AIMS

JOURNAL

I am writing to complain

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The AIMS Journal spearheads discussions about change and development in the maternity services.

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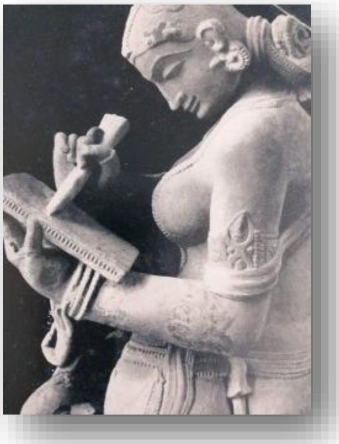
Journal Vol. 36, No. 1
I am writing to complain

I am writing to make a complaint
By Alex Smith
Navigating a hospital mistake that could have changed everything
By Julia Mihaylov
My Complaint
By Grace Hall
Playing the Long Game: Threads of Protest and Human Rights in Childbirth
By Gemma McKenzie
Doulas supporting clients to make a complaint
By Anne Glover
My complaint about complaints
By Laura Mullarkey
The AIMS Guide to Resolution After Birth
Reviewed for AIMS by Sakina Ballard
Report of Parliamentary Debate on Birth Trauma
By Elle Gundry
Birth Activists Briefing: Making a complaint about NHS services
By The AIMS Campaigns Team
The British Intrapartum Care Society (BICS) conference 2023
By The AIMS Campaigns Team
How can digital consultations best be used in maternity care?
By Dr Georgia Clancy and Professor Catrin Evans
MBRRACE-UK Reports – Shocking Racial and Socioeconomic Inequalities Continue and Even Widen
By Catharine Hart
Screening for twins: Why good guidelines matter
By Stephanie Ernst
What has the AIMS Campaigns Team been up to this quarter?
By the AIMS Campaigns Team

I am writing to make a complaint

by Alex Smith



Welcome to the 2024 March issue of the AIMS journal. The theme for this quarter focuses on the experience and process of making a complaint.

Over the years I have made two complaints about NHS staff. Neither of them was directly related to maternity care, but the parallels were striking. Both complaints included:

- not being listened to
- no regard or respect for approaching the consent process in the proper way
- no regard or respect for the knowledge we held
- extreme pressure (amounting to bullying) to comply with a treatment that was not in line with NICE guidelines in one instance, and strongly challenged by current research in the other
- no concern for holistic care needs
- defensiveness and irritation from staff who clearly felt thwarted in their authority by our non-compliance
- and in one case, three (seemingly malicious) safeguarding referrals from nurses about us - all of which (we later read in the notes) were turned down by the safeguarding team with increasing levels of annoyance expressed by the team towards the nurses.

Unfortunately, these were not our first experiences of poor care (only the first we had complained about). We had learned from earlier experiences that we often bitterly regretted not trusting ourselves, not speaking up, and not standing our ground. I want to give examples at this point but they are too emotive. Suffice to say, we became determined to stand our ground in situations where standard care was inappropriate or unacceptable, while remaining calm, clear, courteous, reasoned - and within our rights.

That should do it, I thought.

But no, even now, if I or a family member are in a medical situation where a little ground-standing is required, it feels as if daggers have been drawn (*not every time*, but often enough). Expectant parents instinctively anticipate the possibility of this type of response, when they explain that they did not assert themselves in a maternity care situation for fear of 'getting their backs up'. I wrote in one complaint that it seemed as if anything short of grateful compliance was a trigger for the nurses, that anything else simply did not 'compute'. At points where I remember feeling frustrated and distressed in trying to advocate for my dying mother's preferences (at her request), I found from their notes that I was being perceived as *difficult and hostile* - and when I succeeded in supporting her (and I did), this was when the safeguarding referrals began - echoing the significant rise in referrals to social services for declining aspects of care, that parents report to us on the AIMS helpline. These incidents resulted in lasting feelings of trauma yet, in an academic way, I also found them fascinating.

The question I returned to again and again was why?

- **Why were these (presumably perfectly nice) nurses not practising in line with the Royal College of Nursing's excellent Principles of Nursing?**[1] These principles are intended as a measurement tool for quality improvement and to enable providers and patients to know what quality nursing looks like. They include some wonderful words:

Warming words are also found in 'The Code', the professional standards of practice and behaviour for nurses, midwives and nursing associates[2]. The first standard set out in The Code includes the requirements to:

Treat people with kindness, respect and compassion…avoid making assumptions and recognise diversity and individual choice…respect and uphold people's human rights.

When nursing and midwifery care measures up to these standards, there is very little cause for complaint.

- **Why were the nurses so fixated on the local protocol?** In both of my complaint situations adherence to the hospital protocol and 'what we always do' was literally the only thing that seemed to drive care. It was their unshakeable modus operandi. I could not understand why senior nurses were unaware of up-to-date research and unable to respond to it even when I had it in my hands for them to see. I could not understand why they were unaware that there were legitimate points of debate to be had. In both situations they would or could not engage in respectful nuanced discussion about treatment options when we invited this, but just looked at us like proverbial rabbits in the headlights - and then reiterated the protocol as if this was all they were programmed to say. If they had been on a screen I might have wondered if they were AI generated. This felt so unreal that I actually felt gaslighted. I know that some maternity service users will recognise this.

"Obstetric providers can gaslight mothers when they deny mothers' realities. Gaslighting includes denials of mothers' humanity, knowledge, judgments or feelings. All four denials work to render mothers noncredible and their claims illegible."[3]

- **Why did the nurses appear to have no idea about consent?** Not only did the nurses in both situations assume that the patient's consent to treatment was a given, they seemed shocked, puzzled and annoyed when they were asked not to proceed. The Montgomery ruling about consent[4] was fairly recent at the time (and doctors and nurses can't know everything), so I reminded them that gaining consent now required discussion of the options, up-to-date information, time to consider the decision without undue pressure or coercion, and respect for the decision even if they did not agree. I actually thought that this would get us back on track, but no. in both cases, efforts to gain our obedience were stepped up exponentially. It is still an absolute mystery to me why they didn't just say, "Of course, that's fine", and then document our decision in the notes. In both of my complaint situations that simple response would have made the world of difference.

When I reflect on my complaint situations and their similarities to the complaints of maternity service users, and ask that question 'why?' - why did they behave this way? - I find myself boiling it down to *ignorance* or *malice*. Harsh words, but when nurses, midwives or doctors behave in a way where they appear to have: no respect for the principles of their professional practice; no respect for individualised care; and no awareness of their legal duties in approaching the consent process in the proper way - this can only be for one of two reasons. They either do not know about these things and do not know that forced compliance is harmful (ignorance) or they do know, but choose to ignore this despite the harm[5] they know it will cause (malice). In discussion with others, an almost identical analytical conclusion was proposed but with the gentler words of *naivety* or *wilfulness*, however, it boils down to the same thing.

Of course, the vast majority of nurses, midwives and doctors do not get up in the morning and go to work meaning to be naive or wilful, so there is another '*why*' to ask - why do caring and hardworking practitioners open themselves to being complained about? The professional principles, codes of practice, and the correct approach to seeking consent, would protect them as much as they would the patient or maternity service user - if only they were embraced. In 2020, a study[6] showed that since the Montgomery ruling the number of settled claims directly related to the patient not being fully informed before consenting to treatment rose four-fold, and cases where not being fully informed was a contributory cause of the complaint, settled claims rose nearly ten-fold. No one wants an experience of care that leaves them needing to complain, and no one wants to be complained about. The answer is so simple; the guidelines for it are already in place, but here they are again:

Treat people with kindness, respect and compassion…avoid making assumptions and recognise diversity and individual choice…respect and uphold people's human rights. Did my letters of complaint change things for the better? I wish I knew. I have to say that in 2019, the complaint regarding the nurses who visited my late mother resulted in the promise of county-wide workshops for community nurses, both on *practising with emotional intelligence* and on updating their understanding of consent. Given the disruption to services caused by the pandemic, I do not imagine for one moment that this happened, but it still felt like a good result.

