

COMMENT

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From tokenism to togetherness: the V.O.I.C.E. framework for safety-centred lived experience involvement in perinatal and parenting research

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Abstract

Background Early- and mid-career researchers (EMCRs) in perinatal and parenting research are highly motivated, and increasingly expected, to involve people with lived experience meaningfully in their work. However, substantial structural constraints can reinforce tokenistic approaches. Without practical, context-sensitive guidance, meaningful involvement can feel simultaneously mandatory yet unattainable, ultimately undermining partnership efforts. We aim to support EMCRs navigating these complexities by articulating a set of practice-informed principles to guide meaningful, safety-centred lived experience involvement.

Main body To support EMCRs in implementing authentic lived experience involvement, several key elements are required: voluntary participation, explicit attention to safety and boundaries, person-first relationships, and deliberate efforts to flatten traditional hierarchies between researchers and parents. The VILLAGE (Valued Individuals Living and Learning About Growing Equity) is an Australian network of parents and carers intentionally designed to support life-friendly, opt-in engagement throughout the entire research life cycle. Led by lived experience experts to assist researchers in this integration, the VILLAGE provides a concrete illustration of how relational, strengths-based, and rights-based principles for meaningful lived experience involvement can be operationalised as the Valuing Our Insights through Collaborative Engagement (V.O.I.C.E.) Framework across three interconnected domains: (1) *Relational and cultural foundations*, which focuses on the social conditions that ensure involvement is safe and respectful; (2) *Agency and voice*, which foregrounds who decides and how individuals exercise choice; and (3) *Structural integrity and reciprocity*, which addresses the material and ethical conditions required for credible involvement. Finally, to sustain EMCR practice, academic institutions, funding bodies, and scientific journals must play a critical role in enabling the VOICE Framework.

Conclusions Moving from tokenistic lived experience involvement to true togetherness requires deliberate attention to power dynamics, safety, and institutional recognition, alongside a willingness to value relationships as a core component of research practice. A vital opportunity exists for EMCRs, institutions, publishers, and journals to collectively reshape how partnership is understood and structurally supported in health and social research.

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Plain English summary

Early- and mid-career researchers in pregnancy, childbirth, and parenting want to include people with real, personal experience (lived experience) in their studies. They are often expected to do this, but they face major hurdles. These hurdles can make the inclusion feel like a “box-ticking” exercise rather than something genuine. Right now, there is a lack of practical advice on how to do this safely and meaningfully. We want to change this by creating a practical guide for researchers. By working alongside parents and caregivers from the VILLAGE network (an Australian network of parents and carers intentionally designed to support life-friendly, opt-in engagement throughout the entire research life cycle), we have created the Valuing Our Insights through Collaborative Engagement (V.O.I.C.E.) Framework which is a flexible set of guiding principles for meaningful lived experience involvement in research. These principles focus on respect, safety, human rights, and building on people’s strengths. Our guide is designed to be adaptable to real-world challenges and to other contexts, helping both researchers and everyday experts work together smoothly. Ultimately, our goal is to support meaningful, fair, and lasting partnerships that move far beyond tokenism.

Keywords Lived experience involvement, Consumer and community engagement, Early- and mid-career researchers, Perinatal research, Parenting research, Safety-centred involvement, Power and relational approaches, Tokenism

Introduction

Meaningful involvement of lived experience experts (often referred to as consumer and community involvement) is now widely recognised as an essential component of high-quality health research, including research focused on pregnancy, childbirth and early parenting [1]. Expectations for such involvement are embedded across funding, ethics and publishing systems, reflecting growing recognition that lived experience can strengthen relevance, ethics and impact. In perinatal and parenting research, involvement raises particular challenges due to the emotionally laden, embodied and relational nature of these life stages [2, 3], and the potential risks associated with burden, power imbalance and safety if involvement is poorly designed.

