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From consultation to shared power: a practical workshop on genuine co-leadership with lived-experience partners in maternity and newborn research

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Abstract

Background: Lived-experience partnership is expected in perinatal research, yet practice ranges from consultation to shared decision-making. Barriers arise before consumers enter the room: **Awareness** —do people know partnership is possible? **Access** —who is invited? **Readiness** —are consumers and researchers supported to work as equals?

Aim: To address Awareness, Access and Readiness barriers to genuine co-leadership.

Workshop: This interactive 60-minute session is co-led by lived-experience leaders and researchers from Australia and the UK, with experience spanning the Maternity Consumer Network, Wait a Minute or More (WAMM), co-leadership with prioritised communities, Liverpool Birth Options, CHAPTER, C-STICH2 and Women's Health Innovation (WIN) Studio. Their insights are informing co-design of a proposed UK–Australia Safer Birth at Term platform trial.

Small groups will analyse a trial in which lived-experience partners are invited *after* the research question is set, while the protocol is developing. They will consider what can still change, which decisions should have been shared earlier, and how to redesign the project for genuine co-leadership, including whose knowledge counts, what lived-experience partners can influence, how disagreements are handled and how their influence is documented.

Learning outcomes: Participants will distinguish consultation from shared power, identify barriers to genuine co-leadership, and apply these principles to their research.

Take-home: Participants receive a checklist and curated UK–Australian resources aligned with the UK Public Involvement Standards, NHS Maternity and Neonatal Voices Partnerships, RCOG Women's Voices, 2026 NHMRC–Consumers Health Forum Statement and Health Research Hub, to assess lived-experience partners' access, equality and influence in their research plans.

From lived experience to system change: Australian lessons from consumer-led maternity advocacy

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Abstract

Background

Maternity Consumer Network (MCN) is an unfunded, volunteer-led organisation working across maternity policy, advocacy, research and service reform.

Aim

To examine how consumer-led advocacy translated lived experience into policy and practice, and identify lessons for maternity services.

Approach

A practice-based case study reviewed MCN campaigns, public records, training activity and advocacy since 2016.

Findings

MCN helped secure Australia's national Woman-centred care strategy and served on its Project Reference Group; 535 MCN consumer responses were recorded in the first consultation round. When continuity of midwifery care was downgraded in the draft strategy, MCN mobilised more than 1,500 further submissions. MCN moved from policy to implementation by developing Better Births with Consent, Australia's first Respectful Maternity Care training programme, delivered across more than 60 sites to over 1,400 participants. To address preventable birth trauma, MCN helped catalyse the NSW parliamentary Birth Trauma Inquiry, contributed more than 700 women's stories, and developed Guidelines for the Prevention of Perinatal Trauma for clinical practice and quality improvement. Its Bush Babies campaign also helped prompt Queensland's Rural Maternity Taskforce and rural maternity reforms including re-opening of rural maternity services.

Conclusion

Consumer leadership can influence policy, workforce learning, service reform and accountability. These examples show consumers can be national implementation partners, not merely consultees. Impact was greatest when lived experience was combined with evidence, media engagement and sustained relationships with clinicians and policymakers. However, unpaid consumer labour threatens sustainability and equity.

Further Information: ABC Radio National Breakfast interview, 30 Jul 2026 – Changing Australia: www.abc.net.au/listen/programs/radionational-breakfast/changing-oz-alecia-staines-respectful-maternity-care/106973866

Parent-partners in multidisciplinary quality improvement at birth: implementation lessons from the Australian WAMM (Wait A Minute or More) study

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Abstract

Background: Delayed cord clamping for ≥ 60 seconds (DCC60) reduces death and disability in preterm infants, yet uptake remains inconsistent. WAMM (ACTRN12624000035527) was a stepped-wedge cluster-randomised implementation trial of locally adapted Evidence-based Practice for Improving Quality (EPIQ) interventions in 5,585 eligible preterm newborns across 18 Australian hospitals.