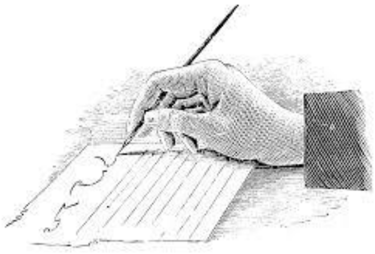


Image Source

We open this March issue with Julia Mihaylov's gently-told personal account of a hospital mistake that could have ended very differently had she not trusted herself. This is followed by Grace Hall sharing the very unsettling story of the birth of her first baby, the events of which continue to haunt her today. While her own complaint at the time got her nowhere - possibly because some of her medical notes mysteriously went missing - Grace believes that the complaint process can be beneficial.

Laura Mullarkey goes on to compare her recent experiences of complaining about her NHS antenatal care, to making a regular consumer complaint. Laura’s comparison is very measured considering that her and her baby’s life had been put in jeopardy by her GP’s failure to provide medical treatment, but Gemma Mckenzie pulls no punches in describing how her experience of obstetric violence, and then the denial of this in a way that amounted to gaslighting, led to her rejecting the futility of the formal complaint and choosing to play the long game instead. Get your crochet hooks ready!

While the complaint process often does end up feeling futile, Anne Glover notes that some of her doula clients receive really encouraging responses from their complaints. Perhaps the process of complaining is like housework in that it doesn’t appear to make a difference - unless we don’t do it. Unfortunately, as Gemma McKenzie experienced, women are often too bewildered immediately after the birth to make a complaint at that time and yet the troubled feelings do not go away. Reading the AIMS guide to Resolution After Birth, reviewed in this issue by Sakina Ballard, can, in Sakina’s words, ease some of the bewilderment.

Thanks to women speaking up about their experiences, the first parliamentary debate on birth trauma took place in the House of Commons in October 2023. AIMS volunteer Elle Gundry reports on the significance of this, and for those of you who may be unsure about how to speak up, Nadia Higson gives a detailed account of how to make a complaint. Members of The Campaigns Team tell us about attending The British Intrapartum Care Society (BICS) conference, and Georgia Clancy and Catrin Evans ask how digital consultations can best be used in maternity care.

Years ago, I remember joking that one day maternity care would be offered online (thinking this the epitome of the world gone mad), but here we are and maybe there are some good things to be said. However, the CORE implementation principles that Georgia and Catrin highlight should perhaps be respected with particular regard to the racial and socioeconomic inequalities that, according to Catharine Hart in her piece on the latest MBRRACE reports, continue and even widen. In our penultimate spot for this issue, and on a happier note, Stephanie Ernst tells us about screening for twins and why good guidelines matter. Finally, to bring the March issue to a close, The Aims Campaigns Team tell us what they have been up to during the last quarter.

[1] RCN (updated 2021) The Principles of Nursing - click on link to their poster www.rcn.org.uk/Professional-Development/publications/pub-003864

[2] NMC (Nursing and Midwifery Council) The Code: the professional standards of practice and behaviour for nurses, midwives and nursing associates www.nmc.org.uk/standards/code

[3] Priya Fielding-Singh, Amelia Dmowska (2022) Obstetric gaslighting and the denial of mothers' realities, Social Science & Medicine,Volume 301 www.sciencedirect.com/science/article/abs/pii/S0277953622002441#preview-section-cited-by

[4] Ashworth E. (2021) The Montgomery ruling and your birth rights www.aims.org.uk/journal/item/montgomery-consent-law

[5] Journal Vol. 34, No. 2 (2022) — The Sound of Violence www.aims.org.uk/journal/index/34/2

[6] D S Wald, J P Bestwick, P Kelly, The effect of the Montgomery judgement on settled claims against the National Health Service due to failure to inform before giving consent to treatment, *QJM: An International Journal of Medicine*, Volume 113, Issue 10, October 2020, Pages 721–725, https://doi.org/10.1093/qjmed/hcaa082

Navigating a hospital mistake that could have changed everything

by Julia Mihaylov

Author Bio: Julia Mihaylov is a passionate birth worker, antenatal teacher and trained as a doula. She is also a yoga teacher, ex-professional gymnast, physics graduate, ex-finance professional for almost a decade and a mother of two. After having two beautiful home birth experiences, her life changed. Her babies gave her a gift of passion for childbirth. She got empowered to help other women with sharing evidence-based information and leading them to trust their instincts that are crucial in the birth process.

On the way to motherhood, every twist and turn draws a unique story, and my second pregnancy took an expected detour. Now, as I watch my vibrant 18-month-old daughter giggling and playing, I reflect on the difficult experience that unfolded exactly two years ago today.

It all kicked off when I found out quite early in the pregnancy that I had a hematoma, an occasional hiccup during pregnancy. Despite the disconcerting bleeding, physically, I felt fine. However, a visit to the hospital became inevitable as the bleeding persisted. Little did I know that this visit would set off a chain of events that could have led to a heartbreaking outcome.

Upon arriving at the hospital, the shocking revelation hit – my waters had broken at just 17 weeks. Or so they claimed. Bewildered and confused, the medical team recommended terminating my pregnancy. Struggling to grasp this sudden and grave news, I called my husband for support. Despite the emotional whirlwind, I decided to take a moment to digest this information, as it was quite a lot to process already.

Hospitalised and left to my own devices for the evening, the isolation and lack of care heightened the distress. Not forgetting to mention that the food was awful, and they even forgot to include me for the dinner all together. Grateful for my husband's intervention, he brought comfort, food, and a semblance of normalcy to an otherwise unsettling environment. It was also distressing, as I had a toddler at home, who was still being breastfed, and had never spent a night without me.

The next day, the doctors came for a discussion again, urging me to terminate the pregnancy. This time, the reasoning was the potential trauma if I lost the baby further down the line, say around 28 weeks. As if you would not experience trauma, if you terminated now, or at any point in pregnancy, thought I. And anyway, nobody explained to me what it would be like to continue with the pregnancy or what the risks would be. My husband and I, both having only experienced the miracle of home birth previously, with our first child, felt out of place in the clinical and cold hospital setting. We decided against the medical advice, and left the hospital, on the condition that we understood the risks that they claimed i.e., I might go into labour in the next 24 hours.

During my time in the hospital I sought information from online communities, as I was not given enough information from the midwives or doctors. I found women who shared similar experiences, and a whole Facebook group with thousands of women who had either lost babies or had incredible survival stories of women with premature rupture of membranes. I was determined to fight for my baby's survival, even to fight through the rupture of membranes.

Days later, we had an appointment with our obstetrician, who delivered surprising news. We had a scan with a specialist doctor, who told us that my water levels were normal, and there was no evidence of a rupture. She questioned the initial results, prompting further investigation.

The same doctor decided to discontinue the use of the test that led to my misdiagnosis. Despite the claims of accuracy from the pharmaceutical company, the hospital acknowledged the fallibility of the test for pregnancies below 20 weeks. After my case, three more women had their babies saved, because of this change within the whole hospital Trust. Instead of using the tests, they started observing the amniotic fluid levels instead. Ironically, this was already the process in the other hospital Trusts, and in some other countries anyway.

