Institution: University of Sheffield		
Unit of Assessment: C-21 Sociology		
Title of case study: Changing post-mortem practice, challenging taboos and supporting parents after infant loss		
Period when the underpinning research was undertaken: 2012–2018		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	**Role(s) (e.g. job title):**	**Period(s) employed by submitting HEI:**
Kate Reed	Professor in Medical Sociology	2004–present
Elspeth Whitby	Senior Lecturer	1998–present
Period when the claimed impact occurred: 2016–2020		
Is this case study continued from a case study submitted in 2014? N		

1. Summary of the impact (indicative maximum 100 words)

Research into post-mortem practice after infant loss has filled a critical gap in training for health professionals on post-mortem consent and bereavement support and led to changes in the support services and clinical practices in three NHS trusts. It has empowered local and national charities to lead changes in creative bereavement support practices, thus fostering the development of support communities across the UK and creating a voice for bereaved parents. Extensive media coverage has also raised public awareness around the taboo subject of baby loss, and in 2019 it was awarded the ESRC *Outstanding Societal Impact* prize due to the substantial impact achieved.

2. Underpinning research (indicative maximum 500 words)

Rationale: The National Health Service (NHS) estimates that one in eight UK pregnancies will end in miscarriage. Furthermore, approximately 5,544 babies were recorded as stillborn or died within the neonatal period in the UK in 2016 (ONS 2018). Post-mortem can play a critical role in establishing cause of death in such cases. But, in evidence submitted to a parliamentary debate on baby loss in 2016, low consent rates for post-mortem were identified as a continued source of concern, an obstacle to the advancement of scientific knowledge, clinical governance and medical education. Our research addressed this gap, uncovering barriers to consent and exploring the pioneering development of Minimally Invasive post-mortem using Magnetic Resonance Imaging (MRI). By offering an in-depth sociological understanding of the role of MRI in post-mortem this research has led to changes in clinical practice, and informed the development of better support mechanisms for bereaved parents both locally and nationally.

Research: This impact case study draws on the research findings from two projects: a pilot project funded by the British Academy 2012-13 on fetal MRI and an ESRC responsive mode project focusing on Minimally Invasive Autopsy 2015-18. Both projects have been supported by three Postdoctoral RAs in sociology. The research was based on a pioneering use of go-along ethnography, conducting mobile observations and in-depth interviews with different types of professionals – from pathologists through to hospital chaplains, coroners and the police (R1). It also included interviews with bereaved parents and other family members.

Findings: The research established the key factors behind low consent rates and how these may be addressed, thus offering a significant contribution to knowledge in this field. The findings emphasized various critical issues for key beneficiary groups: bereaved parents, health professionals and members of the public.

Professionals found it hard to ask parents for post-mortem consent. While parents often felt discouraged from consenting, they also expressed feelings of regret about not opting for post-mortem. *The need for better professional training, and opening training to a wider pool of professionals was therefore highlighted by the research.*

Parents felt overwhelmed by information they received after their baby had died. They also articulated concerns over who would care for their baby during post-mortem (R2). *This highlighted the need to change the content, type and timing of information given to parents.*

While MRI post-mortem was not available to all parents in the study, most would like this to become more accessible in the future (R3, R4). *Professionals endorsed this view, identifying this as an area in need of further development in NHS trusts across the UK.*

The research concluded that professional practices around *consent* could be improved; access to *MRI provision* needs to be widened and the nature and value of *hidden care practices* made visible to parents considering post-mortem. These issues were central to *Remembering Baby* (R5), our collaborative art exhibition which toured the UK in 2017-18 and which led to significant impact.

