



THE UNIVERSITY
of EDINBURGH



Arts and
Humanities
Research Council

RESEARCHING EVIDENCE-BASED ALTERNATIVES IN LIVING,
IMAGINATIVE, TRAUMATISED, INTEGRATED, EMBODIED SYSTEMS

REALITIES

REALISING
RELATIONAL ETHICS
IN COMMUNITY
HEALTH AND SOCIAL
CARE SETTINGS

SUMMARY

Ethics is a central thread running through transdisciplinary research from the University of Edinburgh in partnership with the REALITIES consortium. We're investigating how local, cultural, and **natural assets** and activities support improvements in health inequalities. The inception of the project is rooted in social justice and based on our understanding of the challenges experienced by people who experience "vulnerability" when interacting with the elements of health and social care systems that are set up to provide support to them.

Our findings from this research suggest:

- While health and social care providers, policymakers and researchers may aim to achieve outcomes that are ethically driven, we need to operationalise our work in a way that attends to the relational
- Our efforts should value the experiences of those who find themselves in situations of vulnerability and/or marginalisation
- Engagements with so-called "at-risk" or "vulnerable" individuals or communities should demonstrate care towards those with whom we work, without making assumptions about their experiences
- Labelling people may be counterproductive suggesting we know more about their lived and felt experiences than they do
- We should approach ethical frameworks in a way that is intentional and responsive to the situation of community members with a willingness to adapt our definitions and approaches if don't fit

INTRODUCTION

REALITIES focuses on re-imagining systems with which vulnerable populations engage when seeking help or support. Our approach is person-centred – we don't view these individuals or communities as research "participants". They're locals engaged in our place-based project situated in one of our Scottish community asset hubs. We also connect with migratory and transient populations such as released prisoners, homeless, asylum seekers and refugees.

Ethical considerations arise from the vulnerability of populations with whom these community asset hubs engage, including issues of power, inclusion of marginalised voices, safeguarding and consent. Additionally, consideration is given to data and its management. Our work is underpinned by these key concepts and definitions:

- **Relational vulnerability** (Gordon-Bouvier 2020)
- **Ethics of care** (Laurin and Martin 2022; Jacobs et al 2021)
- **Relational ethics** (Bergum and Dossetor 2005)
- **Ethical placemaking** (Eckinwiler 2016)
- **Ethics of recognition** (Ryan et al 2023)

METHODOLOGY

This briefing is informed by 9 months of **REALITIES** fieldwork across 3 local community hubs in Scotland, as well as engagement with displaced communities. We also explored ethics through an in-depth workshop with consortium members at a 3-day residential in February 2023. Our thinking is enriched by further reading, discussions and reflections of ethical practices in community health and social care settings.

The following section provides a brief description of the concepts identified



above which underpin the details of this resource. The REALITIES model is then used to frame a discussion of ethics and

raise questions under each of the aspects of People, Place, Power, Process, Price and Purpose.

KEY CONSIDERATIONS

VULNERABILITY

The position taken in relation to the concept of vulnerability follows Fineman's (2008) theory which moves away from understanding vulnerability as something which marks a person out as somehow 'less than' in a world that values autonomy and rational thought. Instead, Fineman argues that vulnerability is part of the human condition, that is, everyone is vulnerable and therefore it follows that everyone is also dependent. Thus dependence, which is so often understood as a negative aspect of the person becomes part of what it is to be human; we are all interdependent. Fineman's argument continues that not everyone experiences vulnerability or dependence equally, and argues that a responsible state is obligated to respond with structures to support those who experience significant vulnerability and dependence.

Gordon-Bouvier (2020) builds on Fineman's vulnerability theory, developing it to argue that we should understand those who experience increased levels of vulnerability as 'additionally' vulnerable, where the social structures are understood to create this additional vulnerability. Thus, Gordon-Bouvier understands vulnerability as relational, it is borne out of the relation of the person with the social structures which provide the context for their existence.

Both Fineman's and Gordon-Bouvier's theorising of vulnerability and dependence provide the opportunity for people engaging with REALITIES and other community-based projects to have their vulnerability understood not as some kind of failure to achieve the criteria for being a fully paid-up member of society, but to understand it as a product of the interaction between person and socio-



political context.