This made me wonder about the whole hospital Trust system in the UK, and how it operates. How can it be that when other hospital Trusts are not using these tests anymore, my Trust persisted in using them? Clearly other Trusts adopted up-to-date research evidence regarding the use of these tests, whilst in my hospital Trust, they needed my case to happen before they changed their practice.

Reflecting on my story, it was a great reminder of the importance of questioning medical information, trusting mother’s intuition, and advocating for evidence-based care. If I hadn't challenged the initial diagnosis and decision, my daughter might not be here today. This narrative serves as a call to women everywhere – question, demand the evidence for recommendations, and be your own advocates. Healthcare decisions can be life-changing and mother’s intuition is a formidable force that should never be underestimated.

My Complaint

by Grace Hall

Editor's note: In this quite shocking account of disrespect and neglect, Grace describes the arrival of her first baby. With Grace's permission, the section that explains what actually happened at the hour of his birth is written in my words. This is because, for Grace, the emotions attached to this time are so complex, and her memory of the trauma so detailed, there weren't enough words, or a way of putting them together, that made sense. In fact, what happened was senseless. Not all of her care felt bad though. Her good experiences came from being listened to with respect and trust by practitioners with whom she had built a relationship. If her care had been like this throughout her time in hospital, Grace would have had a very different story to tell.

Author Bio: Grace Hall is a mother, Hypnobirthing educator, holistic doula, complementary therapist and ceremonialist, supporting women to reclaim their autonomy as they enter motherhood. Grace believes that she has inherited her deep calling to this work from her paternal grandmother and great grandmother, both of whom were traditional midwives in Brazil.

Our story starts as first-time parents, full of dreams and preparations for our firstborn's arrival, informing my GP that I was pregnant and really looking forward to the journey. We did much planning and preparation for this magical moment in our lives. I had the majority of the offered screening tests done, saw complementary therapists and followed the suggested guidelines.

I was offered a test for gestational diabetes (GD) due to my apparent ethnicity, and was referred to a consultant despite results being normal, and despite me being very healthy and classed as low risk. The referral was useful however, as I developed pelvic girdle pain later on in pregnancy and the consultant obstetrician was very supportive. He provided me with ideas on how to relieve the discomfort and further explanations on how to have a positive pregnancy and labour experience. He helped me create a birth/care plan based on my preferences, explained how to cope with pregnancy and labour discomforts, and made recommendations for a comfortable labour. I saw the same consultant, who was at the time the Head of Obstetrics at my local hospital, three times through pregnancy and I felt that the continuity of care was reassuring and a positive experience.

When I first went into hospital, after labour started, I saw several different midwives and, after being sent home once for not being in active labour, we returned to the hospital and I was examined, and offered a side room in which to rest – and there I stayed for the next 14 hours. During this time I was given a dose of pethidine, but otherwise was without any assistance. I felt secure being in a place I could call midwives anytime if I felt unwell, however my labour slowed down and I was finally able to sleep.[1] During my awake intervals I ate the food and drank the water I brought in my suitcase and I used hypnobirthing to cope with the pain.

There were systematic errors, broken communication between staff, and all the recommendations made by my consultant obstetrician were disregarded and written off with drastic and long-lasting consequences for both my son and me.

This is what happened: After 14 unsupported hours of labour in a sideroom, a midwife finally came at the very end of her shift and offered a vaginal examination to assess whether Grace's cervix was opening. The midwife apologised and said that she was only 2cm dilated. Grace accepted this and got up to walk about. Only a little while later she felt the need to push and told the midwife. The new midwife responsible for Grace's care said that she could not possibly be ready yet and that she could not perform another vaginal examination so soon after the previous one. Grace insisted on an examination and sure enough, in under one hour she had dilated to 8 cm. At this point she was admitted to the labour ward. The midwife on the labour ward appeared fed up and unwelcoming. She tutted and sighed and told Grace that it would be another three hours

What I did not realise at the time, was that the absence of anyone to check on me after strong pharmacological medication was administered, or even to provide me with food and water, was the start of neglect and a pattern that set the unsafe scene of malignant neglect that almost led to my baby and I not surviving labour and birth.

before her baby was born. Grace then started 'vocalising' (making the sort of noises that women make as they are about to give birth) and the midwife told her (in what felt like an unsupportive tone) not to scream as it was a waste of her energy and wouldn't change anything. Grace's original plan for a waterbirth had already been changed, and now she had her request for an epidural declined. She remembers that no attempt to comfort her physically or emotionally was offered instead. Very quickly Grace felt ready to give birth and asked to be examined again. The midwife asked her to lie on the bed but instead of examining her applied a belt monitor and started asking detailed questions about her name and address - even though it was clear that Grace could not speak at this point. Unable to manage the contractions in this position, Grace tore off the monitor and stood up by the bed. A student midwife asked permission to remove Grace's underwear and a quick look showed a bulging bag of membranes clearly visible at the introitus (entrance to the vagina), a sign that the birth was imminent. Instantly, the membranes ruptured covering the student midwife and going into her eyes so that she could not see properly for a moment. A pillow was quickly placed at Grace's feet, but it was not enough. Her baby followed so quickly that Grace did not have time to catch him herself.[2] He shot head first onto the floor and slid under the bed yanking on the still attached placenta and snapping the cord. This resulted in a very shocked baby (otherwise unharmed), a very heavy bleed for Grace, and a sense of trauma that she carries to this day.

After the birth I was so confused, in shock. My body started to somatise[3] the experience and the midwife made a referral for me to be seen by my GP. The meeting with my GP was generously paced and welcoming and he was able to hold the space for me in a way I had not yet felt or seen since the birth of my child. He was appalled with my birth story and helped me identify several failures in the care we received, issues that I had previously attributed responsibility for to myself. My GP kindly wrote a letter to the Head of Obstetrics to ask for his assistance with a Birth Reflections session and in addressing the negligence.

My GP letter initiated our process of complaint. He was able to articulate the failures from the physician's point of view. He described how I felt, my medical history and how the event was impacting me at that moment. This felt very positive. Being my GP, he already had an idea of who I was, he knew my husband and our family, and he was able to paint a picture of how much the events leading to the birth of my child had affected me.

The consultant obstetrician promptly responded and invited us for a meeting to hear from me about my concerns and grievances, and to try and explain how so many mistakes, that led us to feeling unsafe, scared and scarred, had happened. We attended the meeting at his office in the hospital. He was kind and warm with great listening ability. He held space for us while he explained how the events reflected an unacceptable standard of care. He said that there were several midwifery errors and that he fully supported our formal complaint with PALs (patient liaison services). The consultant also recommended that my labour and son's birth records were reviewed by us in this meeting; however the documentation was not available, so he recommended that we return when he had all the records with him. We were made aware that legally we had the right to copies of my record and to review the documentation with a clinician. So we requested it and agreed to return to discuss it.

Unfortunately, the warm and caring atmosphere of the previous meeting with my obstetrician was not repeated at the following meeting we attended at the hospital. We had a consultant midwife and the Head of Grievances join the meeting. She was extremely formal, cold, and defensive.

She used very harsh language with us and, while she had our records with her, they were missing the page recording the time period in which the negligence at the birth of my son happened. She also mentioned that many of their procedures had changed since we gave birth at the hospital (only a few months prior to this meeting) and that the changes were unrelated to what happened to me - despite the fact that she had heard what happened on the night of the horrific events of my son's birth, as she was on duty at the time.