The originality and need for this commentary were established by practice-informed insights from EPOCH-Connect, an EMCR network building capacities for research to promote healthy growth in early childhood; the Health in Preconception, Pregnancy and Postpartum Early and Mid-career Researcher Collective (HiPPP EMR-C); and VILLAGE, a national lived experience network. Within HiPPP EMR-C, which has supported capacity building for early and mid-career researchers (EMCRs) since 2019, the need for practical resources on working with lived experience experts emerged from members’ experiences of trying to meet growing expectations for involvement within constrained research systems. These practice informed insights were complemented through a targeted narrative search of relevant literature on lived experience involvement, consumer and community involvement, co-production, tokenism, patient and public involvement, EMCR research culture, and perinatal and parenting research. While existing literature increasingly emphasises the importance of

meaningful lived experience involvement, we identified limited practical guidance that explicitly addresses how EMCRCs can enact safety-centred, relational involvement within the structural constraints of perinatal and parenting research.

This Commentary aims to support EMCRCs working within these contexts by articulating a set of practice-informed principles to guide meaningful, safety-centred lived experience involvement. Drawing on partnership with parents and carers through the lived experience VILLAGE network [4], we outline the Valuing Our Insights through Collaborative Engagement (V.O.I.C.E.) Framework which provides a set of principles for meaningful lived experience involvement in research, grounded in strengths-based and rights-based approaches, intended to be adaptable rather than prescriptive, and responsive to real-world constraints. We provide pragmatic guidance for researchers, while also highlighting broader implications for institutions and publishers in supporting ethical and sustainable lived experience involvement practices.

Why meaningful lived experience involvement remains challenging for early- and mid-career researchers

As in many fields, research about pregnancy, childbirth and early parenting spans a wide range of disciplinary traditions, including biomedical and clinical research on pregnancy, labour, breastfeeding and maternal health; health services and maternity care research; population-level and epidemiological studies of perinatal trends; and sociological and qualitative research examining the lived realities of pregnancy and early parenting [5]. Across these diverse research disciplines, there is increasing expectation that parents and families contribute not only as participants but as partners whose lived

experience informs research priorities, design and interpretation [6]. Funding bodies, ethics committees and publishers increasingly require evidence that people with lived experience have been involved in research prioritisation, design, interpretation, implementation and translation [7, 8]. This shift reflects longstanding critiques of extractive research practices and a growing recognition that lived experience expertise strengthens relevance, ethics and impact and should be meaningful in nature.

For EMCRs, expectations for meaningful lived experience involvement often sit alongside structural constraints such as short-term contracts, limited budgets, evolving roles, recruitment to projects already funded or underway, and governance processes not designed for partnership [9]. Although involvement frameworks commonly assume access to lived experience networks, senior mentorship and flexible administrative systems, these resources are not always available [10, 11]. Consequently, involvement can default to late-stage consultation, one-off advisory roles or symbolic activities that satisfy funding or publication requirements [12]. Such approaches risk reinforcing tokenism (i.e. a superficial or symbolic effort, rather than meaningful effort), placing undue burden on parents and carers, and misrepresenting cursory ‘engagement’ as meaningful [13]. EMCRs may also experience anxiety about “getting it wrong”, causing harm, overstepping boundaries, or being unable to manage conflict, particularly in emotionally charged research contexts [14], making meaningful involvement feel simultaneously expected and unattainable. For EMCRs, this is a productive but uncomfortable tension: wanting to practise co-production ethically, while recognising that academic systems often reward speed, outputs and compliance over the slower relational work required for genuine partnership. Further, recent progression in these expectations means that senior researchers are often ill-equipped to support EMCRs to engage lived experience experts in their work. Practical, context-sensitive guidance is therefore needed to help EMCRs navigate the gap between institutional expectations and real-world constraints.

Why perinatal and parenting research requires particular attention to safety

Partnership with lived experience experts must always consider safety, but requirements vary for different lived experience groups. Perinatal and parenting research relates to experiences that are often embodied, emotionally laden, deeply personal and diverse (e.g. birthing and non-birthing parents, first-time versus subsequent parents, and parents of children of varying developmental stages). In this context, safety requires approaches that recognise parents and carers as knowledge-holders with expertise, rather than solely as vulnerable participants.