By thinking this way, we can begin to consider the impact of the “normative vulnerability discourse” – or our standard ways of communicating about who is or isn’t vulnerable. This usually involves ascribing the label of vulnerability to specific social groups as if it were an individual trait. Such approaches can exclude those rendered as vulnerable from full participation in social life, including

ETHICS OF CARE AND RELATIONAL ETHICS

Taking the philosophical position of an ethics of care is consistent with Fineman (2008) and Gordon-Bouvier’s (2020) theorising that vulnerability and dependence are universal aspects of our humanity, rejecting the notion that the defining features of a person are rational thought and autonomy.

An ethics of care positions interpersonal relations and care as central to being a person, so it is not rationality and autonomy but the capacity to form human relations which is important (Jacobs et al 2021; Laurin and Martin 2022; Pollard 2015).

Grounded in ethics of care, relational ethics situates the relationship between so-called “participant” and researcher at the heart of ethical engagement (Bergum and Dossetor 2005). Focusing on the quality of interpersonal relationship across the research project is the central concern of the researcher, health and social care service provider and practitioner, and policymaker.

Bergum and Dossetor (2005) identify five principles of relational ethics:

1. **mutual respect** as a means of managing power asymmetry through acknowledging and accepting

research and service development activities. By understanding vulnerability as relational, we can consider instead what support is required to enable people to be included.

Finding ways to facilitate inclusion of groups who often find themselves marginalised and therefore “without a voice” (another tricky, potentially undermining phrase) is crucial when thinking about ethics.

2. **engagement that involves an embodied presence focused on the other person**
3. **embodied knowledge** that requires the use of cognitive but also, importantly, affective and emotional knowing
4. **interdependency** recognising that the self exists in relation
5. **uncertainty in vulnerability** – “Uncertainty is a truth that asks for humility rather than power, understanding rather than information, and relationship rather than ideology” (Pollard 2015: 367).

Within REALITIES, we take a relational approach to ethics placing the focus on the Research-Practice-Policy partnership and relationship, seeking to mitigate power asymmetries, and engaging in a way that is authentic.

We remain sensitive to the vulnerabilities experienced by many of our communities by placing the relationship at the centre of ethical engagement. In this way, there is the possibility of supporting engagement that can be experienced as safe and purposeful for all.

ETHICS OF RECOGNITION

An ethics of recognition engages with processes of seeing and hearing the Other (Ryan et al 2023). Across the REALITIES project, researchers (community-embedded and academic), project partners and other stakeholders are working with people who are often marginalised. People who belong to marginalised groups often find themselves positioned as “other” by those situated within the dominant discourses (for example, researchers/ academics/partner organisations) where assumptions and power asymmetries define relationships. Such assumptions and power asymmetries can close off the opportunity to recognise the “other”, perpetuating the symbolic violence experienced by marginalised people and creating the environment in which they experience exclusion from participation in the project.

In their paper, Milroy, Cutcher and Tyler (2018) draw on Butler (2005) and Ahmed

(2000, 2010) to argue for a “feminist politics of listening” (p394) which is predicated on an ethics of recognition. Such a move requires of the Research-Practice-Policy partnership that they focus on listening, resisting the urge to assume that we ‘know’ the other and apply a sense of coherence and conclusion to their narrative or identity.

This requires researchers, practitioners and policymakers to develop an ability to sit with ‘not knowing’ (as knowledge is only partial) and ‘not doing’ (a kind of counter to the activist imperative) as an ethical approach to recognising the “other”. Within REALITIES we encourage this practice of listening with openness to hearing community members in whatever way they present themselves.



ETHICS OF PLACEMAKING

REALITIES is focused on places in terms of the regions that form the boundaries of each geographical hub, as well as the different organisations or places that constitute the network of health and social care services within the region.

Eckinwiler (2016) discusses the idea of ethical placemaking, where places are understood as providing the potential for supporting health and human flourishing through providing access to the means for 'bodily integrity' such as healthcare, and upholding human rights such as the right to food and the right to live free of violence.

Engaging ethically in placemaking,

ETHICS UNDER EACH ASPECT OF THE REALITIES MODEL

Our [REALITIES model](#) makes meaning of community members' lived and felt experiences by analysing data – and changes or patterns – in People, Places, Processes, Price, Power and Purpose. We are also interested in the relationships between these 6Ps.

