

**“They’ve walked the walk”: A systematic review of quantitative and qualitative evidence for parent-to-parent support for parents of babies in neonatal care**

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# Project Team



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# Parent Advisory Group



# Background

Improving support for parents of premature babies is an important priority.

- 2011 Picker Institute National Survey
- 2014 James Lind Alliance PSP

Peer support established as an effective means of providing support across different conditions and populations, e.g. depression; stress; PTSD; isolation; emotional support.

What is the evidence for peer support in the neonatal setting

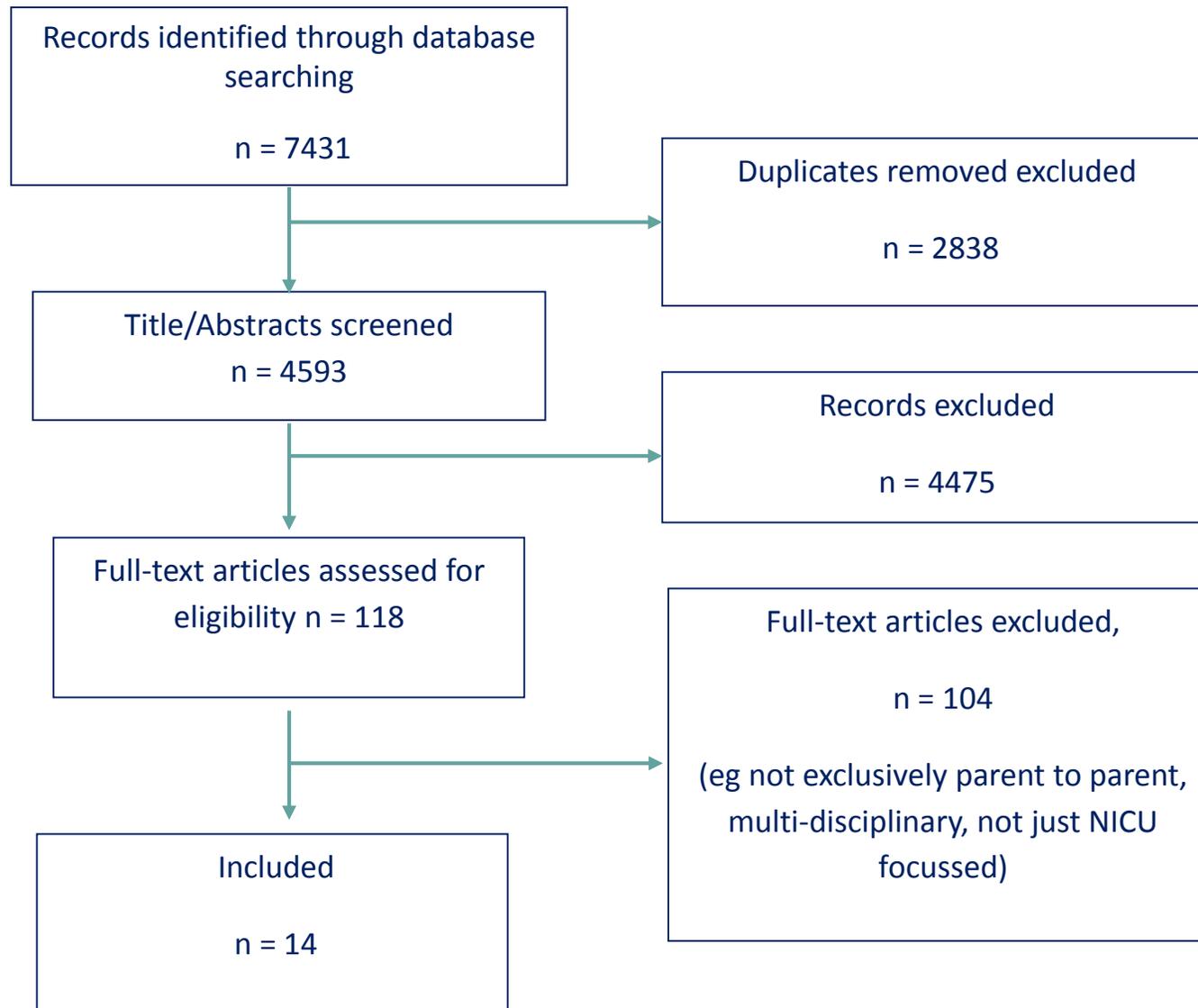
# Systematic Review

**Aim:** To bring together studies exploring the experience of parent-to-parent (P2P) support from the perspective of the persons giving and receiving P2P support, or those involved in implementing P2P support in the context of providing neonatal care.