Methods: Multidisciplinary quality improvement (QI) teams incorporated local parent-partners supported by a central parent-facilitator (Melinda Cruz). Parent-partners were recruited through professional and social networks, undertook EPIQ training, contributed to Plan-Do-Study-Act (PDSA) activities, parent-facing materials, discussions about implementation of DCC60 and received site-managed remuneration. Process measures included recruitment, participation in training and engagement in QI activities.

Results: Fourteen parent-partners were embedded across participating sites and comprised 9.2% of local QI-team membership. Seven of 14 (50%) attended EPIQ training and six of 14 (43%) participated in cross-site collaborative meetings. Parent-partners identified barriers that were not initially apparent to clinicians, including information being provided too close to delivery for families to absorb, prompting earlier communication. Challenges included lack of a national parent-partner registry, difficulty attending in-person meetings and inconsistent remuneration pathways.

Conclusion: Embedding parent-partners within multidisciplinary maternity and neonatal QI was feasible and well received. These lessons are informing consumer-partnership structures, including systematic recruitment, preparation and training, flexible participation and reliable remuneration for parent-partners, in a proposed UK–Australia Safer Birth at Term platform trial.

Trust, cultural safety and relational decision-making: Aboriginal and Torres Strait Islander and Pasifika women's perspectives on participation in a future perinatal platform trial

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Abstract

Introduction: Aboriginal and Torres Strait Islander and Pasifika communities in Australia experience inequities in perinatal outcomes, yet remain underrepresented in perinatal research. The iSEARCH Pre-Platform Pilot explored how a future platform trial could support culturally safe and equitable participation.

Objective: To explore Aboriginal and Torres Strait Islander and Pasifika women's perspectives on participation in pregnancy and birth trials, including barriers and enablers, perceptions of risk, preferred engagement approaches, and expectations of culturally safe research.

Methods: Twenty-three women participated in the study, including 15 Aboriginal and Torres Strait Islander women and 8 Pasifika women of reproductive age residing in NSW, Australia. Data were collected using Yarning and Talanoa, culturally informed qualitative methodologies grounded in relational engagement, storytelling, collective knowledge sharing, reciprocity, and community leadership. Discussions were audio-recorded, transcribed and analysed using reflexive thematic analysis, with findings interpreted within respective cultural contexts.

Results: Nine interconnected themes were identified. Trust and cultural safety were foundational. Decision-making was relational, involving family, community and responsibility towards the unborn child. Respectful relationships, continuity, listening and recognition of cultural knowledge shaped willingness to participate. The word "trial" could evoke uncertainty or exploitation, underscoring the importance of strengths-based, culturally meaningful communication. Invitation timing, health literacy, previous trauma or miscarriage, and experiences navigating health systems influenced participation. Community endorsement, family involvement and culturally guided recruitment pathways were important.

Conclusion: Culturally safe participation is not simply a recruitment strategy. Trust, relationships and community leadership must shape trials from the outset, including a proposed UK-Australia Safer Birth at Term platformTrial.

From evidence to routine practice: four shared UK–Australian implementation themes from PERIPrem and the Wait a Minute or More (WAMM) stepped-wedge trial

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Abstract

Background: Delayed cord clamping for ≥ 60 seconds (DCC60) reduces mortality and disability in preterm infants but remains inconsistently implemented. PERIPrem implemented an 11-item preterm care bundle across 12 NHS Trusts using quality-improvement (QI) methods; full-bundle delivery rose from 3% in 2019 to 29% in 2021. In South-West England, DCC60 in babies < 34 weeks increased from 45% at baseline in April 2019 to 84% by March 2026. WAMM combined routine data feedback with QI across 18 Australian hospitals.

Methods: PERIPrem themes emerged from quantitative and qualitative process evaluations, implementation experience and dashboard data. WAMM themes emerged from its protocol and structured reflections by the central implementation team.