People

In REALITIES, a range of marginalised groups were identified as representing those people who are likely to be understood as vulnerable. This might be expected as vulnerability and marginalisation are bound up together: marginalisation exposes people to increased vulnerability (through lack of power) and vulnerability creates the conditions for marginalisation (through the perception that the vulnerable are dependent and therefore lacking autonomy). This creates a risk that those who find themselves in marginalised groups are not included and have no impact on service design or delivery because they are deemed vulnerable. It also

she argues, is predicated on two moral capacities of 'recognition' and 'responsiveness' (Eckinwiler 2016: 1946). In order to operationalise the capacity for recognition "requires attention to whatever is threatening the requisite conditions for care, bodily integrity, mobility, rootedness, and equity in particular places and, often, the relations between places" (Eckinwiler 2016: 1946).

The complementary capacity of responsiveness requires that we are attentive to the possibility that vulnerability leaves people open to abuse, and that where harms are done, we need to address these.

creates a risk of labelling and stigmatising – these categorisations somehow defining how these individuals and communities are perceived and treated.

The contextually dependent nature of vulnerability was also recognised. Researchers, practitioners, community members and other partners demonstrated some understanding that people might experience additional vulnerability in some contexts. Recognition of the impact of this additional vulnerability on a person's ability to participate can be facilitated through a relational approach to ethics which places caring at the heart of the ethical relationship.

Place

Our fieldwork identified a few places – defined as unhealthy systems – which might be connected with vulnerability including those connected to the care system and care homes, which suggest the idea of dependence (of looked after children and aging populations).

The justice system was also identified as a place connected with vulnerability and represents marginalised populations – marginalised by virtue of being labelled as a criminal and then additionally likely to belong to a marginalised population labelled as those with mental disorder, people (especially men) of colour, drug addicts and those defined as low socio-economic class.

Place was also simply defined as "geography" presumably meaning rurality, but possibly also urban places. Geography is connected to access to material resources, and also connected to lack of access to resource (including [greenspaces](#)), which might create vulnerability.

The lack of place-based identification of vulnerability is interesting and may be interpreted in two ways. Firstly, vulnerability is understood as being possible for people who are anywhere or displaced (note the reference simply to geography) and so the potential list of 'vulnerable places' is too expansive. Or secondly, that assumptions followed the normative approach which attaches vulnerability labels to groups of people rather than considering places as creating or maintaining positions of vulnerability.

If we revisit the notion of ethical placemaking proposed by Eckinwiler (2016) here, we have a responsibility to consider access to places that promote 'bodily integrity' (Eckinwiler 2016: 1945) such as healthcare, nutrition, greenspaces as well as upholding of other human rights. REALITIES focuses on how the places that people who experience vulnerability go to for help can best support them to meet their needs to ensure bodily integrity. As such, we take a situated approach to understanding the interdependence between people and place.

Power

Much of our data identifies marginalising systems or marginalised groups, recognising that marginalisation is about positioning in networks of power. Interestingly 'education' is also identified, resonating with Foucault's idea of the inextricable link between knowledge/power (Gavanta and Cornwall, 2008). But there is also some identification of power as agency – that the vulnerable can exercise autonomy and (or through) understanding their vulnerability. Other statements such as 'vulnerability or disruption?', 'strength or weakness' and 'liberating vulnerability – reducing guardedness' give a sense of the possibility of being both vulnerable and taking up positions of power; that the vulnerable, through 'owning' their vulnerability might have agency and exercise power.

Whilst power was discussed in the data primarily at the level of individual, it is important for this work to note the potential power hierarchies that exist when looking at the organisational level. This has potential to silence some organisational voices where third sector and statutory health and social care organisations are working together. Such hierarchies may be perpetuated by funding models where funding relies on particular relationships with bigger, statutory partners.

Some of the data was purposely situated between power and process – productivity, differently-abled, people with long term conditions. Productivity might be reference to the value systems against which we are judged; those who are unproductive are vulnerable to marginalisation (note the history of the mental health system) through lack of access to social goods. The placing of 'differently-abled and people with long term conditions' in the space between power and process is perhaps



a means of exemplifying the possibility of having agency/power (partly through their expert knowledge of the challenges they experience in the world and how best to navigate these) whilst also being vulnerable (to systems, to discrimination from individuals or systems).