**Population:** Parents, peer parents and staff in the NICU

**Intervention:** Peer support provided to parents by parents (P2P) - (with further support provided by a wider network if applicable). We excluded studies relating to interventions offered by professionals or interventions which offer instruction or training to parents rather than support, studies of peer support specifically for families affected by bereavement or for those whose babies are receiving palliative care.

# PRISMA flow diagram showing study screening and selection process



# Overview of results

|   |  |
|---|--|
| <b>QUALITATIVE</b>  | <b>8 studies</b> <ul style="list-style-type: none"><li>• <b>2 with a focus on breastfeeding</b></li></ul> <b>Sample size ranged from: 4-50</b><br><b>2 Canada, 6 USA</b><br><b>1980-2013</b>                           |
| <b>QUANTITATIVE</b><br>(2 RCTs, 1 pre-post study, 3 case-control) | <b>6 studies (7 papers)</b> <ul style="list-style-type: none"><li>• <b>3 with a focus on breast-feeding</b></li></ul> <b>Sample size ranged from: 28- 596</b><br><b>2 Canada, 3 USA, 1 Finland</b><br><b>1980-2016</b> |

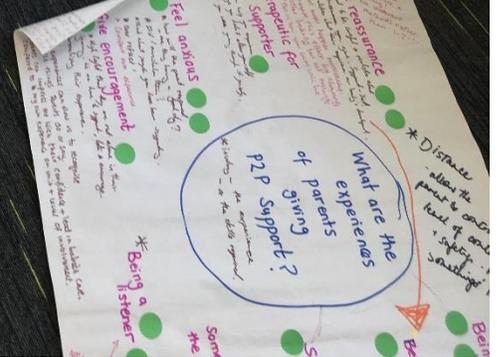
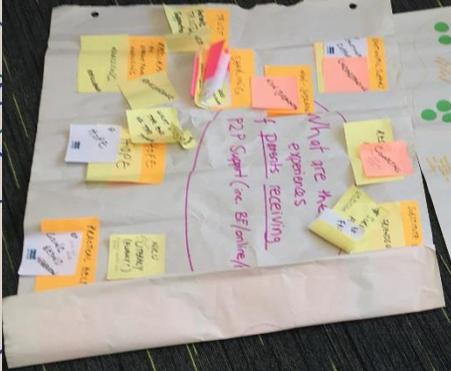
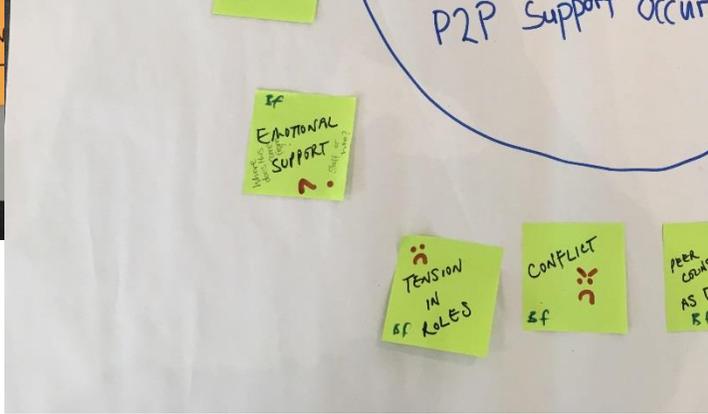
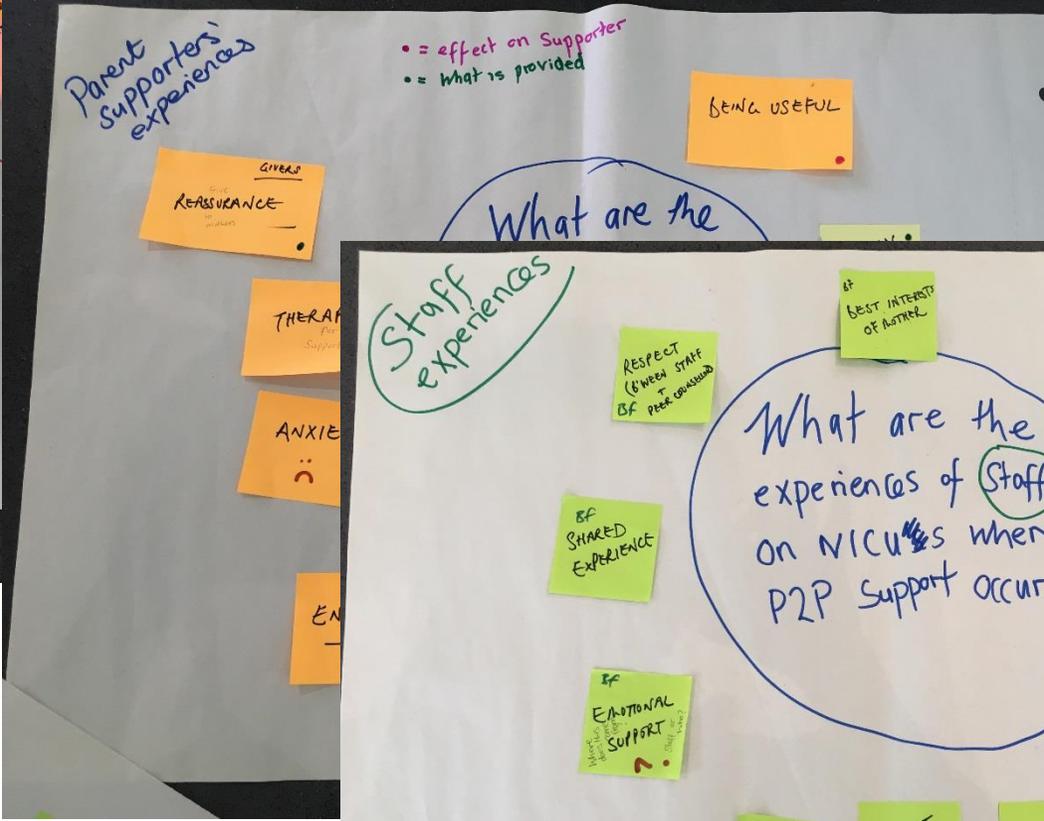
# Quantitative 'snapshot'

