Section A		
Institution: Durham University		
Unit of Assessment: UoA 22 Anthropology & Development		
Title of case study: Changing approaches to Infant Sleep Safety		
Period when the underpinning research was undertaken: 2000 – 2012		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s): Professor Helen Ball	Role(s) (e.g. job title): Professor of Anthropology	Period employed by submitting HEI: September 1993 to present
Period when the claimed impact occurred: August 2013 to present		

Period when the claimed impact occurred: August 2013 to present Is this case study continued from a case study submitted in 2014? N Section B

1. Summary of the impact

From the 1990s to 2014 United Kingdom guidance to reduce sudden unexpected infant deaths (SUDI) advised parents to avoid bed-sharing with their babies. Durham research explored and explained why half of UK parents rejected this guidance; when and how United Kingdom parents and babies co-slept; and why bed-sharing was an important part of night-time infant care for many United Kingdom families. <u>Our research evidence underpinned a</u> rethink of official infant sleep safety guidance in the United Kingdom to accommodate the <u>needs of culturally diverse families and acknowledge the benefits to mothers and babies of sleeping together while providing information about hazards to avoid, culminating in national guidelines on infant sleep safety by Public Health England, and an international protocol by the Academy of Breastfeeding Medicine. Durham University was awarded the Queen's Anniversary Prize for this work in 2018.</u>

2. Underpinning research

Night-time infant care and parent-infant sleep behaviour in the United Kingdom has been a core research theme for Durham Anthropology Department's Infancy & Sleep Centre (formerly the Parent-Infant Sleep Lab). A 20-year body of work (1999-2020) encompassing qualitative and quantitative studies has been conducted in community, hospital, and lab settings, using sleep diaries, interviews, focus groups, video observations, actigraphy, and large-scale surveys. Outputs relating to bed-sharing, co-sleeping and Sudden Infant Death Syndrome (SIDS) include over 50 journal articles and book chapters that are represented below by six frequently cited publications **[R1-R6]**. Key findings from this research include:

- 1. Around half of United Kingdom babies (350,000 per year) have bed-shared with one or both of their parents before they are 3 months of age **[R2, R3]**.
- 2. Parents bed-share with their babies for multiple rational reasons, but some do so accidentally and without foresight. These parents need information about when and where to avoid sleeping with their baby, and how to prepare in advance to do so safely **[R1, R6]**.
- 3. Most babies who bed-share (73%) are breastfed. Breastfeeding mothers bed-share to cope with frequent night-time feeds and to maximise sleep. They need information about practical bed-sharing safety and what to avoid [**R2**, **R3**, **R4**, **R5**].
- 4. Breastfeeding mothers sleep with their babies in a characteristic way, documented in our home, hospital, and lab-based videos. This provides safety benefits that parents should be made aware of. Other parents use this position less frequently and need specific guidance to ensure infant safety [**R4**, **R5**].
- 5. Parents reject or ignore SUDI reduction information that is dogmatic, inflexible, shames parents or adopts a fear-based approach. Based on our research we proposed that safe sleep guidance in the United Kingdom would be more effective if moved from the 'Authoritative' to 'Negotiated' quadrant of Beattie's (1991) Health Promotion model [**R5**].
- 6. A 'one-size-fits-all' approach to infant sleep safety is unhelpful for parents and practitioners; recommendations should be sufficiently elastic to allow for the range of cultural and familial contexts within which infant care occurs [**R5**, **R6**].

7. How infant care messages are received and perceived by minority groups, and how culturally determined infant care practices are prioritised by immigrant mothers seeking to raise their infants according to the traditions of their culture of origin [**R5**].