This was so heartbreaking to hear and face as we hoped that by reading the records we could make sense of what happened. But this was not possible. I felt even more lost and broken inside to see that what happened to my son was not worth one single acknowledgement from the midwife responsible for grievances. Midwives are professionals supposedly responsible for supporting women emotionally during one of the most crucial life changing events in their life. My husband even cheered to hear that some of the procedures had changed, believing that it was due to our near-death experience. However, as mentioned previously, the consultant midwife took pains to say that these changes were unrelated to events that occurred at the birth of our baby, which felt like continued gaslighting - so much so that the consultant obstetrician asked for the meeting to come to an end until further investigation was carried out to discover what had happened to the missing page in my records.

I believe this doctor put a stop to the meeting as a compassionate gesture because he could see how the consultant's midwife's cruel indifference, and her defensive way of using legal terminology and detached jargon, was affecting us - especially so recently after the experience that would mark us for the rest of our lives.

Once the consultant midwife left the room, the consultant obstetrician was very empathic and said to us that this was such a tragic and embarrassing incident, and that further investigation would be done to find my missing records. The doctor said to us that we could continue to bring our grievances forward and beyond the NHS.[4] However, he questioned whether this was something we would be able to cope with or wish to do for the next few months and probably years while the whole case went further. He graciously explained to us that continuing with the grievances would be like a dark shadow of a cloud over our heads accompanying us wherever we went, preventing us from enjoying our son who was alive despite all the occurrences. The consultant obstetrician then said that many couples who come to see him with lesser complaints, and who sit in the very same seats as we were sitting, did not have the opportunity to hold an alive baby in their arms.

We walked away feeling very reflectful, grateful for our lives, looking forward to meeting again to understand what happened to my records and to having some sort of closure. Months after this meeting, we were contacted once again by the obstetrician and informed that a part of my records was still missing. He asked if we would like to come in and discuss next steps. We decided against it. Despite his very strong remark about other parents who had fatal outcomes for their babies, we appreciate that my obstetrician's intentions appeared to be good.

In hindsight, was his gentleness and supportive ways a tactic of "good cop, bad cop"? We will never know.

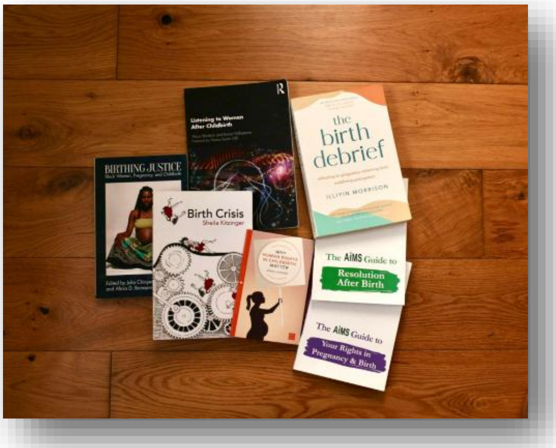
The only thing we know is that being listened to, acknowledged and validated made us feel held enough to move on, at that time.

What is my take from experiencing the complaints and debriefs processes first hand? It is that it can be extremely draining. It can be very upsetting to have to review and learn from the information recorded (if they have not lost it) as it is often in medical jargon and comes from a different perspective than the parents' experience. Sometimes the notes are written in a way that makes it sound as if the events were a failure or incapability of the mother. It can be extremely hard to relive the labour story and accept that the things that could and should have been done did not occur. However, there are some people who have found the experience an aid to their healing process. I work with birthing families every day and I see all situations in the birthing rooms (at home, in ambulances, birthing centres, labour wards or theatre) and some of the families I have worked with have found consolation, validation and understanding from the process of a birth debrief with their Trust and facilitation through PALs.

So, please do not think that making a formal complaint is a useless exercise, or something to fear. Women who feel broken, guilty, let down and unable to cope with caring for themselves and their families, should not have to suffer in silence. It is your midwife and doctor's moral, ethical and legal duty to provide safe and dignified care to you and your baby. Making a complaint can be very beneficial both for your recovery process and for highlighting your concerns about the standard of care provided by the professionals that may be letting you and the system down.

The main thing I would love is for families to set their expectation at the right level when deciding to pursue a complaints process, as, in my observation, NHS members of staff will rarely admit error if their admittance will lead to a court case being lost. Nevertheless, parents may find closure to their stories and be able to restart their journey with a better understanding for next time.

The journey has not been easy, however, being able to express my truth in safe places, and being supported through the process, enabled me to transcend the pain to a place where, after some years, I was able to reframe my experience and give birth to my second baby at home, calmly, respectfully and well supported by those that I love.



Grace's useful reading list:

Birth Crisis by Sheila Kitzinger - ASIN: B000OI18QI

The AIMS Guide to Resolution After Birth - ASIN: B086T266KQ

The AIMS Guide to Your Rights in Pregnancy and Birth - ASIN: B08SWTVFMJ

The Birth Debrief by Illiyin Morrison - ASIN: B09DK3MYJ9
Listening to Women after Childbirth by Alison Brodrick - ASIN: B084PY476Q

Why Human Rights in Childbirth Matter by Rebecca Schiller - ASIN: B01LYGNL1J

Birthing Justice edited by Alicia D. Bonaparte and Julia Chinyere Oparah - ASIN: B0BX9HTYKB

[1] Pethidine will slow labour in the early stages and it also acts as a powerful sedative.

[2] Editor's note: Had Grace been given empathic support and not disturbed by the opinions and moods of others, her own perception and instincts might well have guided her to move closer to the floor where she could have received her baby safely into her own hands. This powerful instinct is completely disrupted when other people tell you what to do and when they suggest that you cannot trust what you are feeling in your own body. A note to anyone who is with a woman in labour: Listen to the mother, believe her and support her.

[3] Editor's note: Somatise means to manifest (psychological distress) through physical symptoms.

[4] Editor's note: When the outcome of a person's complaint is unsatisfactory, they can take it to the ombudsman.

Playing the Long Game: Threads of Protest and Human Rights in Childbirth

by Gemma McKenzie

Author Bio: Gemma is currently an ESRC post-doc fellow and research associate at King's College London. She centres her research on maternity care, obstetric violence and the experiences of women who exercise their right to decline services they do not wish to access. Her website is: www.gemmamckenzie.co.uk

What do obstetric violence, human rights in childbirth, and crochet have in common? Well, it's quite a long story and spans the last 15 years of my life. It starts with misogyny and ends in protest. And it includes a way in which we as women and activists can come together to challenge the widespread abuses we experience and hear about in the UK maternity system and beyond.

Last summer, as I was daydreaming, strolling alone to pick my 9-year-old daughter up from school, a car full of laughing men sped past and threw water over me. The incident joins a long list of other indignities that I – and no doubt most women reading this – have experienced on the street as they go about their day-to-day lives.

What strikes me as I look back on this type of street abuse is that I was unable to complain. Who could I complain to? I might tell my girlfriends at some point, and they would likely recount similar stories. But in a society in which these incidents are so frequent they have almost become normalised, who is going to appropriately respond to this misogyny? The reality is, on all these occasions, I had no choice but to shake off the experience and carry on with my day.

It is with this same understanding that I entered the birth room. At twenty-eight and pregnant with my first baby, I was acutely aware of the misogynistic society in which we live, but blindly naive as to how that could manifest in NHS maternity care. Infantilised, coerced, uninformed and manhandled, I left that birth physically and mentally scarred. I had been sucked into the obstetric machine, crushed, and spat back out again.

At the time, I was too bewildered to complain. I didn't understand whether I even had anything to complain about. When I spoke to other women, almost everyone else's birth seemed to be as dehumanising and unnecessarily violent as mine. Sometimes, their accounts were even worse than what I experienced. In a routine that I have seen countless times since, women conferred with each other about the violence they had experienced, but so normalised was the abuse, that there seemed to be nowhere to turn.