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

R1. **Reed, K.,** & Ellis, J. (2018). Movement, Materiality, and the Mortuary: Adopting Go-Along Ethnography in Research on Fetal and Neonatal Postmortem. *Journal of Contemporary Ethnography, 48*(2), 209–235. https://doi.org/10.1177/0891241618769997

R2. **Reed, K.,** & Ellis, J. (2020). Uncovering Hidden Emotional Work: Professional Practice in Paediatric Post-Mortem. *Sociology, 54*(2), 312–328. https://doi.org/10.1177/0038038519868638

R3. **Reed, K.,** Kochetkova, I., & **Whitby, E.** (2016). Visualising uncertainty: Examining women's views on the role of Magnetic Resonance Imaging (MRI) in late pregnancy. *Social Science & Medicine, 164*, 19–26. https://doi.org/10.1016/j.socscimed.2016.07.012

R4. **Reed, K.,** Kochetkova, I., & Molyneux-Hodgson, S. (2016). 'You're looking for different parts in a jigsaw': foetal MRI (magnetic resonance imaging) as an emerging technology in professional practice. *Sociology of Health & Illness, 38*(5), 736–752. https://doi.org/10.1111/1467-9566.12398

R5. **Reed, K., Whitby, E.,** & Ellis, J. (2018). Remembering Baby. *Bereavement Care, 37*(3), 88–91. https://doi.org/10.1080/02682621.2018.1539299

4. Details of the impact (indicative maximum 750 words)

This research has provided parents with an important source of support and enhanced both professional practice and service delivery. It has also facilitated a change in public attitudes towards post-mortem.

Empowering people and communities: The research team created a model for creative bereavement support workshops which are being rolled out nationally by bereavement support charities (8 conducted so far with over 1,000 participants) (e.g. Lullaby Trust, *Wings of Love* project S1, S2). Bereavement support charities (e.g. Teardrop, Northumbria) have used the research to raise awareness in "*communities that often feel sidelined"* in the North East, and to lobby local NHS Trusts for change in service delivery (S3). Other charities have used the research to raise public awareness, encouraging bereaved parents to seek organised support (e.g. Zephyrs, Nottingham S4). Online parent support communities have emerged as a result of our project exhibition *Remembering Baby* (S5). Testimonials and letters of support show the sheer significance of this research impact on bereaved parents: *"you have brought light and broken the taboo. I think the world should see your work! Please keep going and bring a voice for us and our beautiful babies"* (S5).

Professional development: The research team created a film *Matter of Fact*, based on qualitative interview transcripts with professionals. This film, which featured in our exhibition, is used to train staff in NHS trusts across the UK (e.g. APTs, Northumbria; Neonatal Nurses, Yorkshire & Humber and East Midlands), and has also been implemented as a bereavement support tool by charities (S1, S3). The film has been translated into Spanish and featured in various international events on Stillbirth, SIDs and Perinatal Post-mortem (S6, S7). Professional testimonials demonstrate how the film provides essential professional training: *"Highly useful tool for families and healthcare professionals"* and parent accounts highlight its emotional impact "*The word "post-mortem" used to scare me, now it doesn't, as now I know my baby was treated with love, care, dignity and respect. Thank you"* (S7, S5). Our pioneering multi-professional approach has led to innovative consent training for midwives (S7), an approach that has been showcased at elite national medical events such as the *Royal College of Radiology* annual conference. The research team have also created CPD opportunities for neglected professionals such as paramedics, fostering essential connections between hospital-based care and emergency services (S7).

Changing practice and service delivery: The research has had a direct impact on practice across Sheffield Teaching Hospitals (STH) and Sheffield Children's Hospital (SCH). STH have developed a creative bereavement support group based on our original *Festival of Social Science* workshop *Lasting Impressions* which has significantly enhanced parent support mechanisms (S8). Information materials given to parents about post-mortem have been re-written to include professional care practices (S6, S9, S8). Midwives routinely use our *Remembering Baby* quilt during their family visits because "*it visually displays to parents that they are not alone and are not the only ones who have experienced loss"* (S8). All parents across STH can now create a fabric square for a memorial quilt (S8). The research has fostered new dialogue across different NHS Trusts, leading to changes in clinical practice in hospitals beyond Sheffield. For example, Northumbria NHS Foundation trust are piloting the feasibility of a Minimally Invasive Post-mortem service (S3). Without this research professionals within and across NHS Trusts would continue to work in silos and bereaved parents wouldn't receive the care currently being established (S1, S3, S6, S7 & S9).

