussing

Vignette 2: The ethics of representation

In our two projects, although the lack of funding to provide remuneration to the co-researchers meant that we kept their commitment discrete and hence the academic researchers conducted the analysis, we discussed how the findings were represented with the research advisory groups in each project and sent drafts of the analysis for comments and feedback to participants. Creating space for reflection on the construction of the findings enabled greater authenticity, and more accurate and nuanced interpretations and presentation of the report. From the beginning of the project on aging in place, which had the voice of older people at the heart of the study, it was clear that the older people involved rejected being defined or categorised as vulnerable. Representing their autonomy was therefore central to the analysis and our presentation of the findings. In the West Cork Islands research, decisions were also made on how to represent findings. The question of 'who is an islander?' was discussed by many participants in the course of the research. This related to the dynamics of the community and to community tensions that we were unaware of at the outset of the project. The first draft of the report incorporated a detailed focus on this question. However, in the course of discussing this with the research advisory group, we encountered an ethical dilemma of how to represent the community when several considerations arose. There was a concern that the community was being presented as divided rather than largely cohesive despite these differences, and a fear about the research being divisive or having potential for negative media attention. Another concern was that the focus on identity issues was drawing attention away from the core policy issues and aims and objectives of the research. CBPR aims to produce 'useful research' but as Biddle and Schafft (2015, 330) argue who determines what this means needs to be democratically constructed and based on 'the intelligence of a community of those practising (or participating) in inquiry'.

Working closely with the partners, we therefore edited the focus in the report away from the more divisive, and distracting, identity politics concerned with island living and the final version presented a shorter analysis of the theme. When the analysis was sent to participants for their feedback, one participant wished to keep the deeper focus on identity. While acknowledging the importance of their views, the researchers discussed with them that the primary focus of the report was on housing and the participant agreed with the analysis on that basis. The challenges of presenting data in a small community required close communication with the research partners to understand the implications of the research for their community, while maintaining the rigour and integrity of the research. As explored above, representational consent – attending to 'the ethics of what to tell' (Ellis 2007, 24) is a vital step in CBPR.

All participatory research group members in both projects received a draft of the final report and were asked if they wished to be named in acknowledgements at the beginning. Each participant in the focus groups in both projects was also sent a draft of the findings to obtain any feedback they had (as explored above) and to ensure they were satisfied with the level of confidentiality and identifiability. In both projects, key aspects of focus group participants' situations and identities were omitted to ensure anonymity, including age, location and place names (although counties were named in the aging in place report). Gender, family situations and narratives likely to be linked to certain participants were also omitted in the West Cork islands' research due to the small size of the communities. While the lack of demographic specificity lessened the reader's

ability to form a fuller understanding of the participants in the research, we were guided by the ethics of representing people in small, interconnected communities. This was a particular concern in the smaller West Cork Islands where 'possible unintentional identity disclosure is magnified' (Damianakis and Woodford 2012, 709). Although the limits on the thick description in the qualitative data reduced the richness of the narrative and could be seen to impact on more authentic representation, as Damianakis and Woodford argue (2012, 715) 'if an ethical choice must be made, the preservation of confidentiality – preventing participant harm – takes precedence' over generating new knowledge.

Engaging participants with the outcomes was central to both projects. A dissemination plan was formulated together with the community organisations in each project through the research advisory groups. This included public launches for each report, university seminars and conferences, webpages, YouTube and social media, and media interviews. Members of the research advisory groups and participatory research groups for each project spoke at the launches, at some of the university seminars, and to the media on the findings, the process and their experience of the research. The aging in place research was presented at two international academic conferences where we incorporated audio recordings of focus group participants (with their permission) and a video of a member of the participatory research group. This meant that the academic audience did not just hear the words of participants spoken by an academic but heard it from the participants themselves, enabling another form of representation and engagement with the findings through hearing the emotional resonance of the spoken word. Through the months of dissemination, we stayed in contact with the participants, and the CSOs kept us updated on their use of the research, including in advocacy for policy change and action to the national government. This advocacy is continuing long beyond the research timeframe and, in the case of the West Cork islands project, one year beyond the end of funding. Once a final presentation to the national government has been conducted, there will be a handover to the CSOs and the community to direct the outcomes from the research and involve us as appropriate to their needs.

data analysis and presentation with community partners can also draw attention to who the data represents, who speaks for the community, and how to deal with unflattering data (Brugge and Kole 2003, 499). This is especially important in communities where there is recognised division on local issues or themes within the research, which may raise ethical dilemmas about the research contributing to conflict in the community or attracting negative press attention. Successful CBPR needs to produce tangible benefits and promote the policy objectives of the community as participants in Brugge and Kole's (2003, 498–499) study highlight, without potentially or inadvertently contributing to any existing divisions.