By the time I was pregnant for the second time, I had sought help from AIMS. I remember being supported by Debbie Chippington-Derrick. She had suggested I contact my maternity unit to explain that my previous experiences at the hospital had traumatised me and that I would need extra support. Numb, I read the midwife's response out to Debbie over the phone. Instead of reaching out to me in a supportive way, the midwife had instead gone through my hospital notes and against every medical intervention I had endured she had written in bold: You consented. You consented. You consented.

I had been dismissed. I had been gaslit. I had been blamed for not speaking up at the time. Like the street abuse, I was now expected to shut up, shrug my shoulders and carry on with my day. With that letter, I knew that no amount of complaining to midwifery staff would alter the fact that their abuse of me was systemic; it was so frequent, so common, so widespread, that the behaviour was not recognised as problematic. Mirroring approaches we often see in other forms of violence against women – her skirt was too short, she walked in an unlit area alone, she should have left her partner sooner – *I* was now to blame for the violence that had been inflicted against me.

I was left reeling from that letter. Unlike other forms of gender-based violence that I had experienced in the past, I couldn't just shake this off. I never made any official complaint about my treatment at the maternity unit as I knew it would be futile. Instead however, I decided to play the long game. As my babies became toddlers and children, and then teenagers, I investigated these violations against women and the way in which their human rights were often decimated during pregnancy and childbirth. Now armed with a postgraduate certificate, a master's degree and then a PhD, I knew with certainty that the treatment I was subjected to was not only immoral, but unlawful – and perhaps even criminal.

I could also see the parallels with all the other forms of misogyny and violence against women that permeate our society. Whether a woman is cat-called on the street, coercively controlled by a partner or subjected to a non-consensual vaginal examination by a midwife, she is treated as something less than human. Her right to move freely and safely through the world is compromised. Problematically, the more frequently this abuse happens, the more normalised it becomes and the harder it is to make a complaint that is taken seriously and acted upon. Instead, there is the expectation that we remain silent, submissive, and accepting of the abuses that people and institutions dish out to us. The violence we experience becomes just another ordinary event in the life of a woman.

When those men drenched me last summer, an exhausted yet furious thought hit me: *I am so fed up with this sh$t*. I concluded that I am not in a position to challenge all forms of violence against women (yet), but given my job and my educational background, I am now in a position to speak up about abuses during childbirth. With funding from the Economic and Social Research Council, I decided to do something that at first blush seems totally bizarre – I would create a crochet exhibition promoting human rights in childbirth.

You may consider crochet and human rights to be a million miles apart. However, when I was really struggling after the births of my children, I learned crochet as a way of calming my mind. By watching YouTube videos and copying what I saw, I could begin to mentally switch off and the weaving and bending of the yarn became cathartic. Before I knew it, I had a house full of random crochet blankets and an official craft cupboard housing all my paraphernalia.

The exhibition I came up with is called 'Threads of Protest: Human Rights in Childbirth' and almost unbelievably, it will run for 3 months at the Atkinson in Southport from July to September 2025 and then for 3 months at the Curiosity Cabinet in London until January 2026. As always, AIMS is supporting my efforts. In fact, one of the pieces I will present links to the Wellcome funded graphic zine we worked on together, entitled 'My rights in the Maternity System.' Using tapestry crochet, I will recreate sentences from the zine[1] in crochet, such as, You can't touch me without my consent; I have rights; I am an individual; I am more than my pregnancy. I am also pairing professional crochet artists up with charities that support asylum seeking women, LGBTQ communities and those birthing in the criminal justice system, to highlight the human rights issues associated with these situations.

But perhaps most ambitiously, I am asking members of the public to donate a granny square to the exhibition. The idea is to sew the squares together and present them as a form of yarn bombing or craftivism. There is a whole history of women protesting using thread, ranging from the embroidery of the Suffragettes to the numerous examples of yarnbombing challenging violence against women (see here for an example). I want this piece to demonstrate how people – especially women – come together to challenge human rights abuses during childbirth. I aim to highlight that it is not normal or acceptable to be abused during birth and that these abuses are part of the wider problem of misogyny that we experience in society.

If this is the type of social activism that you are interested in, then I would encourage you to get involved. Whether you are an experienced crocheter or you fancy learning for free like I did via YouTube, all you will need is a ball of yarn and a hook. All squares can be any pattern, any colour, any yarn – and don't worry if your stitches aren't perfect or things look a bit wobbly. It's more important to get involved in raising awareness of the issue. I only ask that squares are a maximum of 15cm x 15cm (6 inches by 6 inches) and don't contain any offensive or derogatory wording. Once you have completed your square (or squares!), you can send them to:

Threads of Protest
PO Box 239
Liverpool
L37 8YU

If you live in the North West, you may find it easier to drop your square(s) off at A Modern Yarn, 39 Chapel Lane, Formby, L37 4DL.

Do I expect the crochet exhibition to change the world overnight? Of course not.

However, it might get people talking - and perhaps more dangerously - it might get people thinking. It might also help people to understand the way gender-based violence we see throughout our society emerges in the birth room. Perhaps this way, we can stress the point that we do not lose our rights once we become pregnant or enter the hospital, and that our bodies belong to *us* - they are not to be manhandled, penetrated, or cut without our consent. And possibly most importantly, when we are abused or violated, it has a hugely negative impact. No longer can abuses be normalised in a system that does not understand these acts as violent. We need ways to be heard, to challenge and to call out this behaviour. I refuse to shrug my shoulders any longer and just accept that this violence is too monumental, too ingrained, and too widespread in our society to challenge. I couldn't complain at the time – *but I am complaining now*. I might not be able to eradicate the misogyny that runs through our society and our birth rooms, but I can chip away at it – one granny square at a time.

[1] Editor's note: A zine (/ziːn/ ZEEN; short for **magazine or fanzine**) is a small-circulation self-published work of original or appropriated texts and images, usually reproduced via a copy machine.
[2] Gemma McKenzie - Threads of Protest: Human Rights in Childbirth
- www.gemmamckenzie.co.uk/threadsofprotest

Doulas supporting clients to make a complaint

By Anne Glover

Author Bio: Anne has been working as a doula for almost 9 years in Northern Ireland and has supported well over 150 women at some stage in their birthing journey. She currently volunteers on the AIMS Campaigns Team.

I work with women from all walks of life, but one thing that is important to them all, is having a positive and satisfying birthing experience. It is important as a doula to provide a safe space for them to chat about previous births, to unveil any fears, to talk about why their birth unfolded as it did, and to discover what is important for any future births. It's important for everyone to have the confidence to ask questions, and to understand why their birth happened the way it did. Feeling powerless, not being listened to, not understanding what is happening and feeling out of control can all contribute to birth trauma, which is exactly what we are striving to avoid for the mental health and well-being of the whole family.

Sometimes I am asked to support my clients to make a compliment, comment or a complaint about the care they received during their birthing journey. When making a complaint, it's usually about something someone said or implied to them, or subjected them to, or when they felt scorned or laughed at. Sometimes it's the fly-away comments that stick and are the most scathing. More often it is something someone did to them during their care, for example, performing a sweep without their consent, prising open their legs, or taking their baby into another room.

It can be very difficult and extremely challenging to talk about hurtful memories when you are a new mum trying to get to grips with a newborn. Being in the throes of motherhood and adapting to parenthood are not conducive to raking up disturbing memories and can feel like rubbing salt into raw wounds. And it's because of these reasons that many don't make any comments or complaints.

