Bliss: briefing on the published evidence underpinning our impact framework

Bliss works with parents, health professionals, policymakers and researchers so that babies born premature or sick receive the best care, which in turn will ensure those babies have the best chance of survival and quality of life. Specifically, Bliss' work helps ensure that babies can have:

1. Better short-term and long-term outcomes
2. Increased attachment with parents
3. Reduced mortality and morbidity rates
4. Equitable experiences of the above

This document summarises the evidence of the difference that Bliss' work can lead to.

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1. Better short-term and long-term outcomes

Improved physiological, developmental and neurodevelopmental outcomes for babies
Parental involvement in their baby's care is proven to be best for babies' developmental outcomes. Evidence has shown that long periods of direct care lead to increased weight and improved breastfeeding rates, and skin-to-skin care has been linked to better infant reflexes at term and better gross motor development at 4-5 years.

- *O'Brien et al (2018) Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial, Lancet Child Adolesc Health, 2(4):245-254*
- *Pineda et al (2017) Parent participation in the neonatal intensive care unit: Predictors and relationships to neurobehavior and developmental outcomes, Early Human Development, 117:32-38.*

There is increasing understanding of the vital role that parents and families play in supporting their baby whilst in neonatal care. Evidence shows that the outcomes for babies of increased parental involvement include improved physiological stability and neurodevelopmental outcomes, increased weight gain and breastfeeding rates, and reductions in length of stay and subsequent readmissions to hospital.

- *Banerjee et al, (2019) Improving infant outcomes through implementation of a family integrated care bundle including a parent supporting mobile application, Archives of Disease in Childhood – Fetal and Neonatal Edition, 105(2)*
- *Liu, Ting-Ting & Lei, Meng-Jie & Li, et al. (2018) Effects of parental involvement in infant care in neonatal intensive care units: a meta-analysis. Frontiers of Nursing*
- *O'Brien et al (2018) Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial, Lancet Child Adolesc Health, 2(4):245-254*
- *Head LM. (2014) The effect of kangaroo care on neurodevelopmental outcomes in preterm infants. J Perinat Neonatal Nurse.*

Babies receiving skin-to-skin contact (also called kangaroo care) begin breastfeeding earlier, and there are long-lasting social and behavioural protective effects, even 20 years after the intervention.

- *Mekonnen, A.G., Yehualashet, S.S. & Bayleyegn, A.D. (2019) The effects of kangaroo mother care on the time to breastfeeding initiation among preterm and LBW infants: a meta-analysis of published studies. Int Breastfeed*
- *Charpak, N (2016), Twenty-year Follow-up of Kangaroo Mother Care Versus Traditional Care. Pediatrics.*

Babies in neonatal care often experience multiple painful experiences every day. Prolonged and unmanaged pain can have short- and long-term effects for babies, from decreasing their heart rate and respiratory effort, to structural and functional reorganisation of the central nervous system. By providing skin-to-skin, comfort holding and other interventions to their baby during painful procedures, parents can play an active and effective role in helping to manage their baby's pain and discomfort.

- *Hatfield, LA et al (2018) A Systematic Review of Behavioural and Environmental Interventions for Procedural Pain Management in Preterm Infants, Journal of Paediatric Nursing Vol 44*
- *Zargham-Boroujeni A, et al (2017) The Effects of Massage and Breastfeeding on Response to Venipuncture Pain among Hospitalized Neonates, Iranian Journal of Nursing and Midwifery Vol 22 Issue 4*
- *Goldstein-Ferber, S et al, (2008) Neurobehavioural assessment of skin-to-skin effects on reaction to pain in preterm infants: a randomized, controlled within-subject trial, Acta Paediatrica, Vol 97 Issue 2*
- *Korstandy, R (2008) Kangaroo Care (Skin Contact) Reduces Crying Response to Pain in Preterm Neonates: Pilot Results, Pain Management Nursing, Vol 9 Issue 2*
- *Axelin A, et al. (2006) 'Facilitated tucking by parents' in pain management of preterm infants – a randomized crossover trial, Early Human Development.*

Evidence of need (worse outcomes without intervention) – outcomes for babies:
Prematurity and/or neonatal admission are recognised as an Adverse Childhood Experience (ACE) for the infant, with associated risks for behavioural, neurobiological and physical health outcomes, as well as on babies' longer term neurodevelopmental outcomes.