Working co-productively aims to position those who participate (as organisations or individuals) as having relevant expertise derived from their experience. Working with Kahane's (2021) writing on facilitation, REALITIES actively seeks to create the conditions for full participation through careful, close listening and attending to what is happening in relationships, as well as taking a position where the facilitator's contribution is shaped by the needs of the participants in relation to supporting them to come to solutions. In this way the facilitator needs to work in a position of not knowing what the outcome of the work will be, allowing this to arise through the engagement of participants/partners and team. This is contrast to working from a position where the facilitator knows the solution/what needs to happen and works to push the group toward this.

Process

Our data showed that processes – and systems – create experiences of vulnerability through lack of boundaries and a lack of responsiveness to individual and community needs. The systems identified include to process of “research”.

On an individual level, there was also an observation that people who are positioned as vulnerable – and are aware of their label of vulnerability and how it impacts them and their lives – will have developed ways of responding to this. This suggests that systems, institutions, and those belonging to dominant social discourses need to trust people to do this and by inference not act paternalistically, which can in itself inflict injury.

Care as a process was also identified, and is central to the practice of relational ethics. Within the systems of health and social care organisations and research, the management, processing and sharing of data is regulated tightly for the protection of people who use these systems through the General Data Protection Regulation (GDPR) and other related policies. Whilst the tight management of data is necessary for public protection, it also impacts individuals and organisations where it generates difficulties in sharing data for instance between statutory and non-statutory organisations which might increase risk around safeguarding issues and the ability of people to receive integrated health and social care (see for instance NDG 2020; NAO 2017). Within REALITIES we ask how data can be shared in a way that supports the legal responsibilities of organisations, but also supports a good experience for those people using health and care services.

For our communities and consortium, data includes conversations and observations – including artistic, creative and embodied experiences (not always spoken) – within partner organisations or between organisations and community-embedded researchers. Our evidence-base moves beyond what is generated in a formal research data collection interaction such as an interview or focus group.

This means thinking carefully about informed consent for participants (individual and organisations) across the

life of the project. Drawing on relational ethics, research ethics can be understood as an ongoing process throughout a period of participation, where consent is checked verbally with individual and organisational participants following conversations or observations that would be relevant data to the project. This approach works at grassroot level with community-embedded researchers facilitating exploratory and experimental work with locals. Data are co-created and analysed between community-embedded researchers, community members and partners.

Is it possible to have a process of engagement with communities that allows for ethical collection of information from experiments and creative workshops that will retain the naturalistic and informal nature of the interactions through which data is generated?





Price

Price was not originally included in the REALITIES model, but through our foundational phase of research it became visible as an axis of decision-making in relation to ethical engagement with partners, participants and community-embedded researchers. Questions such as who should be paid, how much and what form payment should take require a balancing of the ethical imperative to demonstrate the value of partnerships and participation through payment with the finite resource of the project budget. The initial consideration of whether a person or partner should be paid is then complicated by issues such as how their contribution is evaluated in a context where academic pay scales offer little guidance, and therefore room for inequity and undervaluing.

Payment, either monetary or in-kind, is associated with status; it conveys the relative importance of a partner or participant to the project. As such, choices around who is paid, and how, impact the structures of relationships across the

consortium making some partners or participants more 'in' than others.

Purpose

Purpose was also not included in the REALITIES model, but also surfaced in our fieldwork as a key factor affecting wellbeing in relation to health inequalities. Several community members felt they had little to look forward to on a daily basis. Taking part in REALITIES sessions – creative workshops quite often in nature or simply connecting with frontline practitioners and researchers in a meaningful way – made them feel heard and gave them something to do.

We need to be mindful of the ethical implications of this in community-based research, where projects are funded for finite (often short) periods of time. Is it ethical to offer short-term engagements that provide a sense of purpose only to take these away once funding ends? Are we doing more damage to communities by not creating more sustainable and ethical solutions for creative engagements?

