Original Article

Research Ethics
1–14

DOI: 10.1177/17470161251388131
journals.sagepub.com/home/rea
Sage

Grounding ethical governance: Co-produced, community-based research ethics in qualitative and oral history practice with vulnerable groups

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Abstract

This article examines an embedded model of ethical governance, as practised by the Mind in Bexley Research and Ethics Advisory Board, in overseeing the *Unpaid Mental Health Carers in Bexley* oral history project. Unlike conventional university-based research ethics committees (RECs), this Board was rooted in the local community, comprising unpaid carers, mental health service users, clinicians, safeguarding leads and qualitative/oral history researchers. Its deep contextual knowledge, direct links to support and safeguarding pathways, and procedural rigour enabled ethical deliberations grounded in lived realities and local service infrastructures. The Board's design transformed ethics from a pre-approval checkpoint into an active safeguarding partner, exemplified by real-time crisis interventions during fieldwork. Meetings in accessible community venues, the use of plain-language documentation, and a collaborative approach fostered trust and transparency, aligning with the concept of "everyday ethics." Drawing on this case, the article argues that de-centralised, co-produced ethics governance can enhance contextual sensitivity, strengthen lived experience participation, and mitigate participant risk more effectively than standard institutional models. It concludes by considering implications for research governance frameworks seeking to embed ethical oversight within the relational and place-based contexts in which research unfolds, while recognising that statutory research ethics committees remain essential in biomedical and NHS-facing domains.

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Keywords
research ethics, participatory governance, mental health, lived experience, safeguarding, oral history

Introduction

Research ethics governance in the United Kingdom is dominated by centralised, institutional structures, primarily university-based Research Ethics Committees (RECs) and NHS Research Ethics Committees operating under the Health Research Authority (HRA) framework. Centralised ethics systems were developed after the Second World War to prevent research abuses such as those at Nuremberg, Tuskegee, and Willowbrook (Emanuel et al., 2004). This history explains why they remain strong in regulating biomedical research, but it also shows their limits when applied to narrative or community-based studies. The Mind in Bexley Research and Ethics Advisory Board does not dismiss this tradition. Instead, it adapts ethical oversight to contexts where relationships, trust, and co-production matter most. In doing so, it echoes critiques of Institutional Review Boards, which are often shaped by biomedical models that do not fit well with qualitative research (Stark, 2012). While these bodies play a critical role in ensuring compliance with legal, procedural, and professional standards, they are often "remote" from the communities in which research is conducted and constrained by procedural uniformity. For qualitative and oral history research with vulnerable populations, this institutional distance can limit the responsiveness, contextual sensitivity, and relational depth required to conduct ethical inquiry (Banks et al., 2013; Guillemin and Gillam, 2004). The Mind in Bexley Research and Ethics Advisory Board offers an alternative model, one in which ethical review and ongoing oversight are embedded in local networks of care, co-produced with participants, and grounded in community-based safeguarding frameworks. For clarity, this body is formally titled the Mind in Bexley Research and Ethics Advisory Board; throughout the remainder of this article, it is for ease referred to as the Mind in Bexley Ethics Board or the Board.

This model shifts the centre of ethical authority from distant, procedural committees to embedded, participatory bodies capable of sustained, iterative engagement with researchers and participants. While biomedical paradigms still dominate university and NHS ethics governance, it is important to acknowledge the more complex and uneven terrain of institutional ethics in the social sciences. ESRC and UKRI frameworks explicitly recognise iterative consent, relational ethics, and safeguarding (Carpenter et al., 2020). Yet these principles often remain proceduralised, implemented as regulatory checklists rather than embedded practices. The Mind in Bexley Ethics Board demonstrates how such principles can be reconstituted as lived, relational governance: not merely stated in protocols but enacted in practice, co-owned by researchers, participants, and community representatives. In this sense, the model operationalises what Banks et al. (2013) call "everyday ethics" by anchoring institutional aspirations in a participatory structure that resists reduction to compliance (Hammersley, 2009; Mauthner et al., 2002).

Such an approach aligns closely with oral history's longstanding concern with voice, representation, and the ethics of co-authorship (Portelli, 1997; Thompson, 2000). It is also consistent with the NHS Long Term Plan's emphasis on integrated, community-led care (NHS England, 2019), the Care Act 2014's safeguarding principles, and the NIHR's UK Standards for Public Involvement in Research (2019). By examining the Board's development and its application in the *Unpaid Mental Health Carers in Bexley* oral history project, this paper situates community-based ethics governance as a viable, scalable complement to institutional RECs, capable of delivering both procedural robustness and relational trust.