| Study             | Design & aim   |
|-------------------|--|
| Merewood 2006     | RCT to determine whether peer counsellors impacted breastfeeding duration, 108 mothers   |
| Niela Vielen 2016 | RCT to determine whether an Internet-based peer support intervention has an effect on the duration of breastfeeding or breast milk expression, 124 mothers |
| Oza-Frank 2014    | Pre-post Study to assess the effect of lactation staff type on breastfeeding outcomes, 596 mothers   |
| Minde 1980        | Case control evaluation of a 12 week programme of a GROUP P2P support program, 57 families   |
| Preyde 2003       | Case control evaluation of parent Buddy programme in alleviating stress, anxiety and depression and providing social support, 60 mothers                   |
| Preyde 2007       |  |
| Roman 1995        | Case control evaluation of 1:1 P2P in maternal mood states, self-esteem, family functioning, 58 families   |

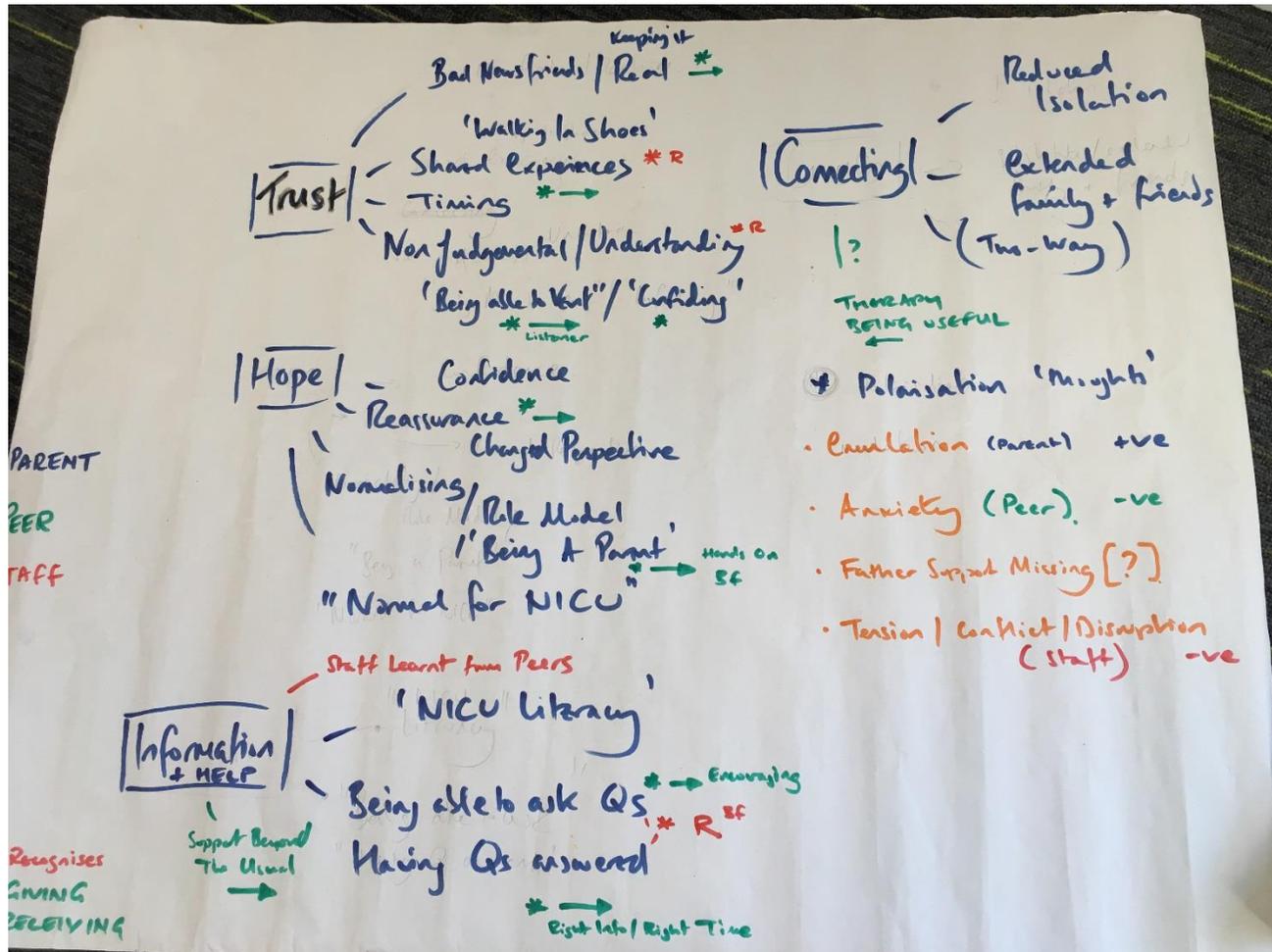
| Category  | Effect of P2P compared to control   |
|---|---|
| Psychological outcomes<br>(2 x C/C)                         | <ul style="list-style-type: none"> <li>• Significant reductions in perceived parental stress at 1/12 and 4/12 (n=2)</li> <li>• Reductions in anxiety 1/12 and 4/12, but not sustained to 12/12 (n=2)</li> <li>• No effect on depression (n=2), anger and fatigue (n=1)</li> </ul>     |