3. References to the research (maximum of six references)

R1. Helen L Ball: Reasons to bed share: Why parents sleep with their infant. *Journal of Repro and Infant Psychology* 2002; 20(4):207-21. DOI:10.1080/0264683021000033147

75 international citations (Web of Science 8.11.20)

R2. Helen L Ball: Breastfeeding, Bed-Sharing, and Infant Sleep. *Birth* 2003; 30(3):181-8. DOI:10.1046/j.1523-536X.2003.00243.x

109 international citations (Web of Science 8.11.20)

R3. Peter S Blair, Helen L Ball: The prevalence of characteristics associated with parent– infant bed sharing in England. *Archives of Disease in Childhood* 2005; 89(12):1106-10. DOI:10.1136/adc.2003.038067

69 international citations (Web of Science 8.11.20)

R4. Helen L Ball: Parent-infant bed-sharing behaviour. *Human Nature* 2006; 17(3):301-318. DOI:10.1007/s12110-006-1011-1

30 international citations (Web of Science 8.11.20)

R5. Helen L Ball, Lane E Volpe: Sudden Infant Death Syndrome (SIDS) risk reduction and infant sleep location - Moving the discussion forward. *Social Science & Medicine* 2012; 79(1):84-91. DOI:10.1016/j.socscimed.2012.03.025

49 international citations (Web of Science 8.11.20).

R6. Lane E Volpe, Helen L Ball, James J McKenna: Nighttime parenting strategies and sleeprelated risks to infants. *Social Science & Medicine* 2012; 79(1):92-100

DOI:10.1016/j.socscimed.2012.05.043

29 international citations (Web of Science 8.11.20) Abstracted in WHO SafetyLit database and rated one of 6 best childhood injury articles of 2013.

4. Details of the impact

The above work <u>has significantly changed a</u>) policy discourse around co-sleeping, b) <u>guidance for parents in the United Kingdom and overseas, and c</u>) recommendations for <u>practitioners about night-time infant care and SUDI risk reduction</u>. Prior to 2014 the official United Kingdom stance was to advise against all co-sleeping. Our work showed this position to be restrictive and unsustainable, amplified the voices of parents who chose to co-sleep, and demonstrated the close link between bed-sharing (a specific kind of co-sleeping) and breastfeeding. It has been used to change guidance in the United Kingdom and beyond, underpinning new practice guidelines, policies, and recommendations issued during the Research Excellence Framework (REF) assessment period.

In April 2012 we launched the Infant Sleep Information Source (ISIS) a knowledge exchange and research translation project funded by the Economic and Social Research Council (ESRC), renamed in 2018 as the Baby Sleep Information Source / Basis (www.BasisOnline.org.uk). In collaboration with three infant care NGOs (Unicef UK, National Childbirth Trust (NCT) & La Leche League GB) we aimed to provide easily accessible research evidence regarding infant sleep (particularly research on co-sleeping, SIDS, and the sleep behaviour of breastfeeding parents and babies) for practitioners working towards the Department of Health's target to increase breastfeeding rates in the United Kingdom, and for parents who breastfed their babies. As few researchers were studying the sleep of breastfeeding parents and babies, we drew heavily on our own research [R1-R6]. The Basis/ISIS website is now endorsed by all 7 United Kingdom breast-feeding support organisations and is widely cited in recommendations and policy documents by National Health Service (NHS) trusts, Safeguarding boards, Local Councils and information sources across the United Kingdom. We provide evidence of 70+ United Kingdom sources signposting parents and practitioners to the Basis website [E1a] during the REF period, and unsolicited testimonials from practitioners and parents who have found the website and its research information helped them in better understanding infants' sleep, again during this REF period [E1b]. The Basis website averages 12,000 users per month, with 60% from the

United Kingdom, the rest being from 215 different countries **[E1c, E1d]** and was mentioned as a key element of our work in the citation for Durham University's award of the Queen's Anniversary Prize in 2018.