Historical background: From minding histories to the Mind in Bexley Research and Ethics Advisory Board

The origins of the Mind in Bexley Ethics Board lie in a 2012 UK National Lottery-funded oral history project, *Minding Histories*. The project set out to collect, preserve, and share life histories from Bexley residents with lived experience of mental health challenges, carers, and community activists in the London Borough of Bexley, with a particular focus on the intersections between migration, settlement, and wellbeing. Over 60 in-depth interviews were recorded with residents from Albanian, Bangladeshi, Burmese, Chinese, Ghanaian, Indian, Jamaican, Irish, Nigerian, Sri Lankan, Trinidadian, and Vietnamese backgrounds, representing both voluntary and forced migration histories. The findings revealed rich, deeply personal accounts of migration journeys, cultural adaptation, racism and discrimination, economic hardship, and resilience (Palmer, 2012). They also exposed recurring ethical challenges that standard university or NHS ethics review processes were ill-equipped to manage in practice. Many participants recounted traumatic events, from surviving Sri Lanka's "Black July" anti-Tamil violence to witnessing killings during the Ugandan Asian expulsion, in ways that required sensitive support and/or safeguarding responses. Others disclosed ongoing experiences of racism, housing insecurity, or carer strain that impacted their mental wellbeing and, in some cases, required direct signposting to additional support.

Two critical lessons from *Minding Histories* directly shaped the later design of the Board. First, the project demonstrated the importance of continuous consent and narrative control: in oral history, participants often wish to revisit their contributions after reflection, amending transcripts, altering attribution, or withdrawing material. In *Minding Histories*, this iterative consent process became central to sustaining trust and protecting agency, yet it was incompatible with the fixed, one-off consent models typically required by institutional RECs. Second, the project highlighted the need for embedded safeguarding and local response capacity. Disclosures during interviews occasionally signalled acute distress, and without embedded safeguarding professionals, the project team relied on improvised referral pathways. This experience prompted the later inclusion of the Mind clinical lead and safeguarding colleagues from the Bexley Safeguarding Adults Board permanent membership, ensuring that future projects could respond effectively to such situations.

From the outset, *Minding Histories* was conceived as both a cultural intervention, redressing testimonial silences (Fricker, 2007) by amplifying marginalised migrant voices, and a methodological stress test for ethical governance in community-based oral history. It demonstrated the necessity of an ethics structure embedded in local networks of care and support, co-produced with participants, and capable of sustaining long-term relationships beyond the life of a single project. The Mind in Bexley Ethics Board emerged from these insights, intentionally multidisciplinary and rooted in the lived and statutory contexts of Bexley. Its founding members included people with lived experience of mental ill health, unpaid carers, NHS clinicians, safeguarding leads and experienced oral historians. This composition ensured that ethical decision-making was informed not only by procedural standards but also by the relational and place-based knowledge that had proved essential in the *Minding Histories project.*

From procedural compliance to relational governance in oral history

Unlike biomedical research, oral history depends on ethics rooted in relationships: iterative consent, authorial control, and relational safeguarding (Thompson, 2000). These practices demand governance that is close to the field, participatory, and adaptive, rather than distant and procedural.

Ethical governance in qualitative and oral history research increasingly intersects with UK health policy, particularly in the wake of NHS England's drive to embed research within communities through Integrated Care Systems (ICSs; NHS England, 2022). The *NHS Long Term Plan (2019)* commits to research that is *"embedded in clinical and community services*" and delivered in partnership with voluntary and community sector organisations as part of a strategy to address entrenched health inequalities. This policy direction creates fertile ground for de-centralised, co-produced ethics structures such as the Mind in Bexley Ethics Board, whose authority is embedded not only in formal governance frameworks but also in place-based, lived community relationships. The National Institute for Health and Care Research's (NIHR) *UK Standards for Public Involvement in Research (2019)* and its updated *Learning for Involvement* resources (NIHR, 2023) frame ethical integrity as a practice that extends beyond procedural compliance. Research must be designed and conducted "with" and "by" communities, not merely "to" or "for" them. Recent NIHR-funded evaluations of co-production in integrated care (Conquer et al., 2024; Madden et al., 2020) emphasise that ethical governance should be flexible, iterative, and rooted in shared decision-making, especially when engaging participants whose voices are marginalised within traditional institutional research cultures.