| Perceptions relating to care and support<br>(2 x C/C)       | <ul style="list-style-type: none"> <li>• Greater confidence in being able to care at discharge and at 4/12 (n=2)</li> <li>• Higher parental satisfaction with nursing and medical care (n=2)</li> <li>• Greater perceived support at 4/12 (n=1)</li> </ul>                            |
| Interaction and parenting behaviours<br>(2 x C/C)           | <ul style="list-style-type: none"> <li>• Mothers visited babies on NICU more (n=1)</li> <li>• Interacted more with baby while on unit and at 12/12 (n=2)</li> <li>• Interacted with other parents more (n=1)</li> <li>• No difference in family functioning at 12/12 (n=1)</li> </ul> |
| Knowledge and understanding<br>(2 x C/C)                    | <ul style="list-style-type: none"> <li>• Better understanding of baby's condition at 1/12 and 4/12 (n=2)</li> <li>• Greater knowledge of resources available (n=1)</li> </ul>   |
| Breastfeeding rates and attitudes<br>(2 x RCT, 1 retro C/C) | <ul style="list-style-type: none"> <li>• No effect on exclusive BF at 3-4/12 (n=2)</li> <li>• No effect on BF attitudes at 4/12 (n=1)</li> <li>• Higher BF by mums with P2P and LC, than by either alone (n=1)</li> </ul>   |