Importantly, vulnerability does not equate to incapacity to make informed decisions about involvement [15]. Parents and carers may be navigating fatigue, caregiving responsibilities, financial stress, trauma, grief or ongoing health concerns, but these circumstances do not negate their agency, expertise or right to decide whether and how they wish to contribute [15, 16]. Participation in research, including involvement beyond traditional participant roles, therefore carries potential emotional, psychological and practical risks ranging from discomfort to substantial burden on time, emotions and finances. These impacts may be unevenly experienced and further shaped by cultural context, including differing expectations or stigma around parenting practices.

Involvement approaches that prioritise efficiency or researcher convenience, without explicit attention to safety, choice and power, risk excluding those who cannot participate in conventional research pathways or may inadvertently cause harm, highlighting how the system itself acts as a barrier for meaningful engagement practices [17]. This includes pressure to disclose personal experiences, expectations of unpaid emotional labour, or assumptions about capacity and availability [16, 18–20]. These risks are intensified in perinatal and parenting contexts, where gendered expectations of care and responsibilities, inequities in whose knowledge is valued, and normative assumptions about parental responsibility can shape who is invited to contribute and how [21]. Without deliberate, safety-centred approaches, involvement risks reinforcing existing inequities rather than mitigating them.

For EMCRs, these important relational dynamics intersect with their own precarious positions within academic hierarchies. EMCRs are frequently responsible for enacting lived experience involvement in practice while having limited authority over study design, timelines, budgets or institutional processes shaped by more senior decision-makers, and many are still learning how these hierarchies operate in practice. As a result, they may feel simultaneously accountable for creating safe, inclusive spaces for lived experience involvement while also navigating upward power, institutional expectations and constraints [9]. At the same time, EMCRs often bring strengths to this work, including reflexivity about power, openness to relational approaches and a willingness to question established norms; harnessing these strengths requires involvement models that explicitly support safety, clarity and shared responsibility for lived experience experts and researchers alike.

Table 1 The Valuing Our Insights through Collaborative Engagement (V.O.I.C.E.) Framework: principles, purpose, pragmatic actions and illustrative examples for meaningful lived experience involvement

Principle	Purpose	Pragmatic actions for EMCRs	Illustrative example
Relational & Cultural Foundations			
Person-first relationships [6, 12]	Builds trust and reduces hierarchy.	Introduce yourself beyond title; invest in relationships before outputs. Begin and end meetings with brief check-ins that allow all members to share energy, pressures or needs, with responses acknowledged rather than problem-solved.	Researchers and lived experience experts share background and motivations for involvement in research and follow up on changes made. Meetings begin with a check-in and acknowledgements of contributors' time, expertise, and competing responsibilities.
Strengths- and rights-based language [6, 13]	Language signals values and inclusion.	Avoid jargon; check terminology preferences; invite tone review.	Guidance materials are revised to be more accessible, and participants have active input on chosen terminology where appropriate. Reports reflect contributors as partners and co-thinkers rather than "participants" or "subjects."
Safety as shared and intentional [11, 18, 19]	Enables honest contribution and reduces harm.	Co-create group agreements; check-ins; flexible participation.	Confidentiality norms are agreed and revisited. Normalise and enable breaks throughout discussions—by clearly inviting pause, allowing flexible participation, and offering supportive follow-up where needed.
Agency & Voice			
Opt-in, choice and control [11, 16]	Supports autonomy and safer participation; reduces pressure to disclose.	Offer multiple contribution modes; make passing (opting out) acceptable; clarify how input will be used.	Parents contribute in ways that suit them, e.g., via online chat function or follow-up email without explanation for response choice. Contributors choose whether their input is anonymised, attributed, pseudonymised, acknowledged or co-authored.
Power awareness and shared decision-making [8, 12, 16]	Addresses tokenism and enables genuine influence.	Name power dynamics; share agenda-setting; ask what decisions lived experience experts want to influence.	Meeting agendas are co-created with parents and carers. Contributors shape the project from conceptualisation to publication.
Structural integrity & reciprocity			
Fair recognition and remuneration [7, 11, 13]	Treats lived experience as expertise; supports equity.	Budget early; be transparent about budget and expected involvement; minimise admin burden; explain any changes clearly; offer choice where possible in remuneration and recognition; discuss authorship transparently.	Contributors can choose from options for recognition and remuneration, such as payment, voucher, reimbursement, supervision or mentoring opportunities, authorship, conference/networking opportunities, acknowledgement, certificate or future research opportunities. Payment processes are explained upfront and delivered promptly after contribution.
Accountability and responsiveness [1, 12, 16]	Prevents extractive involvement; builds credibility.	Close the loop; document what changed and why.	A brief "you said / we did" summary is shared. When suggestions cannot be acted on, a clear explanation is provided to contributors.