This position resonates with relational ethics (Ellis, 2007), in which consent, safeguarding, and narrative agency are ongoing commitments rather than one-off administrative tasks. For example, in the *Unpaid Mental Health Carers* oral history project, consent was explored, revised and renegotiated during multiple stages of the interview and curation process, enabling carers to adapt how their narratives were used as their comfort and confidence evolved, a process that would have been difficult to achieve within a fixed, pre-authorised university REC framework. By contrast, the Health Research Authority's (HRA) Research Ethics Committee (REC) system, while robust for biomedical and interventional studies, often applies risk assessment frameworks ill-suited to qualitative methodologies. Biomedical paradigms can encourage default anonymisation, rigid methodological prescriptions, and procedural sign-off that is temporally fixed. Critics argue that these frameworks can misrecognise or undermine the epistemic needs of oral history, where named authorship and participant control over narrative are often ethically and methodologically preferable (Fricker, 2007; Guta et al., 2013; Hammersley, 2009; Portelli, 1997).

The NHS *Safeguarding Accountability and Assurance Framework* (2022) positions safeguarding as a shared, multi-agency responsibility, a principle operationalised by the Mind in Bexley Ethics Board through the direct inclusion of mental health and safeguarding professionals. This structure enables immediate, proportionate responses to disclosures of harm during research, ensuring that ethical review is not simply procedural but actively protective in practice, a capacity rarely found in university RECs.

Qualitative research with vulnerable groups

Centralised ethics regimes, though created to safeguard participants, often misinterpret vulnerability by reducing it to procedural uniformity rather than relational responsiveness (Banks et al., 2013; Hammersley and Traianou, 2012). This risks overlooking the situated and negotiated forms of protection required in qualitative and community-based research. Qualitative inquiry with vulnerable populations presents distinct ethical challenges that institutionalised review systems have historically struggled to address in context-sensitive ways (Banks et al., 2013; Hammersley and Traianou, 2012; Palmer, 2008).

While centralised RECs are designed to protect participants and ensure procedural compliance, their processes can inadvertently produce what Haggerty (2004) terms *ethics creep*, the incremental expansion of formal oversight into all aspects of the research process, often privileging bureaucratic

uniformity over the adaptive, relational responsiveness required in community-based work. Guillemin and Gillam's (2004) distinction between procedural ethics and ethics in practice is particularly relevant here. In community-based qualitative and oral history research, especially when working with individuals who have experienced trauma, discrimination, or social marginalisation, ethics in practice entails the real-time negotiation of consent, emotional boundaries, and interpretive authority. These negotiations depend on sustained engagement, trust, and local knowledge, qualities exemplified in the Mind in Bexley Board's approach, where ethical review is treated as a continuous partnership between researchers, participants, and governance bodies.

Institutional RECs, which review proposals at a distance from the field and to fixed timelines, often lack the mechanisms and local embeddedness required to sustain ongoing ethical deliberation (Guillemin and Gillam, 2004). In contrast, the Mind in Bexley model couples procedural rigour with embedded local relationships and safeguarding integration, enabling it to operate as an active ethical partner throughout the research lifecycle rather than merely as a gatekeeping mechanism.

Co-production as ethical governance: Mechanisms and limits

The concept of co-production has been widely discussed in health and social care as a means of ensuring that services, and by extension, research, are designed and delivered in partnership with those who use them (Boyle and Harris, 2009; Staley, 2017). In the context of research ethics, co-production extends beyond the inclusion of "lay members" on a research ethics committee; it entails a redistribution of power within ethical decision-making, ensuring that participants and community stakeholders have a meaningful voice in shaping research governance (Cornwall and Jewkes, 1995; Madden and Speed, 2017). This approach aligns with the UK Standards for Public Involvement in Research (NIHR, 2019), which emphasise inclusivity, partnership, and support as key principles. It also resonates with NHS policy commitments to personalised, integrated care (NHS England, 2019) and the Care Act 2014's emphasis on safeguarding as a shared community responsibility. Embedding ethics review within local organisations, as with the Mind in Bexley Ethics Board, operationalises these principles by ensuring that review processes are grounded in the lived realities and safeguarding frameworks of the communities involved. Analytically, our claim is that co-production functions here as a governance modality, redistributing decision authority, rather than as a recruitment or advisory method.