RESEARCH-PRACTICE-POLICY PARTNERSHIP IMPLICATIONS AND RECOMMENDATIONS

PEOPLE

- **Actively seek to include those who are members of marginalised groups** and work in ways that support them to be able to participate in whatever way feels right for them.
- **Draw on a relational approach to ethics** where there is constant reflection on the person or group's experience of participation, discussing with them at points where there are concerns about their wellbeing.
- **Safeguarding of participants is essential.** The Social Care Institute for Excellence (SCIE) provides excellent training materials which all partners, university and community-based researchers and practitioners should engage with to provide an underpinning knowledge of safeguarding and related procedures.
- **All engagement with individual participants should be within the context of the organisations with which they engage.** In the case of any safeguarding concerns, the organisation's safeguarding procedures should be followed. Where there are gaps in this provision, Research-Practice-Policy Partnerships should work together to attend to this need. Frontline practitioners and lone researchers should not be expected to carry this responsibility alone.

POWER

- **Engage with participants and partner organisations in a way that acknowledges and seeks to understand how power circulates** in the relationships between community members, partner organisations, researchers, practitioners and other team members.
- **Close listening and a position of openness** to hear and engage with the ideas proposed by all community members and partners will aim to support engagement and a sense of being valued.
- **As far as is possible, facilitation should come from a position of 'not knowing'** where the focus is on the knowledge generated through participant engagement to create solutions.

PROCESS

- **Participant information should be provided to all participating organisations and individuals who might choose to engage.** Community-embedded researchers should meet with all potential participant organisations to explain community-based projects and answer any questions. There should be an opportunity for community members to ask questions to a person who knows the details of the project and is identified as independent of the research team.
- **Data should ideally be co-created within participating organisations,** where they are analysed and used to understand the impact of the engagements that are happening as a means of testing out new systems and approaches. Community-embedded researchers should facilitate this process.
- **Research-Practice-Policy Partnerships should consider if or how raw data should be transferred between participating organisations and other partners.** Think carefully about who can and should receive raw data, where data are stored and how community members' identities are protected. The sharing of interpreted or co-analysed data may be necessary to safeguard community members, but it's important to think about if or how this process disempowers community members by censoring their views if they explicitly wish to be heard.
- **Where a community-embedded researcher or other member of the team becomes concerned about a potential safeguarding issue, the procedures within the participant organisation should be followed.** Data should only be shared only on a need-to-know basis and advice sought from consortium, project or team members following existing legal and ethical frameworks, also highlighting where these are not acting in the best interest of community members if they say, for example, that they are being silenced.
- **Partners involved in community-led projects should receive training using Social Care Institute for Excellence (SCIE) materials.**

PLACE

- **Working co-productively enables participants to explore the relations of people and place** and create opportunities for making changes that will promote human flourishing through identification of those structures and processes that threaten or create a barrier to such flourishing.
- **Work in a way that is mindful of power asymmetries within places** and the need to facilitate in a manner that supports participation.

PRICE

- **Decisions about which partners and participants are paid, how much and how need to be carefully considered** alongside sensitivity to the impact of payment on relationships between the project team, partners and community members.
- **Structures and processes should support ethical decision-making around payment and be co-produced** with partners, community members, community-embedded researchers, academics and university Human Resources and research support officers.
- **Payments to partner organisations should be equitable and transparent.**

PURPOSE

- **Is it ethical to fund short-term community-led projects** that end just when meaningful relationships are formed and community members feel a sense of purpose?
- **Community assets – including interpersonal relationships, artists and arts organisations, libraries, museums, heritage sites, green and blue spaces such as parks, the coastline and waterways, gyms and other sports and exercise-related assets, legal or debt advice services – can be mobilised through community-led Research-Practice-Policy Partnerships**, providing a sense of purpose in communities. That said, efforts are likely to be counterproductive – possibly exacerbating inequities – without sustainable funding at a larger scale and a long-term vision embracing a holistic approach to health and wellbeing.

CONTACT DETAILS

This policy brief was written by Rosie Stenhouse (Rosie.Stenhouse@ed.ac.uk) and Marisa de Andrade (Marisa.deandrade@ed.ac.uk), School of Health in Social Science, University of Edinburgh in collaboration with the REALITIES consortium.

REFERENCES AND RESOURCES

Our [Measuring Humanity website](#) has a range of resources including other Research-Practice-Policy Partnerships briefings in this series.

See also:

Bergum, V., & Dossetor, J. B. (2005). Relational Ethics: The Full Meaning of Respect. University Publishing Group.