Practice-informed principles for meaningful lived experience involvement

This Commentary draws on practice-informed partnership with parents and carers to illustrate an approach to involvement in perinatal and parenting research that is itself informed by lived experience. The VILLAGE (Valued Individuals Living and Learning About Growing Equity) is an Australian network of parents and carers, intentionally designed to support life-friendly, opt-in engagement with research throughout the entire research life cycle, from inception to evaluation. The development of the VILLAGE was led by lived experience experts, designed to support researchers to meaningfully involve lived experience in their work.

The VILLAGE was established to address a recurring gap in research practice: the absence of accessible spaces where lived experience expertise can shape research questions, design and decisions early, rather than being

consulted late or selectively [12]. Key features include voluntary participation, explicit attention to safety and boundaries, person-first relationships, and deliberate efforts to flatten hierarchy between researchers and parents. The VILLAGE provides a concrete illustration of how relational, strengths-based and rights-based principles can be operationalised in practice. While the VILLAGE provides the practice example for this commentary, EMCRs should also seek out and learn from existing lived-experience researcher networks, including discipline-specific, local, national and international networks where appropriate. Drawing on this practice- and lived experience expertise, we propose the VOICE Framework, a set of principles that EMCRs can adapt to support meaningful involvement of lived experience in research, even within real-world constraints (Table 1). The VOICE Framework offers a flexible, practice-oriented set of principles rather than a prescriptive checklist

that emphasises that meaningful involvement is less about specific activities and more about how relationships are built, maintained and valued.

The VOICE Framework is organised into three interconnected domains. Relational and cultural foundations focus on the social conditions that make involvement safe and respectful, including person-first relationships, strengths- and rights-based language, and safety as an intentional, shared practice. Agency and voice foreground who decides and how people exercise choice, encompassing opt-in participation, choice and control, and explicit attention to power and shared decision-making. Structural integrity and reciprocity address the material and ethical conditions required for credible involvement, emphasising fairness, accountability and reciprocal recognition of lived experience expertise.

Importantly, the VOICE Framework provides principles that are mutually reinforcing rather than standalone. For example, opt-in participation strengthens safety, accountability helps prevent extractive practices, and fair recognition signals that lived experience expertise is valued alongside academic expertise. In practice, it may not always be possible—particularly for EMCRs—to enact all principles fully in every context. Reflective tools such as the ladder of co-production may also help researchers assess whether involvement remains consultative or tokenistic, or moves towards shared decision-making and partnership. Some actions are relatively easy to implement, while others require more time, resources, or institutional influence and may add to workload. However, being explicit about this framework can help EMCRs identify where they can exert influence and prioritise actions that are feasible. Attending first to foundational relationship-building can enable later principles to be enacted, and even incremental progress across multiple areas is likely to improve the quality, integrity, and sustainability of involvement over the long term.

Implications for EMCRs, institutions and journals

Adopting relational, safety-centred approaches to ensure meaningful involvement has implications beyond individual research projects. For EMCRs, this work requires time, emotional labour and confidence to name uncertainty, limits and power dynamics [9, 14]. These demands are often invisible within traditional academic metrics and research timelines, yet are central to ethical partnership. Supporting EMCRs in this work requires recognition that involvement is not an “add-on”, but a core research activity that warrants resourcing, training, mentorship and institutional support [12, 22]. The VOICE Framework can also be applied by more senior academics and in diverse contexts, outside of parenting and families, to assist meaningful involvement of lived experience by all researchers.