In December 2014 the National Institute of Health & Care Excellence (NICE) published a review of the international evidence around SUDI and co-sleeping that examined the international case-control study data and issued new United Kingdom guidance for health professionals [E2a]. The Durham Infancy & Sleep Centre director, who served as a topic specific expert on this panel, was invited to explain the relevance of our research (including **R1-R6**) for the panel. This was reinforced by the comments of multiple stakeholder organisations who cited **R1-R6** in their responses to the draft guidance [E2b]. The NICE update [E2a] recommended that parent-infant co-sleeping be recognised as a common nighttime caregiving strategy in the United Kingdom and encouraged health professionals to discuss the pros and cons with parents to facilitate informed choice. This was the guidance our research had determined was most appropriate for the United Kingdom [R5, R6]. Subsequently NICE endorsed the Basis/ISIS information sheets (part of the Basis website) for parents on bed-sharing as resources for practitioners implementing the new guidance [E2c]. NICE guidance is issued for use by all health and care practitioners in England and Wales and it is expected to be implemented by all NHS Trusts, affecting 700,000 babies born in the United Kingdom every year.

This Durham research directly and extensively influenced Unicef UK Baby-Friendly **Initiative (BFI)** guidance to health professionals on co-sleeping. Unicef BFI produces various resources to support facilities in meeting Baby-Friendly accreditation criteria. The Unicef UK BFI booklet Caring for your Baby at Night – A guide for Health Professionals [E3a] (updated 2016) assists practitioners in delivering the 'Caring for your Baby at Night' information to parents following birth. It provides the rationale behind the guidance provided to parents, with references to the evidence sources used. The Practitioner's Guide highlights our research extensively, citing R1, R2, R3, & R4, (plus an additional 9 publications from our work). The Unicef UK BFI resource Co-sleeping and SIDS – A Guide for Health Professionals [E3b] (updated 2018) provides information to help practitioners discuss co-sleeping and SIDS with parents (following NICE guidance [E2a]). It references R2 and R3, plus 2 additional publications by our team. Both above guides [E3a and E3b] signpost to the Baby Sleep Info Source website [E1], and [E3b] carries the Basis logo. 92% of United Kingdom babies are born in hospitals that have achieved or are working towards Unicef UK BFI accreditation. therefore our research is used by the majority of the United Kingdom's midwives and influences the care of 630,000 babies born annually in the United Kingdom. Because they are freely downloadable from the Unicef website, these two resources are also used widely around the world affording our research global exposure and impact.

In 2018 we (as Basis) were invited to co-produce the most recent United Kingdom infant safer sleep guidance with Lullaby Trust, Unicef UK BFI, and Public Health England. New national infant sleep safety guidance *Safer Sleep: saving babies lives* launched in 2019 supports implementation of NICE CG37 providing parents with an illustrated booklet [**E4a**] and reminder card [**E4b**] and practitioners with more detailed explanations about supportive conversations with parents [**E4c**]. Information in this guidance on safe co-sleeping (including key images) comes directly from our research in **R4**, **R5** and **R6**. All sources underpinning the guidance are in the Lullaby Trust evidence base document [**E4d**] which cites **R3** and **R5**, along with **4 of our other publications**. These leaflets were issued to parents of 125,000 babies born in the United Kingdom in 2019 (2020 figures not yet available). Twins Trust also used our information to produce a Safer Sleep information leaflet for parents of twins available from their website [**E4e**].

We spoke about our research in Vancouver (2015) at the invitation of the British Columbia Lactation Consultants Association [**E5a**] and 3 talks were live-streamed to health facilities across the province. The British Columbia Office of Public Health found our research into the uptake of safer sleep messaging 'particularly compelling' and requested to use some of our

resources in their safer sleep campaigns **[E5b]**. Working with the Co-ordinator of Public Health and Health Promotion in the Perinatal Services Division we delivered a webinar to staff about our research to facilitate the development of 'more nuanced messaging around bed-sharing' **[E5d]**. This culminated in the publication of **state-wide safer sleep guidance and resources** for **British Columbia** in late 2017; the above co-ordinator noted "...so far it has been very well received. People are so appreciative of the harm reduction approach to bed-sharing and are find (sic) it very helpful in their practice." **[E5c]** The British Columbia materials titled '*Safer Infant Sleep – a practice support tool for health professionals'* [**E5f**] and '*Safer sleep for my Baby – Helping parents and caregivers create a safer sleep plan'* [**E5e**] use a bed-sharing quiz derived from our research, and information on safe positioning while bed-sharing from **R4** to implement the risk minimisation / harm reduction approach to co-sleeping that we recommend in **R1**, **R2**, **R5** and **R6**. British Columbia Perinatal Services.