At the same time, co-production cannot be assumed to be inherently egalitarian. Power imbalances inevitably persist, with clinicians, safeguarding leads, and academics often carrying "institutional weight" that can overshadow lived experience perspectives. Within the Board, these risks were acknowledged and actively managed: rotating chairs prevented the concentration of authority, plain language documentation minimised exclusion through technical jargon, and lived experience members were supported and encouraged to set parts of the agenda to ensure their concerns remained central. Such measures did not erase tensions but created conditions in which hierarchies could be surfaced, negotiated, and, where necessary, challenged. In this way, co-production functioned not as a seamless consensus but as an ongoing negotiation of power (Beresford, 2016; Rose and Kalathil, 2019).

Oral history methodology, exhibitions, and ethical authority

Oral history's distinctive ethical tradition, anchored in iterative consent, participant control over narrative, and commitments to testimonial justice (Thompson, 2000; Yow, 2005), highlights the limits of procedural, institutionally centred governance while offering alternative principles through which research authority can be redistributed, safeguarded, and co-owned. Oral history

presents a distinct set of ethical considerations that challenge conventional REC procedures. As Portelli (1997) and Thompson (2000) emphasise, oral history interviews are not simply the extraction of data but co-constructed narratives shaped by the interaction between interviewer and narrator. Participants often speak about deeply personal and sometimes traumatic experiences, making trust, agency, and control over representation central ethical concerns (Bornat, 2010; Yow, 2005). Furthermore, oral history ethics extend beyond the moment of data collection to encompass questions of ownership, interpretation, and dissemination. Unlike in many social science methodologies, where anonymisation is the default, oral history participants may wish to be named as the authors of their stories, raising complex questions about intellectual property, public representation, and potential long-term impacts on the participant and their community. Institutional RECs, often designed for biomedical research, can struggle to accommodate these nuances (Guta et al., 2013).

By embedding oral historians, safeguarding professionals, and people with lived experience into its structure, the Board addresses these challenges through a relational and iterative model of ethical review. This allows for flexible consent processes, co-authored interpretation, and community-led decisions about public dissemination including exhibitions, aligning with Fricker's (2007) concept of testimonial justice, the ethical obligation to recognise and respect the credibility and interpretive authority of marginalised voices. The Oral History Association's (2018) *Principles and Best Practices* and the Oral History Society's guidance endorse iterative consent, narrative control, and participant authorship. These frameworks challenge biomedical defaults of anonymisation and validate named authorship when participants desire recognition (Bornat, 2010; Yow, 2005). The Board upheld these principles through layered consent and participant-led dissemination, demonstrating that oral history's distinctive ethical tradition can be embedded within community-based governance structures.

The literature suggests a growing convergence between participatory ethics, co-production in health research, and oral history's commitment to agency and co-authorship. However, the structural integration of these approaches into formal research governance remains limited. NHS policy documents such as the Long Term Plan (2019) and the Safeguarding Policy (2022) call for partnership-based approaches and community integration, but these commitments have yet to be fully realised within research ethics infrastructure. The Mind in Bexley model offers a practical instantiation of these principles, demonstrating how decentralised, community-based ethics boards can meet statutory obligations while enhancing participant agency and trust.

Methods transparency: Embedded ethical governance in practice

The ethical governance of the *Unpaid Mental Health Carers in Bexley* project was anchored in local embeddedness, relational trust, and procedural rigour rarely matched by conventional, university-based research ethics committees (RECs). The Mind in Bexley Ethics Board functioned not as a distant oversight body but as an "active partner" in the research, drawing strength from its diverse membership, deep contextual and local knowledge, and direct links to safeguarding and service delivery pathways. We specify the mechanisms, membership mix, layered consent workflow, escalation thresholds, and referral pathways, through which governance-in-action produced distinct ethical outcomes, moving beyond procedural compliance towards a situated and responsive ethics.

The Board integrated lived experience, professional expertise, and local knowledge, ensuring that ethical deliberations were grounded in Bexley's mental health and social care realities, sensitive to cultural context, and responsive to participant risk. All possessed current, lived knowledge

of Bexley's mental health and social care landscape. This combination of expertise ensured ethical deliberations were grounded in the realities of local provision, cultural context, and potential participant risk. Safeguarding and mental health professionals were embedded in statutory structures, enabling immediate responses to disclosures; in one case, a participant's account of severe distress led to a same-day referral to out-of-hours crisis support and provision of respite support. Such capacity transformed oversight from a static pre-approval mechanism into a dynamic safeguarding function, aligned with the Care Act 2014's principles of shared safeguarding responsibility.