Results: (1) Implementation required local multidisciplinary leadership, dedicated time and resources. (2) Data collection alone was insufficient: timely feedback helped teams identify barriers, test solutions and adapt. (3) Both programmes paired central support, coaching and peer learning with local adaptation. (4) Sustained effort, protected time and infrastructure were essential; workload, staffing and system constraints limited progress. Programme-specific challenges included data-system and governance issues in WAMM, and bundle complexity and professional hierarchies in PERIPrem.

Conclusion: Four shared requirements for bridging the *evidence-to-practice gap* are: funded local leadership; timely feedback with iterative improvement; central support with local adaptation; and sustained effort with adequate infrastructure. This gap has been called the “valley of death.” Crossing it may require as much investment in implementation systems as in trials that generate evidence. These insights are informing development of a UK–Australia Safer Birth at Term platform and learning system

EASing Oxytocin in Early Labour - OUTcomes for Mothers and Babies (EASE-OUT): a feasibility randomised controlled trial

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Abstract

Background: Optimal oxytocin dosing during induction of labour remains uncertain. In the UK iHOLDS trial (SSRN 7110027), high-dose versus standard-dose oxytocin did not significantly reduce caesarean birth (45% vs 40%) and it increased uterine tachysystole (43% vs 35%). EASE-OUT (ACTRN12622001342707; medRxiv 2026.07.18.26358404; doi:10.64898/2026.07.18.26358404) asked the complementary question: can oxytocin exposure be reduced once active labour is established?

Objective: To assess feasibility of a definitive randomised trial comparing halved- versus routine-concentration oxytocin during active labour after induction.

Methods: Multicentre, double-blind, 1:1 randomised feasibility trial in two Australian hospitals. At active labour, participants received 5 IU/L or 10 IU/L oxytocin, titrated using the same NSW Health protocol. Feasibility outcomes included recruitment, randomisation, treatment separation, retention and outcome ascertainment.

Results: Of 771 women assessed, 572 were approached, 293 (51%) consented and 101 (34%) were randomised. During active recruitment, randomised participants represented 9.2% of all births. Median total oxytocin dose was 3.6 versus 7.2 IU and median maximum infusion rate 10 versus 15 mL/min (both $p < 0.0001$) in reduced- and routine-dose groups respectively. Short-term outcomes and readmissions were ascertained in 100%. No between-group differences in maternal, neonatal or participant-reported outcomes were observed; the trial was not powered for effectiveness. Twenty-nine participants expressed interest in co-developing a larger trial.

Conclusion: Halving oxytocin after active labour was feasible and achieved substantial treatment separation. Together with iHOLDS, these findings support definitive evaluation of lower oxytocin exposure and identify oxytocin dosing as a candidate domain for a proposed UK–Australia Safer Birth at Term platform trial.

Improving perinatal outcomes in low-resource settings with mnemonic checklists 'COPE' and 'BOND'

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Abstract

Background: Poor perinatal outcomes in low-resource settings are largely due to failure to implement simple evidence-based interventions. Healthcare provider behaviour is inherently resistant to change. At Princess Marina Hospital in Gaborone, Botswana we have had some success with quality improvement projects based on buy-in from staff, training, champions, supportive supervision, wall posters as reminders and simple mnemonic clinical checklists.

Methods : To break the cycle of abuse and disrespect in labour, negative labour experiences and preference for caesarean birth, we have implemented the four supportive care principles of the WHO Labour care Guide with the checklist mnemonic 'COPE': Companions, Oral fluids, Pain relief and Eliminate the supine position

To promote evidence-based third stage care we use the checklist mnemonic 'BOND': Baby skin-to-skin, Oxytocin, iNitiate blood loss monitoring and Delay cord clamping (especially in preterm births).

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Results : Over two years of the COPE intervention, patients' experience of labour improved about 10-fold for most parameters ($p < 0.001$).[i]

Evaluation of the BOND approach is ongoing.

Conclusions : The implementation materials are promising and available from the authors.

[i] Nassali MN, et al. Promoting respectful maternity care with the WHO labor care guide and the checklist mnemonic "COPE": A quality improvement project. *Int J Gynaecol Obstet.* 2025;171(2):798-804