Eckinwiler LA (2016) Defining ethical placemaking for place-based interventions American Journal of Public Health 106:1944–1946. doi:10. 2105/AJPH.2016.303433)

Fineman M (2008) The vulnerable subject: Anchoring equality in the human condition Yale Journal of Law and Feminism 20(1) https://papers.ssrn.com/sol3/papers.cfm?abstract_id=1131407

Gaventa, J., & Cornwall, A. (2008). Power and knowledge. The Sage handbook of action research: Participative inquiry and practice, 2, 172-189.

Gordon-Bouvier E (2020) Relational vulnerability: theory, law and the private family Palgrave Macmillan

Jacobs P, Quayle E, Wilkinson H, McMahon K (2021) Relationships matter! — Utilising ethics of care to understand transitions in the lives of adults with severe intellectual disabilities British Journal of Learning Disability 49:329–340.

Kahane A (2021) Facilitating breakthrough Berrett-Koehler Publishers inc: Oakland CA

Laurin AC and Martin P (2022) Towards democratic institutions: Tronto's care ethics inspiring nursing actions in intensive care Nursing Ethics 29(7-8): 1578–1588

Milroy T, Cutcher L, Tyler M (2019) Stopped in our tracks: From 'giving an account' to an ethics of recognition in feminist praxis Gender Work and Organisation 26:393–410.

National Audit Office (NAO) (2017) Health and Social Care Integration HC 1011 SESSION 2016-17 8 FEBRUARY 2017 Accessed on 25 June from <https://www.nao.org.uk/wp-content/uploads/2017/02/Health-and-social-care-integration-Summary.pdf>

National Data Guardian (2020) NDG report on barriers to information sharing to support direct care Accessed on 23 June 2023 at [NDG_survey_report_v1.4.pdf](https://publishing.service.gov.uk) (publishing.service.gov.uk)

Pollard CL (2015) What is the Right Thing to Do: Use of a Relational Ethic Framework to Guide Clinical Decision-Making International Journal of Caring Sciences 8(2): 362-368

Ryan A, Geiger S, Haugh H, Branzei O, Gray BL, Lawrence TB, Cresswell T, Sndreson A, Jack S and McKeever (2023) Emplaced Partnerships and the Ethics of Care, Recognition and Resilience Journal of Business Ethics 184:757–772 <https://doi.org/10.1007/s10551-023-05368-2>





THE UNIVERSITY
of EDINBURGH



Arts and
Humanities
Research Council

Grant Ref: AH/X006131/1
GRANT TITLE: REALITIES in Health Disparities: Researching Evidence-based Alternatives in Living, Imaginative, Traumatized, Integrated, Embodied Systems
Funder: UKRI AHRC-led grant - Mobilising community assets to tackle health inequalities
Grant holder: Marisa de Andrade, University of Edinburgh, School of Health in Social Science
Authors: This policy brief was written by Rosie Stenhouse (Rosie.Stenhouse@ed.ac.uk) and Marisa de Andrade (Marisa.deandrade@ed.ac.uk), School of Health in Social Science, University of Edinburgh, in collaboration with the REALITIES consortium.
Publication date: 1 November 2023

This output is the result of close collaboration between the REALITIES consortium hub investigators and partners. REALITIES is led by Marisa de Andrade at the University of Edinburgh (UoE) in collaboration with these co-investigators:

Nicholas Barton-Wines (freelance artist in collaboration with North Lanarkshire Council), Rhiannon Bull (UoE), Lucy Campbell (WEA), Scott Davis (UoE), Toby Lowe (Centre for Public Impact), Alan Marshall (UoE), Aileen Neilson (UoE), Mark O'Hare (Pre-employability in Clackmannanshire), Sneha Raman (The Glasgow School of Art), Sam Rowe (Bethany), Christina Sachpasidi (UoE), Candela Sanchez-Rodilla Espeso (UoE), Rosie Stenhouse (UoE)

And these partners: APEX, Architecture and Design Scotland, Dancebase, Ochil Youths Community Improvement (OYCI), North Lanarkshire Council, Scottish Opera

Cite this publication as: Stenhouse, R. and de Andrade, M, et al. (2023), Realising Relational Ethics in Community Health and Social Care Settings, Edinburgh: University of Edinburgh.

Creative Commons: This work is made available under a CC BY-NC-ND 4.0 license:
<https://creativecommons.org/licenses/by-nc-nd/4.0/>