The Board's plural composition generated productive tensions. Safeguarding professionals sometimes emphasised statutory thresholds, while carers highlighted lived realities of sustained risk. Rather than resolving these prematurely, the Board institutionalised deliberative practices in which difference itself became an ethical resource (Flyvbjerg, 2001). Structured disagreement allowed governance outcomes to be more nuanced and reflexive than those produced by conventional RECs, which often favour procedural consensus (Mouffe, 2000). The Board's multi-perspectival composition meant no single institutional or professional voice dominated. Lived experience was central rather than tokenistic, consistent with the NIHR UK Standards for Public Involvement (2019). Meetings were held in community venues with plain-language documentation and a collaborative, problem-solving ethos, creating an environment where researchers could raise ethical dilemmas without fear of judgement. This reflected Banks et al.'s (2013) concept of everyday ethics: iterative, relational practice sustained by trust, in contrast to the legalistic and procedurally distant processes common in institutional RECs, which often review research outside their own geographic and service contexts (Hammersley and Traianou, 2012).

Crucially, the Board's integration into Bexley's mental health ecosystem extended its reach beyond review. Established partnerships with Oxleas NHS Foundation Trust, the Bexley Voluntary Service Council, welfare and housing support services, and carer-specific peer networks meant that ethical review was coupled with the ability to act on risks in real time. In practice, governance became inseparable from safeguarding, community connection, and the co-production of solutions, a model that regulated, protected, and enriched the research simultaneously.

NHS policy, co-production, and ethical governance

Clarifying the boundaries of ethical oversight involves distinguishing where HRA or REC approval is legally required, where locally embedded community governance provides a proportionate alternative, and how hybrid or dual arrangements can be configured to ensure both compliance and contextual responsiveness. Ethical governance in qualitative and oral history research increasingly intersects with national health policy in the UK, particularly in the context of NHS England's ambitions to embed research in communities through Integrated Care Systems (ICSs; NHS England, 2022). The *NHS Long Term Plan (2019)* commits to "research that is embedded in clinical and community services" and this policy shift creates an opening for decentralised, co-produced ethics structures such as the Mind in Bexley Ethics Board. Recent NIHR publications, including the UK Standards for Public Involvement in Research (NIHR, 2019) and the Learning for Involvement updates (NIHR, 2023), emphasise that ethical practice extends beyond procedural compliance to ensuring that research is developed in genuine partnership with communities. This calls for governance models that foster collaboration, relational ethics, and reflexive engagement, enabling processes of continuous consent, safeguarding, and shared ownership of narratives.

In the NHS context, the Health Research Authority (HRA) manages the Research Ethics Committee (REC) system, which was originally developed to regulate biomedical and clinical trials (Health Research Authority (HRA), 2024). Although RECs now also consider qualitative

studies, commentators argue that biomedical assumptions continue to shape review practices, resulting in risk assessments that can be ill-suited to social research and an undue insistence on anonymity, even in cases where attribution or named authorship is ethically justified (Guta et al., 2013; Hammersley, 2009). In oral history, for example, default anonymisation may strip participants of agency and erode the testimonial justice that Fricker (2007) identifies as critical to correcting credibility deficits. The NHS Safeguarding Accountability and Assurance Framework (NHS England, 2022) provides another important policy touchpoint. It frames safeguarding as a collective responsibility across health, social care, and community partners, aligning closely with the Mind in Bexley Board's integration of safeguarding professionals into its governance structure. By contrast, most university RECs lack operational safeguarding capacity, leaving researchers responsible for navigating disclosures without direct institutional pathways for participant protection during fieldwork.

The carers project did not require NHS REC approval under the UK Policy Framework, as confirmed through the HRA decision tool, since it did not involve NHS patients, staff, data, or premises (HRA, 2024). In this context, community-based review was both proportionate and legitimate. However, the Board was never conceived as a wholesale substitute for statutory RECs, but as a complementary model particularly suited to qualitative and oral history research conducted outside NHS domains. Its remit is therefore bounded: when projects intersect with NHS patients, staff, or infrastructure, statutory REC approval remains essential. In such cases, a dual system, combining statutory procedures with community-grounded review, can secure both regulatory compliance and the ethical sensitivity that comes from embedding lived experience and local context into governance. This complementarity resonates with NHS and NIHR policy commitments to co-production. The NIHR's *Going the Extra Mile* review (2015) and subsequent guidance emphasise the need to move beyond "tokenistic consultation" towards shared decision-making and redistribution of power. Yet, as Madden and Speed (2017) caution, co-production can falter when absorbed into bureaucratic structures that privilege organisational risk over participant agency. The Mind in Bexley Ethics Board provides a counter-example: it embeds co-production at governance level itself, ensuring that ethical decisions are shaped by lived experience, local knowledge, and safeguarding expertise. This literature and policy landscape points to a growing recognition that ethical governance should be flexible, relational, and locally grounded, qualities that are difficult to achieve in centralised, institutionally bound RECs. As NHS policy continues to move towards integrated, place-based models of care and research, there is an opportunity to formally recognise and resource community-based ethics boards as equal partners in research governance.