Institutions and funders play a critical role in enabling meaningful involvement through flexible governance processes, accessible remuneration systems and realistic timelines. Without such support, responsibility for “making it work” is pushed onto individual researchers, increasing the risk of burnout or superficial involvement.

More broadly, meaningful lived experience involvement has implications for the research product itself. When parents and carers are engaged voluntarily, safely and with genuine influence, their expertise can shape not only research priorities and methods, but also how findings are interpreted, contextualised and communicated. This may lead to outputs that are more relevant, accessible and ethically grounded, including publications, reports, resources, policy recommendations and dissemination strategies that better reflect the realities of families’ lives. Voluntary engagement is particularly important because it helps ensure that contributions are offered with choice and agency, rather than through obligation or pressure. This can strengthen the credibility of the final research product by making transparent whose perspectives informed the work, how those perspectives shaped decisions, and where limits remain. At the same time, researchers should avoid presenting lived experience input as universally representative; rather, it should be understood as situated expertise that can deepen interpretation, challenge assumptions and improve the usefulness of findings for communities, services and systems.

Journals can support this shift by encouraging authors to report not only whether lived experience involvement occurred, but how it influenced interpretation, outputs and dissemination decisions. Further, by valuing reflective, practice-informed contributions and recognising diverse forms of expertise, including lived experience authorship without academic affiliations, journals can help legitimise relational approaches to involvement [11]. Clear and consistent guidance on authorship, acknowledgement and reporting of lived experience contributions would further support equitable practice.

Conclusions

Meaningful involvement of parents and families in perinatal and parenting research is essential, but it cannot be achieved through procedural requirements alone. For EMCRs, relational, strengths-based and safety-centred models offer a way to engage ethically and sustainably, even within structural constraints. Moving from tokenism to togetherness requires deliberate attention to power, safety and recognition, and a willingness to value relationships as a core component of research practice.

As expectations for lived experience involvement continue to grow, there is an opportunity for EMCRs, institutions and publishers to collectively reshape how

partnership is understood and supported in perinatal and parenting research. Doing so will not only reduce harm and burden, but also strengthen the relevance, quality and impact of research for parents, families and communities. The VOICE Framework offers a practical, adaptable tool to support EMCRs in navigating lived experience involvement as an essential component of high-quality research.

Abbreviations

EMCRs Early- and mid-career researchers

Acknowledgements

Thank you to the VILLAGE network and their contributions to developing the recommendations. We acknowledge the expertise of the lived experience experts who guide and support the work of the VILLAGE as well as the voices that came before us to strengthen this work and practice. We value and thank the strength that comes from these very personal and real sharings to change greater health, social and educational outcomes for all. We would also like to acknowledge Professor Helen Skouteris, principal mentor for the HiPPP EMR-C and VILLAGE, for her support in preparing this manuscript. VILLAGE was established with the support of a Maureen Brunt Professorial Fellowship awarded to Professor Skouteris to establish the SEMPRe program of research: Strengthening impleMentation Practice and Research with Equity (SEMPRe) - ALWAYS putting equity front and centre.

Author contributions

MLG, JA, KK and BH conceived the Commentary and led its development as researchers. AG and TM are members of the VILLAGE lived experience network, and together with RT contributed as lived experience authors, shaping the conceptual framing, principles and illustrative examples based on their expertise as parents and carers. All authors contributed to drafting and revising the manuscript, approved the final version, and agree to be accountable for the work.

Funding

This paper was written with the support of grant funding from the Theo Murphy Initiative (Australia) administered by the Australian Academy of Science (TMI_706-TMIAMP25).

Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Declaration of generative AI use in the writing process

During the preparation of this manuscript, the authors utilised Microsoft Copilot and Google Gemini solely to improve readability, grammar, and syntax. The tool was applied exclusively to refine the authors' original work and enhance linguistic clarity. After using this service, the authors reviewed and edited the output to ensure accuracy, and take full responsibility for the final content and integrity of the publication.

Competing interests

The authors declare no competing interests.

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Received: 16 June 2026 / Accepted: 26 August 2026

Published online: 02 September 2026

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