Several United Kingdom and international breastfeeding organisations use our research in the information they offer new parents about infant sleep. La Leche League GB (LLLGB) and La Leche League International (LLLI) use our research in their information sheets, website and published books for mothers. LLLGB's *Safe Sleep and the Breastfed Baby* leaflet (revised 2017) cites R3 and R4 as well as 2 other recent publications by our team [E6a]. LLLI also provides information sheets for parents on bed-sharing safety [E6b], and information summaries on its website citing our work [E6c citing R5], [E6d citing R4], [E6e citing R1, R2, R3, R4, R6 and 5 of our additional publications], [E6f citing R1, R2, R3, R4 and R6 and 2 of our additional publications]. *Sweet Sleep* published by LLLI also references our work extensively. La Leche League is the oldest breastfeeding organisation in the world (61 years in over 70 countries). LLLGB has 77 active groups supporting 25,876 mothers. LLLI covers 2000 local support groups operating in over 60 countries worldwide.

The reach of our work is illustrated by <u>numerous international professional and parent support</u> organisations who use our work in information for parents. The Australian Breastfeeding Association cites **R1**, **R2** and **R4** in their 2014 parent-leaflet *Bed-sharing and your baby: the facts,* and acknowledge the Infant Sleep Info Source [**E7a**]. The Australian College of Midwives' *Position Statement on Bed-sharing & Co-sleeping* [**E7b**] cites the **Basis/ISIS website**, **R3** and **3 of our additional publications**. The Red Nose (Australian SIDS charity) guidance *Sharing a sleep surface with a baby* (2018) [**E7c**] cites **R2**, the **Basis/ISIS website**, and **6 further publications** from our research. The Hong Kong Department of Health (Family Health Service) refers to our work in their statement on *Co-sleeping in Infancy: the controversies* (2018) [**E7d**] citing **R1**, **R3**, **R6** and **4 of our other publications**. The International Childbirth Education Association uses **R2**, **R5**, **R6**, **4 other of our publications** and the **Basis/ISIS website** in their Position Paper *Safe Infant Sleep* (2016) [**E7e**]. The *Academy of Breastfeeding Medicine* Protocol on Bed-sharing and Breastfeeding cites **R1**, **R2**, **R3**, **R4**, R6 and 15 of our additional publications [**E7f**].

Our research is also cited in a variety of NHS trust policy documents on infant feeding, infant sleeping, and mother-baby bed-sharing. Some indicative examples that were in force during the assessment period include: Blackburn with Darwen NHS Trust *Infant Feeding Manual* (2010-2013) [**E8a**] cites **R1**, **R2**, **R3**. Wirral Community NHS Trust's *Safe Sleeping Guidance* (2017) [**E8b**] cites **R2** plus Unicef documents based on **R4**. Chelsea & Westminster NHS Trust & West Middlesex Hospital *Safer Sleep Guidance* (2016) [**E8c**] extensively uses information from ISIS (acknowledged) and cites **R1**, **R2** and **R3**. Salisbury NHS *Mothers & Infants Bed Sharing Policy* [**E8d**] cites publications **R2**, **R3**, **R5**, **R6**. Basildon & Thurrock NHS policy (2018) on *Management of bed-sharing for mothers and babies* [**E8e**] cites **R3**. <u>These documents guide practitioners employed by each Trust in the care of mothers and babies</u> so affect variable patient numbers. NHS Scotland's *Ready, Steady, Baby!* (2018) guidance for new parents and *Parent Club* (2018) website both draw on publications **R1-R4** and provide links to Basis for information on bed-sharing. Both sources are free to all new parents in Scotland [**E8f & E8g**].