Case study: The unpaid mental health carers in Bexley project

The case study illustrates how these governance principles were enacted in practice, producing concrete innovations in layered consent, responsive safeguarding, and participant-led dissemination that reconfigured ethical oversight from a procedural checkpoint into a continuous, co-produced practice. The *Unpaid Mental Health Carers in Bexley* project (2024–2025) was a qualitative audio-visual oral history study exploring the experiences, agency, and support needs of unpaid carers supporting relatives and friends with mental health challenges. It involved 15 participants, all of whom contributed extended narrative interviews, and many of whom engaged in follow-up workshops to co-produce thematic analysis, co-curate an exhibition and dissemination materials. Ethical governance was provided not by a university REC but by the Mind in Bexley Ethics Board, which oversaw the project from its inception through to dissemination. From the outset, the Board recognised that the project's oral history methodology required flexibility in both consent

processes and safeguarding responses. Participants were invited to revisit their consent decisions at any stage, including after interviews had been transcribed or edited for public exhibition. This continuous consent model was critical in cases where participants disclosed distressing or potentially identifying information. One carer reflected on the relief of knowing she could withdraw or edit her material:

> I didn't feel like I was signing my life away when I agreed to take part. It was more like. . . we're doing this together, I've got things I want to say and if I change my mind, that's fine. That meant I could speak more honestly.

The Carers project demonstrates how governance can generate concrete methodological and ethical innovations. The Board's system of layered consent enabled participants to decide between anonymity, pseudonymity, or open identification across different forms of dissemination, with the option to revise these choices retrospectively (Guillemin and Gillam, 2004). This not only extended the principle of ongoing consent but embedded it within a structured, participant-led framework. Safeguarding deliberations likewise exposed contrasting perspectives: statutory professionals tended to emphasise thresholds of crisis, whereas carers highlighted the cumulative effects of chronic stress, a form of vulnerability often overlooked by institutional ethics. By negotiating across these epistemic registers, the Board developed a hybrid safeguarding model responsive to both acute episodes of crisis and the cumulative harms of long-term caring (Liamputtong, 2007).

This illustrates the ethical value of continuous consent, as outlined by Guillemin and Gillam's (2004) distinction between procedural and in-practice ethics. By embedding consent renegotiation into the process, the Board ensured that participants retained agency over their narratives, an approach rarely available in standard institutional ethics frameworks, which typically treat consent as a one-time, pre-fieldwork formality. Several participants spoke about the trust that emerged from the relational nature of the project:

> I'd never told anyone that part of the story before. . . and I think that's because I knew the people involved understood what it's like to be a carer. It wasn't just a research formality. . . it felt like they genuinely cared.

Here, trust is grounded not in procedural assurances but in relational credibility, echoing Fricker's (2007) concept of testimonial justice. The Board's composition, including carers and mental health practitioners, meant that participants could see themselves reflected in the ethical governance process, reinforcing the sense that their accounts were understood and valued. The Board's safeguarding links were activated in instances where participants disclosed ongoing risks to their well-being or safety. In one case, a participant described the acute strain of caring for a family member in crisis:

> Sometimes I don't sleep for days. I'm scared to leave the house because I don't know what will happen if I'm not here.

This disclosure, while not the primary focus of the research, required an immediate conversation, facilitated by the researcher and supported by the Board's Clinical Lead. This demonstrates the practical advantage of a locally grounded ethics structure: where institutional RECs may provide general health and/or safeguarding guidelines, the Board could act directly, drawing on established relationships with local health and social care services. The Board also influenced dissemination practices. In oral history, public sharing of narratives is often integral to the research purpose

(Bornat, 2010; Portelli, 1997). However, in this project, the Board encouraged a multi-layered dissemination strategy, allowing participants to choose between anonymised excerpts, attributed narratives, or private archiving. One participant explained her choice to be named:

> This is my life. I don't want it hidden away. I want people to know what carers go through. . .and I want them to hear it from me, not from someone else telling my story.