"Sure you're fine now and you have a healthy baby" can be persuasive enough to stop an emotional mum in her tracks. Most people don't want to be a nuisance, or to be seen as a trouble maker. Also they ponder, what's the point in going through everything again as it can't be undone?

So, why do some people go ahead and make a complaint? In my experience, many clients are looking for their account of the situation to be acknowledged and respected, and ultimately, for an apology to be given. They want to understand why something happened the way it did, or why someone spoke to them the way they did. Also the thought that it shouldn't happen to anyone else is enough to drive them to make a complaint. In many situations it's sufficient to have a chat with a midwife or doctor and go through their maternity notes to achieve clarity and understanding. However I have heard mixed reactions on the outcome of these meetings. Some women feel enlightened and very content, whilst others come away from these meetings feeling very low and unhappy, with unanswered questions and wishing they hadn't bothered.

It's heartbreaking to see the dismay and disappointment especially when some women go to great lengths to have their voices heard, and then realise that some authorities just appear to close ranks and dismiss their complaint as a normal expected situation. A sincere apology does not always come through, and too often they feel they have been fobbed off with a headed piece of paper saying they will discuss their comments with staff. Generally this is thought of as a complete waste of time and energy on their part.

To end on a positive note, I can share that there are really encouraging responses from some complaints. Often these may be promises of steps to better educate midwives and facilitate further training, and sometimes a complaint can even be used, with the mother's permission of course, as a case study in the training or further training of midwives and doctors. So, while the complaint process can be frustrating it also has the potential of making a real difference.

My complaint about complaints

by Laura Mullarkey

Author Bio: Laura Mullarkey is a lawyer with over a decade of experience. She is a volunteer on the AIMS helpline, a peer supporter for Pregnancy Sickness Support (where she was shortlisted for their 2024 Rising Star award), and recently trained as a doula. In her spare time, she's also a mum of three.

Laura Mullarkey, lawyer, AIMS volunteer, and mum of three, compares her recent experiences of complaining about her NHS antenatal care, with making a regular consumer complaint. The juxtaposition highlights some reasons why the former can be so dissatisfying for service users, and she concludes with an idea for an alternative model for NHS complaints.

I've made two complaints in the last year or so. In both cases, I had received refusals from a service provider to carry out the service that I was entitled to. In both cases, armed with my legal training to help me marshall my arguments, and buckets of determination, I called this out. And in both cases the service provider first tried to minimise and dismiss my complaint, but I persisted.

However, there the points of commonality end. Because whilst the first was a regular consumer complaint to a service provider, the second was a complaint to the NHS (in my case, my GP, who had repeatedly refused to listen to me or prescribe the medication I needed to combat my hyperemesis gravidarum[1] (HG)).

As a result, whilst in the consumer complaint case I ended up satisfied that my complaint had been heard and the right, fair and sensible outcome prevailed, in the NHS complaint case, I honestly don't even know what the outcome was. It was dissatisfying and disheartening and added a final sour note to what was already a deeply upsetting experience.

I fully appreciate that for some people, making a complaint about their maternity 'care' can make a really positive difference to how they feel about their experience. The mere act of writing and sending a complaint can be cathartic, and receipt of a validating response and a commitment to change, even more so. Sharing my experience, therefore, is not intended as a general statement that NHS complaints are inevitably fruitless, but simply a personal account of my own recent frustrations with the system, which left me with the question: *why is complaining to the NHS so difficult, even for someone who is a pretty effective complainer?*

Lack of a clear contractual relationship

The first thing that makes life tricky is the absence of a single contract or other legal document that you can point to that expressly covers all the services to which you are entitled, and the manner in which they should be provided. Yes, I know we have protected legal rights in all medical settings – we have human rights protections, the wonderful Montgomery[2] ruling on consent, and the Health and Social Care Act 2012[3], plus other "soft law" we can reference like the NHS Constitution,[4] and the professional standards that doctors, nurses and midwives sign up to when they enter their professions.[5] However, the difference between trying to set out in an email the full factual matrix to prove how the conduct of a GP fell short of the standard of shared decision making, how that left you feeling, and what you think ought to have happened - and a simple, "you have not performed your obligations under clause 9; please now do so", is stark.

Lack of effective remedies

The next issue lies with the 'remedy', or solution, to the complaint. The first part of this problem is that, with a complaint to an NHS institution there is often a lack of clarity as to what the remedy can and should be (for this purpose I am talking about complaints that fall short of clear negligence and do not require a medical professional to be disciplined or struck off). You can, of course, suggest your own remedies, but there is generally no requirement for the body receiving the complaint to agree to what you have asked for, even if they are sympathetic to the complaint itself.

By contrast, with my consumer complaint, it was obvious – ask for the breach of contract to be rectified and, if it was not, I would have the right to pursue a damages claim for non-performance of the contract. This instantly meant my email of complaint carried weight.

And this brings me to the second part of the problem with successful resolution to NHS complaints – the difficulty in actually obtaining a remedy. As mentioned, with my consumer complaint, there was no way the company could simply fail to respond without serious risk of legal action. Furthermore, I had other weapons in my arsenal to help improve my chances of obtaining an appropriate remedy – when the company tried to minimise my concerns and argue I was not protected under the language of the contract, I had the ability to publicise their disingenuous behaviour, and/or go to the Consumer Ombudsman (or, at least, threaten that I might do so).

On the other hand, when I first wrote my complaint to my GP surgery, I did not even receive a response. It took me two and a half months of chasing, by phone and in person, before finally receiving a letter back, which excused the behaviour of the GP, dismissed my concerns, and ignored all of my suggested solutions as to changes that could be made to improve procedures and care.

Lack of transparent follow through

Of course, I did not leave it there, and was in the end offered a meeting with a senior partner in the practice, the assistant practice manager and the GP concerned to discuss. I really believed at this point that, finally, there would be a chance for a meaningful discussion.

And then, on the day, with less than an hour before the meeting was due to be held, I received a text. The complained about GP could no longer attend – did I still wish to go ahead? We were now seven months on from the original GP appointment which started all this. The GP in question was apparently out of the country for “family reasons” and had no date set to return (it was implied that she might be away for some months). Did I really want to cancel today’s meeting, which was fixed and certain and which I had fought for, in exchange for a possible future meeting on an unspecified date, which could happen only if and when the GP returned? Plus, there were questions of logistics - my mum had already travelled to support me for today’s meeting, and I really wanted her there. She might not have been available when a new date finally arrived. And whilst I had been happy to bring my three-week-old into this meeting, I knew from experience that having to bring an active, older baby was likely to be distracting and difficult, making it harder for me to get my points across effectively.

So, for all these reasons, I went ahead with the meeting. The other, senior GP and the practice manager were both sympathetic, and they promised some long overdue changes to their appointment booking procedures for patients with conditions like HG, that home visits would be made available, and that the GP in question would be required to undertake some compulsory learning about HG, and would then be asked to present to the practice on what she had learned. Wonderful, I thought. Success.

However, I left that meeting, and that was that. No written follow up from them (not even a response to my email where I thanked them for their time, and set out what I had understood the outcomes to be), no timeline for carrying out what they had promised, nothing to evidence whether any procedures had changed, or whether the GP in question was ever even communicated with, let alone required to learn anything or present on it. And, of course, no one external to the practice, able to hold them to account. And so, I'm left wondering – was I an idiot to believe them? Am I being unreasonable to have expected more? Has anything at all changed for HG sufferers at that practice?

Compare that to my consumer complaint where, after some admittedly increasingly irate trading of emails, the company agreed to honour their contractual obligations and then actually did so. Job done, we could all move on.

And an alternative model?