Child Death Overview Panels (CDOPs) & Local Children's Safeguarding Boards (LCSBs) (England & Wales) review evidence from unexpected infant deaths in order to make recommendations about infant mortality prevention. These deaths may include SIDS, accidents, or infanticides. Some CDOPs & LSCBs issue sleep safety guidance when infant death reviews highlight a cause for concern. Our work is used in several of these guidance documents: e.g. Pan-Lancashire *Safer Sleeping Guidance for Children* (2018) [**E9a**] refers to the Basis/ISIS website, and signposts to our bed-sharing decision tool; Suffolk's Safeguarding Children's Board's *Suffolk Safer Sleep Strategy* (2017) [**E9b**] cites **R6** and cites extensively from our research on the **Basis/ISIS website;** Merseyside CDOP's *Multi-Agency Safe Sleeping Guidance* (2015) [**E9c-d**] cites **R2** and several Unicef documents drafted in collaboration with our team. Although these CDOP and LSCB recommendations have limited reach in comparison with national guidance they serve an important purpose in highlighting local gaps in implementation.

In 2016 we expanded Basis to offer **practitioner training workshops and study days**, based on our research and other information from the Basis website. We have been invited to hold 30 Basis workshops to date, training over 1500 health practitioners, peer supporters and student midwives from Portsmouth to Aberdeen, Chelsea to Port Talbot, and been funded by the Scottish Government (2019-2021) to provide webinar training to all relevant NHS staff in Scotland. This training upskills practitioners around SUDI/SIDS, infant sleep safety and co-sleeping, providing them with knowledge and confidence to discuss these issues with families and help them to understand and follow the new guidance in practice. A synopsis of evaluations from these events confirm the importance of the research evidence we produce and share with practitioners who support parents with breastfeeding and sleep safety [**E10**].

The evidence confirms the international reach and the significant depth of impact from our research in underpinning policy, practice and recommendations regarding infant sleep safety.

5. Sources to corroborate the impact (maximum of ten references)

E1. Examples of 70+ indicative organisations (NHS Trusts, Local Councils, Safeguarding Boards etc) signposting staff and practitioners to the Baby Sleep Info Source website **[E1a]**; reviews / testimonials from Basis users **[E1b]**; plus google analytics reports showing hits/users **[E1c]** and google analytic report showing countries **[E1d]** (to Nov 2018).

E2. NICE Clinical Guidance Update (2014) on co-sleeping & SIDS **[E2a]**, stakeholder responses to draft guidance **[E2b]**, endorsed ISIS resources **[E2c]**.

E3. Unicef UK Baby Friendly Initiative guidance publications for Health Professionals: *Health Professionals Guide to "Caring for your Baby at Night"* **[E3a]** and *Co-sleeping & SIDS: a guide for Health Professionals* **[E3b]**.

E4. Public Health England, Lullaby Trust, Unicef UK, Baby Sleep Info Source Safer Sleep: saving babies lives. A guide for professionals [E4c], a guide for parents [E4a] and a quick reference card [E4b], Lullaby Trust Evidence base [E4d] and Safer Sleep Guidance for Twins [E4e].

E5. British Columbia Perinatal Services *Safer Infant Sleep a practise support tool for health professionals* [E5f] and *Safer Sleep for my Baby for Parents* [E5e] plus relevant correspondence and conference programme [E5a-d].

E6. La Leche League GB *Safe Sleep* information sheet [**E6a**]. La Leche League International: various infant sleep information articles on their website [**E6b – E6e**].

E7. Selection of publications by **international organisations** using our work including Australian Breastfeeding Association; Australian College of Midwives; Red Nose (Australian SIDS Charity); Hong Kong Department of Health; International Childbirth Education

Association (US) and Academy of Breastfeeding Medicine (international) [**E7a-E7f**]. E8. Five indicative policies from NHS Trusts in England [**E8a-E8e**] plus NHS Scotland's publications *Ready*, *Steady*, *Baby* [**E8f**] and *Parent Club* [**E8g**].

E9. Three example CDOP/ LSCB documents issued 2015-2018 addressing safer sleeping guidance for infants in Lancashire [**E9a**], Suffolk [**E9b**] and Merseyside [**E9c**]. E10. Indicative feedback from participants in the Basis workshops 2013 – 2020 [**E10**].