This position reflects a challenge to default anonymisation practices, consistent with oral history's ethos of recognising authorship and agency (Thompson, 2000; Yow, 2005). By supporting this choice while ensuring that participants understood the potential long-term implications, the Board upheld both the right to be heard and the duty of care. The *Unpaid Mental Health Carers in Bexley* project demonstrates how a community-based ethics board can facilitate ethical responsiveness, safeguard participant wellbeing, and uphold narrative agency in ways that institutional RECs often cannot. The Board's continuous involvement, from design to dissemination, ensured that ethics was not a procedural hurdle but a relational, participatory practice embedded in the life of the project.

Discussion: Agency, voice, and the redistribution of ethical authority

The Mind in Bexley Ethics Board challenges the assumption that ethical authority in research must reside within centralised, institutional structures. Embedded in the borough's networks of care and support, it demonstrates that governance can be rigorous, responsive, and empowering when anchored in the lived realities of the communities involved. Its authority derives from the voluntary sector's grounded presence, long-term relationships, and intimate knowledge of local challenges, enabling it to anticipate issues and act immediately when safeguarding or stigma-sensitive dissemination concerns arise.

Unlike universities or NHS RECs, whose members often review projects far removed from their own contexts, this Board's members are of the place they govern: carers, service users, safeguarding officers, clinicians, and community advocates who share services and histories with participants. This embeddedness allows them to address risks in real time and shape ethical decisions with cultural and social nuance rarely possible in institutional frameworks. The Board's operation reflects what Guillemin and Gillam (2004) term *ethics in practice*, decision-making that is continuous, adaptive, and rooted in trust, rather than the front-loaded procedural ethics typical of institutional RECs. In the *Unpaid Mental Health Carers in Bexley* project, participants could amend or withdraw their contributions at any stage, a flexibility essential to oral history, where narratives are co-constructed, the interviewer becomes part of the story (Portelli, 1997; Thompson, 2000), and meaning emerges in the interaction. Here, that relational sensibility is institutionalised within governance itself. The theoretical payoff is a re-siting of ethical authority from distant proceduralism to place-based boards capable of testimonial justice and real-time safeguarding.

This approach also reframes the politics of research oversight. Critiques of "ethics creep" (Guta et al., 2013; Haggerty, 2004) resonate with Foucault's analysis of ethics committees as disciplinary apparatuses that extend the reach of biopower, normalising researcher behaviour through surveillance, codification, and the production of "docile bodies" within academia. From this perspective, the REC system is not neutral but part of a wider regime of governmentality, shaping what counts as legitimate knowledge and constraining the possibilities of inquiry. By contrast, community-based governance offers a form of what Foucault (2007) terms

"counter-conduct": practices that resist dominant regulatory logics by redistributing authority, valuing local knowledge, and embedding ethics in relational rather than purely procedural forms. By contrast, the Mind in Bexley Ethics Board represents a form of counter-conduct: redistributing authority away from bureaucratic centres towards those with insider knowledge of the community, its vulnerabilities, and strengths. This redistribution is also epistemic. Drawing on Fricker's (2007) concept of testimonial justice, the Board protects the right of marginalised speakers to shape how their narratives are interpreted, owned, and shared. In the carers' project, this meant supporting participants who wished to be named, challenging default anonymisation that can erase voice under the guise of protection.

Co-production is not treated here as a methodological add-on but as an ethical principle. Decision-making power is shared between lived experience experts, practitioners, and researchers, recognising each as equally essential to robust governance. The Board's voluntary sector base ensures safeguarding is an operational capacity, not a theoretical duty: it can act immediately when risk is disclosed, drawing on trusted relationships with mental health teams, housing providers, and welfare services. The Mind in Bexley model offers procedural robustness combined with the contextual intelligence, trust, and immediacy that come from being embedded in the community under study. As NHS England's (2022) Research and Development Strategy calls for embedding research in communities through Integrated Care Systems, such models provide both a complement and a counterweight to centralised proceduralism, redefining ethical authority as a living commitment to justice, trust, and mutual care rather than a distant compliance exercise. To maintain credibility, the Board established clear boundaries. Governance and review were separated from research delivery; members who supported design or analysis did so outside their governance role, within defined co-production workshops. Safeguarding referrals were delegated to professionals under agreed protocols. Conflicts of interest were disclosed and managed through recusal where necessary, for example when a Board member, while not in a direct caring role, knew a participant closely enough to create potential ambiguity about impartiality. These practices ensured transparency and role clarity, consistent with recommendations for ethical governance in social science (Israel and Hay, 2006).