I think it's clear from the above why writing a complaint about maternity care can be so dissatisfying, and that's if you're lucky enough to be starting from a position (as I was) where you aren't traumatised, you aren't continually gaslit during the complaints process, and you aren't targeted for your "audacity" with threats of children's services referrals. And, sadly, things are more difficult still if you are simultaneously having to contend with other barriers: being black or an ethnic minority given the systemic racism in UK maternity services,[6] speaking English as a foreign language, being disabled, not having the education, confidence and/or time to make pursuing a complaint practicable, all compound the unfairness inherent in this system. I write this account in full awareness of all my privilege here.

And so, I am left pondering what alternatives to this ineffectual complaints system might be possible. Loath as I know most people are to hold the banking industry up as a role model for anything, I do wonder if the Financial Ombudsman Service (FOS) might offer a significantly better paradigm. The FOS is an independent body (established by parliament) which investigates consumer complaints against financial services firms. Consumers can apply to the FOS, free of charge, and ask them to resolve most types of complaints regarding financial services and products (provided certain time limits are complied with). Consumers are not required to have any legal counsel or advice in order to make such complaints and the FOS gathers information from the consumer using plain language and no jargon. If, having undertaken an independent investigation, with evidence requested from both parties, the FOS finds the financial institution has acted unfairly or unreasonably, it has the power to make legally binding decisions as to how the financial institution should provide redress to the consumer, including requiring the payment of compensation. If the FOS finds there was no unfairness or unreasonableness, it must provide reasons for this, so that the consumer can understand, and the consumer remains free to reject the FOS's findings altogether and pursue their complaint through the courts.

Furthermore, not only must a financial institution who is found to have acted unfairly take the steps required by the FOS to remedy the issue and apply lessons learned to avoid a repeat, but the FOS shares anonymised information about cases with all businesses under its remit, thereby ensuring that a single complaint can help to raise standards across the financial services industry as a whole.

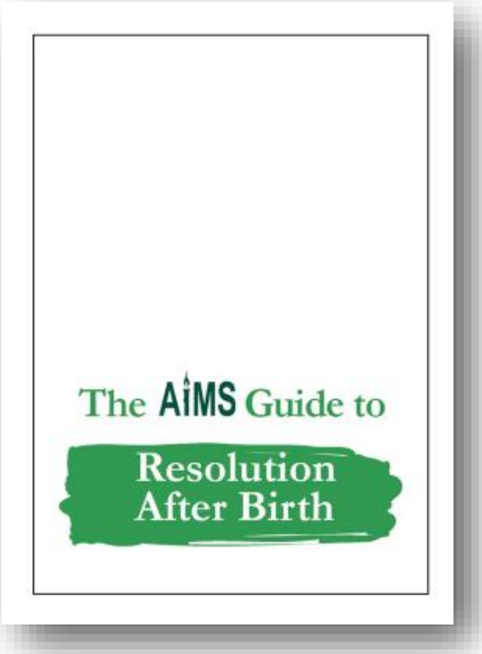
It isn't all good news: the FOS is funded by a specific levy paid by financial institutions, whereas it's hard to see how an NHS equivalent would be funded by anyone other than the taxpayer. And, of course, not everyone who goes through a FOS complaint necessarily winds up happy with the outcome. Nonetheless, the potential of such a scheme to improve individual outcomes and to raise standards right across the NHS ought at least, in my view, to make such a scheme worthy of consideration.
But then again, I won't be holding my breath for impending change. If I feel that my complaint about my antenatal care was not really heard, then who is there to listen to my complaint about complaints?

Author's footnote: As this article goes to print, the failures of Jessica Cronshaw's GP and midwife to recognise the severity of her HG, and their incorrect assertion that she should reduce her medication as it could harm her baby, have made headlines. Her story is devastating and my thoughts are with her, baby Elsie, and their family. It will surprise no one familiar with this condition, that my complaint concerned extremely similar treatment from my own GP. I would urge anyone currently struggling with this illness, or who knows anyone who is, to contact Pregnancy Sickness Support.

[1] Editor's note: Hyperemesis gravidarum is the medical term for severe nausea and vomiting during pregnancy, a condition that often requires hospital treatment.
[2] Montgomery v Lanarkshire Health Board [2015] UKSC 11 www.supremecourt.uk/cases/uksc-2013-0136.html
[3] Health and Social Care Act 2012 Fact Sheets www.gov.uk/government/publications/health-and-social-care-act-2012-fact-sheets
[4] NHS Constitution for England (2012) www.gov.uk/government/publications/the-nhs-constitution-for-england
[5] Professional standards: www.nmc.org.uk/standards/code and www.gmc-uk.org/professional-standards/professional-standards-for-doctors
[6] Birthrights (2022) Systemic Racism, Not Broken Bodies: An inquiry into racial injustice and human rights in UK maternity care. file:///tmp/mozilla_gwelfor0/Birthrights-inquiry-systemic-racism_exec-summary_May-22-web.pdf

The AIMS Guide to Resolution After Birth

Reviewed for AIMS by Sakina Ballard



Principal author Shane Ridley

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£8.00

Buy this book from AIMS

Author Bio: Sakina Ballard birth trauma and perinatal mental health practitioner working inside and outside of the NHS. She is Community Lead for Make Birth Better.

The first thing to mention is how digestible this book is, especially considering the challenge of needing to seek resolution after birth and the complexities of navigating systems that can feel like mazes to the service user. This book breaks down lots of the barriers that may prevent people from moving forward in their practical resolution and is especially helpful for those who need to engage with maternity systems.

The book is succinct, clearly laid out and each chapter packed with the key insights and knowledge in accessible and understandable language, not lots of jargon. The contents page is comprehensive, so the reader can find the parts of the book that feel most relevant with ease. This was a great feature and a welcome relief as a reader, given the topic of birth resolution is often emotive and can feel overwhelming to tackle as a service user.

The introduction of the book sets out who it is aimed at, maternity service users and those that support them, it is definitely highly useful to both, being both accessible and informative in a broad range of areas of resolution after birth, whilst holding the sensitivity this subject requires. There was also some consideration to the different experiences and needs birthing people have, noting the need for language and services to be inclusive for all.

This book covered every topic, from the foundational concepts of human rights and consent in birth, which impact all, to reflective prompts to support maternity service users to process their experiences and emotions around birth, as well as plan for subsequent births.

Whilst the process of resolution is not linear, this book sets out each chapter in a way the reader may often process their experience. From initially understanding what has happened and processing it, to then explaining the feedback and complaints routes, including the legal ones, so the reader can discern what feels like resolution for themselves with knowledge and understanding of the procedures.

It was great to see guest contributors adding further insights: human rights in birth, by Birthrights; birth trauma and diagnostic PTSD (which are not necessarily the same), from Make Birth Better; baby loss (a subject not often covered in maternity literature), by Sands; and a legal perspective on medical harm, from AvMA. Rather than try to brush over these topics, or leave them out entirely, these guest contributions added signposting and a richness to the voice of support this book offers.

Overall, a great resource for service users and practitioners alike, demystifying complex systems and procedures into a concise step by step format, so that those navigating the various paths of resolution, can consider what the next right step is in their individual circumstance.

As someone who has walked down the parent and practitioner paths, I read this book with a sense of relief that firstly, it exists and secondly, I can continue to use it as a valuable resource at work.

I would definitely recommend this book, a thoughtful, informative and vital book that eases some of the bewilderment of how to practically deal with this challenging topic.

Report of Parliamentary Debate on Birth Trauma

by Elle Gundry

Author Bio: Elle began volunteering for AIMS in 2023. She lives near Shrewsbury, and is happiest in the garden learning by trial and error to grow veg with her enthusiastic toddler. She has an interest in human rights, and after experiencing NHS perinatal services first-hand has sought to understand how maternity services can better serve women.