The ethics of representation also raises issues of *who owns the data and how is the research used and shared*. Discussing who takes credit for the research is essential (Banks et al. 2013, 268) and CBPR sees partners as both 'co-learners and co-owners of data' (Cordner et al. 2012; 165 drawing from Israel et al. 1998). Some community/co-researchers and partners may wish to be credited and named as authors or in acknowledgements, while others may not, and this needs to be checked and

respected. Discussing the channels used for dissemination is also important in CBPR (Banks et al. 2013, 267). The multiple publics with whom CBPR is shared include the participants and local community, state and other organisations, the wider public and media, and academic audiences through publications and conferences, referred to as 'representational sites' by Pickering and Kara (2013, 303). Given these different publics, another aspect of the ethics of representation important in the literature on CBPR relates to *how accessible is the data*. This entails ensuring that findings use accessible language and are respectful of community needs (Cordner et al. 2012, 165), that researchers share as much data as possible in an accessible way (Brugge and Kole 2003, 493), and that the data is shared with the community before academic publication – for example, in public forums coordinated through partnerships with community organisations.

As dissemination continues, further ethical issues may arise. Since CBPR entangles scientific research with social movement and community organising (Cordner et al. 2012, 171), this can result in blurred lines between researcher and researched, and academic and activist, and researchers can take on roles associated with community development, advocacy, or community action work (Banks et al. 2013, 267). Research partners may have to consider where to draw the lines in their roles and a dissemination strategy is crucial in that regard – this is especially important with regard to precariously employed researchers where their contracts and pay often do not extend to the dissemination phase. This can be disheartening for researchers given the significant efforts they have put into the research and the relationships which have been forged over extended periods of time. The approach of Pittaway, Bartolomei, and Hugman (2010, 237) with women refugees in the Thai-Burma border regarding what could be done with the materials collected also provides important insights. In their reciprocal research model, the final stage (after training and situational analysis) involved 'strategic planning that seeks to address at least some of the issues involved and plan a programme of advocacy for change' (Pittaway, Bartolomei, and Hugman 2010, 239). This meant that the research moved from researcher-directed outcomes 'to participant and community directed outcomes' (Pittaway, Bartolomei, and Hugman 2010, 247).

Conclusions

In considering approaches to the ethics of engagement and representation in CBPR, the article highlights that while the ethical complexities that arise in the course of research practice can transcend individual projects, they are also often grounded in the particularity of the project and the collaboration with the community and research partners. CBPR aims to create an evidence base through collective decision-making and, in involving people in what research is done and how, the development and embedding of ethical practice from the beginning to the end of a research project and beyond is necessary. As Mena and Hilhorst (2022, 311) state 'an ethical approach to research is a continuous process, not just something that is declared and designed at the beginning. It requires reflecting on ethics before, during and after a research project'. This requires an updated approach from institutional research ethics boards with a widening of understanding to take into account the specific nature of ethics in CBPR.

CBPR extends the understanding of ethics in research towards a situated, relational, and reflexive ethics and highlights the importance of relationship-based ethics (Banks et al. 2013, 274). Reflecting on the building of research partnerships and conducting engaged and participatory research also connects with the ideas of 'slow science' (Temper and Del Bene 2016, 49) and of slow and 'care-full' scholarship by feminist scholars (Mountz et al. 2015, 1245). In CBPR, research partnerships develop slowly and 'may evolve as trust develops and circumstances change' (Banks et al. 2013, 269) and there is a need for a foundation of mutual respect that recognises what researchers can provide to the community and what the community can teach researchers (Brugge and Kole 2003, 497). An ethics of engagement requires considering how to enable engagement and the relations and conditions of engagement. An ethics of representation requires consideration of how participants and communities are represented and findings disseminated, who owns the data, how it is shared and for what it is used. Developing structured opportunities for participation based on an ethics of care, being flexible to adjust to partners and find common ground (Brugge and Kole 2003, 498), and revisiting project objectives, roles and responsibilities, and ownership and representation of data, are all needed throughout CBPR to enact and realise the ethics of engagement and representation.

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