# Qualitative 'snapshot'

| Ardal 2008      | Experience of P2P support from 8 mothers                            | "support like a walking stick"  |
|-----------------|---|---|
| Livermore 1980  | Experience of giving support from 4 veteran parents                 | "I show them how"   |
| Macdonnell 2013 | Experience and perceptions of P2P support from 42 mothers & 8 staff | "they have walked the walk"   |
| Morris 2008     | Experience of online P2P support (March of Dimes website)           | "whether sharing pain or joy there was someone to listen"                                       |
| Roman 1988      | Experience of P2P support from staff, volunteers and 35 families    | "bad news friends"  |
| Rossmann 2011   | Experience of peer BF support from 21 mothers                       | "they've walked in my shoes"  |
| Rossmann 2012   | Experience of peer BF support from 17 staff                         | "lightening the load" "an important asset and could not imagine working in a NICU without them" |



| Theme        | Concepts                                 | Direction | Ardal '11 | Livermore '80 | Macdonell '13 | Morris '08 | Roman '88 | Rossman '11/12 | Preyde '01 |
|--------------|--|-----------|-----------|---------------|---------------|------------|-----------|----------------|------------|
| Trust        | Bad news friends                         |           |           |               |               |            | ✓         |                |            |
|              | Keeping it real                          | →         | ✓         |               | ✓             | ✓          | ✓         |                |            |
|              | 'Walking in shoes'                       |           | ✓         | ✓             | ✓             |            | ✓         | ✓              |            |
|              | Shared experiences                       | →         | ✓         | ✓             |               | ✓          | ✓         | ✓              | ✓          |
|              | Timing/ 'judicious sharing'              |           | ✓         | ✓             |               |            | ✓         |                |            |
|              | Non-judgmental/ understanding            |           | ✓         | ✓             |               | ✓          | ✓         |                | ✓          |
|              | 'Being able to vent'/Confiding           |           | ✓         | ✓             | ✓             | ✓          | ✓         |                |            |
|              | Listener                                 | →         |           | ✓             |               |            | ✓         | ✓              | ✓          |
| Hope         | Confidence                               |           | ✓         | ✓             | ✓             |            | ✓         | ✓              |            |
|              | Reassurance                              |           | ✓         | ✓             | ✓             | ✓          | ✓         | ✓              |            |
|              | Changed perspective                      |           |           | ✓             |               |            | ✓         | ✓              |            |
|              | Normalising/Role Model/ 'Being a parent' |           | ✓         | ✓             |               | ✓          | ✓         | ✓              | ✓          |
|              | Hands-on                                 | →         |           | ✓             |               |            | ✓         |                |            |
|              | "Normal for NICU"                        |           | ✓         | ✓             | ✓             |            | ✓         | ✓              | ✓          |
| Info. + help | Staff learnt from peers                  |           |           | ✓             |               |            |           |                |            |
|              | 'NICU literacy'                          |           | ✓         | ✓             | ✓             |            | ✓         |                | ✓          |
|              | Being able to ask questions              |           |           |               |               | ✓          | ✓         |                |            |
|              | Having questions answered                |           |           |               |               | ✓          | ✓         |                | ✓          |
|              | Support beyond the usual                 | →         |           | ✓             |               |            | ✓         | ✓              |            |
|              | Right place, right time                  | →         |           | ✓             |               |            | ✓         |                |            |
|              | Encouraging                              | →         |           | ✓             |               |            | ✓         |                |            |
| Connecting   | Reduced isolation                        |           |           |               | ✓             | ✓          | ✓         | ✓              | ✓          |
|              | Extended family + friends                |           |           |               | ✓             | ✓          |           | ✓              |            |
|              | Two way                                  |           |           |               | ✓             |            |           |                |            |
|              | Therapy                                  | ←         |           | ✓             |               |            |           |                |            |
|              | 'Being useful'                           | ←         |           | ✓             |               |            |           |                |            |