- *Nelson, C. A., Scott, R. D., Bhutta, Z. A., Harris, N. B., Danese, A., & Samara, M. (2020) Adversity in childhood is linked to mental and physical health throughout life. BMJ (Clinical research ed.), 371, m3048*
- *Coathup V, Boyle E, Carson C, Johnson S, Kurinzcuk J J, Macfarlane A et al. (2020) Gestational age and hospital admissions during childhood: population based, record linkage study in England (TIGAR study) BMJ; 371:m4075*
- *National Institute for Health and Care Excellence (2017). NICE Guideline [NG72]: Developmental follow-up of children and young people born preterm*
- *Payhala R, et al (2017) Self-Reported Mental Health Problems Among Adults Born Preterm: A Meta-analysis, Pediatrics 139(4)*
- *Felitti VJ, Anda RF, Nordenberg D, et al. (1998) Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The Adverse Childhood Experiences (ACE) Study. American Journal of Preventative Medicine. May;14(4):245–58.*

Graduates of neonatal units are at higher risk of developing psychological sequelae, including neurodevelopmental, cognitive, emotional and behavioural difficulties; many require additional support in educational settings and safeguarding risk is also increased in this population.

- *Mason, S.M., Schnitzer, P.G., Danilack, V.A., Elston, B. & Savitz, D.A. (2018) Risk factors for maltreatment-related infant hospitalizations in New York City, 1995–2004. Annals of Epidemiology 28, 590 – 596*
- *Natalucci G, Bucher HU, Von Rhein M, Borradori Tolsa C, Latal B, Adams M. (2016) Population based report on health related quality of life in adolescents born very preterm. Early Human Development;104:7-12*
- *Nandyal, R., Owora, A., Risch, E., Bard, D., Bonner, B., Chaffin, M. (2013) Special care needs and risk for child maltreatment reports among babies that graduated from the Neonatal Intensive Care. Child Abuse Negl. 37, 1114-21*

- *Johnson, S., & Marlow, N. (2011) Preterm birth and childhood psychiatric disorders. Pediatric research, 69(5 Pt 2), 11R–8R.*

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2. Increased attachment with parents

Improved bonding and attachment for babies and families (including positive impact for babies of improved parental mental health)

Parental involvement in care is critical for bonding and forming secure attachment for both babies and parents. Parents who are supported to be with their baby for prolonged periods of time report increased parental confidence, and reduced stress and anxiety scores.

- *O'Brien et al. (2018) Effectiveness of Family Integrated Care in neonatal intensive care units.*

Providing direct, hands-on care allows parents to feel like parents - which may be key for their own perceptions of attachment to their baby - and physical and emotional closeness is crucial for forming strong parent-infant bonds.

- *Treherne et al (2017) Parents' Perspectives of Closeness and Separation With Their Preterm Infants in the NICU, Journal of Obstetric, Gynecological and Neonatal Nursing, 46(5):737-747*
- *Flacking et al (2012) Closeness and Separation in neonatal intensive care, Acta Paediatr, 101(10): 1032–1037.*

Research has demonstrated how physical closeness supports parents to feel emotionally close to their baby, noting that "for many parents these feelings started when seeing their infant…parents emphasized the importance of being face-to-face and having eye contact."

- *Flacking et al (2016) Pathways to emotional closeness in neonatal units – a cross national qualitative study, BMC pregnancy Childbirth 16:170.*

Research shows that comprehensive family-based NICU interventions address parental psychological distress, the loss of the parenting role, and disruptions to parent-infant bonding; leading to positive short-term outcomes including improvements in parental mental wellbeing, sensitive parenting behaviours, and children's cognitive and socioemotional development. Some evidence also points to improvements in longer-term outcomes for babies include brain development, cognitive ability, language skills, and socioemotional behaviours. Further, supporting positive perinatal mental health outcomes is important to ensure the longer-term wellbeing of children, as evidence suggests nearly three-quarters of costs associated with perinatal mental health relates to the adverse impact on the child, rather than the mother.

- *Lean, R. E., Rogers, C. E., Paul, R. A., & Gerstein, E. D. (2018). NICU hospitalization: Long term implications on parenting and child behaviours. Current Treatment Options in Pediatrics, 4(1), 49–69.*
- *Cherry AS, Mignogna MR, Roddenberry Vaz A, et al. (2016) The contribution of maternal psychological functioning to infant length of stay in the Neonatal Intensive Care Unit. Int J Women's Health.*
- *Bauer et al (2014), The costs of perinatal mental health problems.*

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3. Reduced mortality and morbidity rates

Improved mortality and morbidity rates for babies born premature or sick (impact of staffing levels and care pathways)

Evidence shows that adequate staffing levels (specifically 1:1 nursing care) and being born and cared for in neonatal intensive care units reduces mortality rates and morbidity for the smallest and sickest babies.