The Bexley Board can be situated within a wider international movement to reclaim ethical authority for communities historically marginalised in research governance. In Canada, the Community Research Ethics Office (CREO) provides a widely cited example of ethics review embedded in voluntary and community sector organisations, enhancing accessibility, cultural safety, and trust (Community Research Ethics Office (CREO), 2024). In Australia, Kennedy et al. (2025) demonstrate how Human Research Ethics Committees (HRECs) often marginalise Aboriginal and Torres Strait Islander epistemologies, highlighting calls for Indigenous-led ethics structures grounded in cultural sovereignty. Canadian initiatives such as the First Nations Information Governance Centre (FNIGC) advance the well-established OCAP principles (Ownership, Control, Access, Possession), which have become a global benchmark for data sovereignty (First Nations Information Governance Centre (FNIGC), 2014). Similarly, Mi'kmaw Ethics Watch institutionalises collective authority over research, affirming relational accountability and resisting extractive methodologies (Bull, 2010). These developments converge with the influential CARE Principles for Indigenous Data Governance (Carroll et al., 2020), which emphasise Collective benefit, Authority to control, Responsibility, and Ethics. Taken together, these frameworks exemplify a transnational reconfiguration of research governance around epistemic justice and community sovereignty. The Bexley Board extends these global currents into a UK setting, embedding relational ethics and testimonial justice within a mental health and oral history framework.

Conclusion

The Mind in Bexley Ethics Board stands as a decisive challenge to the centralised, procedural orthodoxy of UK research ethics governance. Situated in the voluntary sector and embedded within the borough's networks of care and mental health support, it demonstrates that ethical authority need not, and in some cases should not, reside in distant institutions. By fusing procedural rigour with relational accountability, lived experience expertise, and operational safeguarding capacity, the Board delivers governance that is both compliant and contextually intelligent.

Its distinctiveness lies in being of the place under study, maintaining enduring relationships with residents and participants, and holding an intimate understanding of local services, inequalities, and cultural contexts. This insider knowledge transforms ethics from a front-loaded gatekeeping exercise into an ongoing practice of mutual recognition and care, one that can respond to safeguarding crises in real time, anticipate cultural sensitivities, and actively protect participant agency over narrative authorship. Framed through Foucault, the Board represents a form of counter-conduct, redistributing power/knowledge away from institutional centres and towards embedded, participatory bodies. Read through Fricker, it enacts testimonial justice by protecting the right of marginalised voices to be heard on their own terms, resisting the erasures that standardised anonymity and biomedical risk frameworks too often impose.

As NHS England advances its Integrated Care Systems agenda and commits to embedding research within communities, there is both a policy opportunity and an ethical imperative to formally recognise, resource, and integrate voluntary sector-led ethics boards as equal partners in national governance frameworks. Doing so would not lower standards but raise them, rooting decision-making in environments where research actually takes place, in bodies that combine procedural expertise with local legitimacy, support and safeguarding authority. This recognition should not be seen as a replacement for statutory RECs, which remain indispensable in biomedical and NHS-facing domains, but as a complementary extension that can enhance responsiveness and contextual sensitivity where traditional committees have limited reach. In conclusion, the Bexley model demonstrates how ethical governance, when embedded in community relationships and co-produced authority, can move beyond procedural compliance to enact a relational, responsive, and internationally resonant framework for research ethics in mental health and beyond.

Acknowledgements

The author wishes to thank all unpaid carers who shared their stories, the members of the Mind in Bexley Research and Ethics Advisory Board for their guidance, and Mind in Bexley staff for their support throughout the project.

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Ethical considerations

Ethical governance for the *Unpaid Mental Health Carers in Bexley* project was provided by the Mind in Bexley Research and Ethics Advisory Board. The Board included members with lived experience of mental health, safeguarding professionals, clinicians, and qualitative/oral history researchers, and operated in alignment with the UK *Care Act 2014* safeguarding principles and the NIHR *UK Standards for Public Involvement in Research*.

Consent to participate

All participants gave informed, written consent, with opportunities to review, amend, or withdraw their contributions at any stage.

Consent for publication

All participants gave informed consent for publication of their anonymised or attributed contributions, including in this manuscript.

Author contributions

The author designed the study, conducted interviews, facilitated co-production workshops, carried out the analysis, and drafted the paper. The Mind in Bexley Research and Ethics Advisory Board provided ongoing governance, support and safeguarding oversight.

Funding

The author received no financial support for the research, authorship, and/or publication of this article.

Declaration of conflicting interests

The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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