Parent, peer supporter and staff experiences of P2P condensed into 4 major themes:

- Trust
- Hope
- Information and Help
- Connecting



# Overarching synthesis

- Feelings of trust and reassurance with someone who 'listens' and 'knows'
- Hope for the future
- Experiential knowledge guiding the parent to a 'new normal' and an understanding of life on the NICU

## GAPS

- Limited evidence from support giver or staff
- Almost no evidence from fathers
- Little evidence about how to implement and sustain



- ↓ Anxiety and ↓ stress
- ↑ Perceived support
- ↑ Self-efficacy to care for baby
- ↑ Knowledge of baby's condition

## GAPS

- Uncertainty about most appropriate outcome measure to demonstrate 'effectiveness' of P2P

## Strengths

- Stakeholder involvement to ensure applicability and relevance
- Best practice methods of SR
- Inclusion of qualitative and quantitative data

## Limitations

- Strict definition of P2P
- Variation in models of P2P provision
- Small number of studies & samples, and non robust study design (quant)
- Geographic location

## Implications for practice

- Local knowledge is invaluable - what works in some units may not work in others;
- P2P needs to take an individualised approach (everyone is different);
- P2P is a positive addition for parents with babies being cared for in neonatal units;
- P2P provides an emotional support and can help reduce the experience of isolation;
- NICU staff can also learn from those providing P2P;
- P2P provides a valuable source of information and help within the NICU and beyond.

## Recommendations for future research

- Better outcome measures to demonstrate the benefit of P2P support.
- Establishing how to implement P2P
- Addressing the best model of P2P (including moderated vs facilitated support)
- How does face-to-face P2P compare with remote/social media P2P

### Research questions to address:

- Are there potential negative effects of P2P support? We did not see any reported but this does not mean they do not exist.
- How is P2P support sustained over the short to long term (for example if the support relies on one person and that person is away)?
- Do we know enough about the effect of being a peer supporter? Is there potential harm there (if resources are not available to support them)?

# PARENT-TO-PARENT SUPPORT INTERVENTIONS FOR PARENTS OF BABIES CARED FOR IN A NEONATAL UNIT

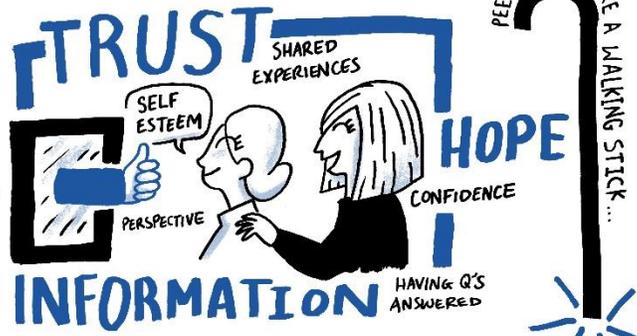
A SYSTEMATIC REVIEW OF QUALITATIVE & QUANTITATIVE EVIDENCE. HARRIET HUNT · REBECCA WHEAR · KATE BODDY · LEANNA WAKELY · ALISON BETHEL · CHRISTOPHER MORRIS · REBECCA ABBOTT · SUSAN PROSSER · ANDREW COLLINSON · JENNIFER KURINCZUK · JO THOMPSON-COON.



NON-JUDGMENTAL UNDERSTANDING



Significant reduction in maternal anxiety and perceived stress.



# Thank you

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Our full findings paper currently being considered, and our protocol is published as open access: Hunt, H., Whear, R., Boddy, K., Wakely, L., Bethel, A., Morris, C., Abbott, R., Prosser, S., Collinson, A., Kurinczuk, J. and Thompson-Coon, J., 2018. Parent-to-parent support interventions for parents of babies cared for in a neonatal unit—protocol of a systematic review of qualitative and quantitative evidence. *Systematic reviews*, 7(1), p.179.

<https://systematicreviewsjournal.biomedcentral.com/articles/10.1186/s13643-018-0850-2>



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