Raising national public awareness and challenging taboos: The exhibition and project have received sustained media coverage, with reviews stating that this is "*pioneering work in breaking down the conversational silence"* leading to a change in public attitudes to baby loss and post-mortem. There have been, to-date, over 20 media reviews and reports including: BBC main news site, BBC Radio 4 PM programme, BBC Radio Sheffield (2018 & 2019), BBC Radio Nottingham (2018), Sheffield Live, SANDS: Stillbirth and Neonatal Death Charity (2017 and 2018), and Yorkshire Post (S10). Furthermore, around 2000 people visited the *Remembering Baby* exhibition during 2017-18. 250 formal FSS ESRC evaluation forms, 213 visitor book entries, around 300 social media responses, 50 emails, 15 written testimonials, and two invited impact publications (e.g. CRUSE affiliated *Journal of Bereavement Care*) all capture the extent of this impact (S1, S5, S7, S10, R5).

As a result of the extent & quality of the impact that this research has achieved, Reed and her team were awarded the ESRC *Outstanding Societal Impact* Prize in July 2019 (S1).

5. Sources to corroborate the impact (indicative maximum of 10 references)

S1. The ESRC created a case study and film about the research impact *changing practices and supporting parents for infant post-mortems* (ESRC *Outstanding Societal Impact Prize* 2019). The film highlights the key research impacts and includes testimonials from one parent and from the National Charity for Sudden Infant Death, *The Lullaby Trust*.

S2. *Wings of Love*, film and website. This demonstrates how our model of creative workshops has been adopted on a national basis by the Lullaby Trust.

S3. Coordinator of *Teardrop Support Group* (affiliated with the National Stillbirth and Neonatal Death Charity SANDs and Northumbria Healthcare NHS Foundation Trust). This letter of support demonstrates how impact has been achieved beyond the immediate geographical context of the research, shedding light on baby loss in neglected parts of the UK. It also shows how the research enabled different charities and NHS Foundation trusts to engage in shared dialogue about post-mortem, and facilitated change in NHS service around Minimally Invasive Autopsy.

S4. Project manager *Zephyr's* (Nottingham Hospital Charity's Bereavement Support Centre). This letter establishes how one Nottingham based charity used the *Remembering Baby* exhibition to open up a dialogue about baby-loss and encourage bereaved parents to seek formal support.

S5. *Parent testimonials and blogs:* These testimonials were collected by members of the research team either at, or after, various events (e.g. the creative workshops and exhibition). Blogs and social media posts were also captured by the research team through the *Remembering Baby* Twitter and Instagram account. These demonstrate the deep and profound impact of the research and exhibition on parent experience both locally and nationally. They also illustrate the ways in which new baby loss communities were created as a result of the research.

S6. Head of Histopathology (Sheffield Children's Hospital Foundation Trust). This letter provides evidence of how the film *Matter of Fact* is being used to train health professionals. It also details the positive effects of the exhibition on bereaved parents and members of the public. It also shows how the research is leading to change in service delivery.

S7. *Professional written testimonials*: These testimonials were collected by members of the research team either at, or after, various events (e.g. the creative workshops, exhibition and professional training events). They detail the impact of the exhibition and *Matter of Fact* film on professional development and training, locally nationally and internationally. Professional statements also show the impact of the research on different types of clinical practice, as well as on academic practice.

S8. Psychological well-being Midwife (Sheffield Teaching Hospitals NHS Foundation Trust). This letter demonstrates the impact of the *Remembering Baby* quilt on bereavement support practices. It also shows how our original ESRC FSS creative bereavement support group *Lasting Impressions* is being embedded within the NHS.

S9. Bereavement Services Coordinator, *Bereavement Services* (Sheffield Teaching Hospitals NHS Foundation Trust). This letter details the impact of the exhibition on bereaved parents, professionals and members of the public. It also shows how the research is leading to change in consent practices at STH.

S10. Media coverage portfolio (includes synopsis of news features and statistics until end of 2017). This demonstrates the significant national impact of the research and exhibition on the opinions of the national public.