- *Desplanches T, Blondel B, Morgan AS, Burguet A, Kaminski M, Lecomte B, Marchand-Martin L, Rozé JC, Sagot P, Truffert P, Zeitlin J, Ancel PY, Fresson J (2019) Volume of Neonatal Care and Survival without Disability at 2 Years in Very Preterm Infants: Results of a French National Cohort Study. J Pediatr ;213:22-29.e4*
- *Helenius K, Longford N, Lehtonen L, Modi N, Gale C (2019) Association of early postnatal transfer and birth outside a tertiary hospital with mortality and severe brain injury in extremely preterm infants: observational cohort study with propensity score matching, BMJ*
- *Watson, S et al. (2016) The effects of a one-to-one nurse-to-patient ratio on the mortality rate in neonatal intensive care: a retrospective, longitudinal, population-based study, Archives of Disease in Childhood – Fetal and Neonatal Edition, 101(3)*
- *Watson, S et al. (2014) The effects of designation and volume of neonatal care on mortality and morbidity outcomes of very preterm infants in England: retrospective population-based cohort study, BMJ Open*
- *Pillay, T, Nightingale, P, Owen S, Kirby D, Spencer, S A (2011) 'Neonatal Nursing Efficacy: practical standards of nursing care provision in a newborn network', Archives of Disease in Childhood, 96(Suppl 1), A36*
- *Milligan, D W, Carruthers, P, Mackley, B Ward Platt, M P, Collingwood, Y Wooler, L, Gibbons, J, Draper, E, Manktelow, B N (2008) 'Nursing workload in UK Tertiary Neonatal Units', Archives of Disease in Childhood, 93(12), pp.1059-1064*
- *Hamilton, K E, Redshaw, M E, Tarnow-Mordi, W (2007), 'Nurse staffing in relation to risk-adjusted mortality in neonatal care', Archives of Diseases in Childhood – Fetal and Neonatal Edition, 92(2), F99-F103*
- *Callaghan, L, Cartwright D, O'Rourke, P Davies, M (2003) 'Infant to staff ratios and risk of mortality in very low birthweight infants,' Archives of Diseases in Childhood – Fetal and Neonatal Edition, 88(2), F94-F97*
- *UK neonatal staffing study group (2002) 'Patient volume, staffing and workloads in relation to risk-adjusted outcomes in a random stratified sample of UK neonatal Intensive care unit: a prospective evaluation,' The Lancet, 359(9301), pp.99-107*
- *Williams, S, Whelan, A, Weindling, A M, Cooke, R W (1993) 'Nursing staff requirements for neonatal intensive care', Archives of Diseases in Childhood, 68(5).*

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4. Equitable experiences of the above

Evidence of need (worse outcomes without intervention) – inequity of outcomes for babies and/or parents:

Parental involvement in care delivery and decision making is crucial for ensuring babies have the best short and long-term outcomes. Family-centred care also supports parental confidence and bonding. However, family-centred care is not experienced equitably. This might be due to different barriers to parents being present on the unit as much as they need or want to be, and can also be driven by variation in facilities and support available between hospitals.

- *NHS GIRFT (2022), Neonatology GIRFT Programme Specialty Report*
- *Bliss (2022) South Asian families' experiences of neonatal care*
- *Bliss (2021) Neonatal care through a young parent's lens*

- *Bliss (2016) Families Kept Apart: barriers to parents' involvement in their baby's hospital care*
- *Bliss (2014) It's not a game: the very real costs of having a premature or sick baby.*

Neonatal clinical care delivery may also be affected by a lack of understanding of how to identify conditions on darker skin tones, or because of assumptions staff may make about individual families based on their ethnicity, the language they speak or other factors, which may affect the care they provide or how they respond to parent concerns about their baby.

- *NHS Race and Health Observatory (2022), Ethnic Inequalities in Healthcare: A Rapid Evidence Review*
- *Department of Health and Social Care (2021), Review launched into the health impact of potential bias in medical devices, accessed here: https://www.gov.uk/government/news/review-launched-into-the-health-impact-of-potential-bias-in-medical-devices*
- *Bliss (2022) South Asian families' experiences of neonatal care*
- *Birthrights (2022) Systemic racism, not broken bodies: An inquiry into racial injustices and human rights in UK maternity care*
- *Muslim Women's Network (2022) INVISIBLE Maternity Experiences of Muslim Women from Racialised Minority Communities*
- *Bliss (2021) Neonatal care through a young parent's lens.*

While neonatal mortality rates are falling, they are not falling equally. Neonatal mortality rates are higher among babies from specific ethnic minorities/born to mothers from deprived backgrounds. There is also unwarranted variation in neonatal mortality rates between different neonatal networks and neonatal units.

- *HSIB (forthcoming – investigation launched 2022) Impact of ethnicity on jaundice detection in newborn babies https://www.hsib.org.uk/investigations-and-reports/impact-of-ethnicity-on-jaundice-detection-in-newborn-babies/*
- *National Neonatal Audit Programme (2022), Summary report on 2021 data*
- *MBRRACE-UK (2022) Perinatal Mortality Surveillance Report: UK Perinatal Deaths for Births from January to December 2020*
- *Webster K, NMPA Project Team (2021) Ethnic and Socio-economic Inequalities in NHS Maternity and Perinatal Care for Women and their Babies: Assessing care using data from births between 1 April 2015 and 31 March 2018 across England, Scotland and Wales. London: RCOG*
- *National Child Mortality Database (2021) Child Mortality and Social Deprivation*
- *Neonatal Data Analysis Unit (2017) NDAU 2017 Report.*