The first parliamentary debate on birth trauma took place in the House of Commons on Thursday 19th October 2023.[1] Thankfully, the word ‘debate’ is a misnomer here; there was no disagreement on the reality of birth trauma, or that NHS services to help women with birth trauma are inadequate. Theo Clarke MP led the debate and started by sharing her own experience of birth trauma and a birth injury. It was powerful to see women MPs supporting Theo Clarke through the difficult moments of sharing her story. The rest of the debate was largely a collection of personal stories with a clear message that more needs to be done to support women with birth trauma. Both psychological and physical causes of birth trauma were discussed with a sense of evenhandedness. I was concerned the focus would be solely on physical causes and psychological factors would be overlooked, so it was reassuring to see acknowledgement and discussion of both.

We heard Maria Caulfield, Minister for Women's Health, confirm the government's commitment to a rollout of postnatal services and acknowledge that birth trauma can often be prevented. Frustratingly she did not commit to actions that directly address preventing birth trauma, the focus was on (much needed) postnatal support. There was also a lack of nuance to the debate regarding the pressures or factors that influence how pregnant women and people feel in the perinatal period. It felt like the complex interplay of power, medical misogyny, an underfunded maternity system, race, sexuality, gender, previous trauma and social pressure, to name a few, were not unpicked or discussed. There was no mention of the role of obstetric violence as a cause of birth trauma. There was also little said about the huge disparity in care and outcomes for Black and Asian mothers. The ways in which hospital policy or culture impede women's decision making was not mentioned. Similarly, the UK’s rising induction and caesarean rates were not discussed nor was there much focus on informed consent or refusal. It is my feeling that this is where the work needs to happen to prevent birth trauma, but this requires us to be willing to listen to traumatised women and understand their experiences.

Perhaps this debate is the start of that broader conversation on preventing birth trauma.

It is important to recognise the significance of this first debate on birth trauma and to thank Theo Clarke MP for organising the debate and sharing her own experience. Dame Andrea Leadsome MP said that Theo Clarke MP had “the support of Members right across the House”. I think she also had the support of women, birthing people and families right across the country who have been failed by our NHS maternity system.

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[1] Debate on Birth Trauma 19th October 2023 | Maria Caulfield MP
" target="_blank">www.youtube.com/watch?v=cvdT9QG_97c
The full debate can be viewed here: https://hansard.parliament.uk/commons/2023-10-19/debates/D9DC6BAC-118F-4EA1-BE02-F815D5BE6436/BirthTrauma, and the transcript is accessible via Hansard Online - https://hansard.parliament.uk/commons/2023-10-19/debates/D9DC6BAC-118F-4EA1-BE02-F815D5BE6436/BirthTrauma

Birth Activists Briefing: Making a complaint about NHS services

by the AIMS Campaigns Team

The procedure for making a complaint about NHS services differs slightly in each of the nations of the UK. In general, there are three stages:

- Raising the issue informally with the care providers or a more senior member of staff. In the case of maternity services this might be the Director/Head of Midwifery, or a Consultant Midwife if the Trust/Board has one.
- Making a formal complaint
- Requesting a review by the relevant Ombudsman (who is appointed by the Government to look into complaints about the health service.)
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Before raising a complaint it is often helpful for the person concerned to request a copy of their maternity notes and any other personal information that the Trust or Board holds about them. Under the General Data Protection Regulation anyone has the right to make a "Subject Access Request." There is more information about what to include in your request here and a link that you can use to make an online request here.
It may also be helpful to contact an independent advocacy service for information and support before making a complaint. (See individual country sections below.)
For more information about making a complaint see our book AIMS Guide to Resolution After Birth

If the complaint concerns an individual member of staff there is the option of complaining to their professional body. For midwives this is the Nursing and Midwifery Council (NMC) and for doctors the General Medical Council (GMC).
Some people may want to consider taking legal action as well or instead of making a complaint. A solicitor who is accredited in medical negligence work should be able to advise whether there are grounds for a legal claim.

The AvMA (Action against Medical Accidents) has a series of self-help guides which cover the processes for making a complaint or taking legal action in each of the four nations of the UK, as well as ones on raising concerns about a healthcare worker.
AvMA should be able to help if someone wants to consider taking legal action. They have a register of AvMA accredited specialist medical negligence solicitors and a Helpline.

England
The NHS Constitution for England lists the rights that complainants have.
This webpage How to complain to the NHS explains the process.

Complaints can be made directly to the service provider (e.g. a hospital trust) or to the local Integrated Care Board (ICB),[1] which is the body that commissions the service, but not to both. ICBs have taken over the commissioning role formerly performed by Care Commissioning Groups (CCGs.) This website lists ICBs Find your local integrated care board (ICB).

Every organisation that provides NHS services is required to have a complaints procedure. Ideally this should be made available on their website and/or on posters in waiting-rooms and reception areas, but sometimes it's necessary to ask for a copy. The ICB should also have a complaints procedure on their website.

Most hospital trusts have a Patient Advice and Liaison Service (PALS) details of which can be found here. These are intended to offer "confidential advice, support and information on health-related matters" including the complaints procedure. They may also be able to help deal with an issue informally without the need for a formal complaint. There are also a number of independent health complaints advocacy organisations such as The Advocacy People, VoiceAbility and POhwer that offer free advocacy services to help people to make a complaint. Different organisations serve different parts of England so check which operate in your area.

There is normally a time limit of 12 months for making a complaint, but it is possible to do it later if there was a valid reason for not meeting the deadline. This could be the case if someone was so traumatised by their experience that they could not face revisiting the event any sooner.

Anyone who makes a complaint has the right to receive an acknowledgement and the offer of a discussion about the handling of the complaint within 3 working days of it being received. This may include a discussion of the timeframe for dealing with the complaint.

Whilst the complaint is being investigated the complainant should be kept informed of progress and if there will be any delay in providing the response. The response must be in writing and set out "the findings and, where appropriate, provide apologies and information about what's being done as a result of your complaint. It should also include information about how the complaint has been handled and details of your right to take your complaint to the relevant ombudsman."

The Parliamentary and Health Service Ombudsman makes final decisions on unresolved complaints about the NHS in England. They can be contacted on 0345 015 4033 or via their website Welcome to the Parliamentary and Health Service

Ombudsman. Note that the Ombudsman will not investigate a complaint until the local complaints process is complete, and now say they "will only look further into the more serious complaints about the NHS." This means that they won't consider things like delays in responding to a complaint.

Scotland
A person's rights to give feedback or complain are set out in The Charter of Patient Rights and Responsibilities (revised June 2022).
There are three stages to the complaints process.

Stage 1 Early resolution
NHS Feedback, complaints and your rights | NHS inform suggests "If you can, first talk to a member of staff involved in your care. If you do this, they can try to sort out your complaint on the spot. If you can't or you do not wish to do this, you can ask to speak to:

- a senior member of staff, or
- the Feedback and Complaints Officer for the NHS organisation involved

If you prefer to complain in writing rather than in person or over the phone, you can send a letter or an email to the relevant NHS organisation."

The organisation should provide an answer within 5 working days of them receiving the complaint.

Each Health Board has a team that works with patients, their families or carers to try to resolve complaints. These have different names in different Boards but the department name and contact details for each area can be found on this webpage Making a complaint about your NHS care or treatment.

Stage 2: Investigation.
If the complainant is not satisfied with the response, they can make a Stage 2 complaint. They can also go straight to stage 2 if they think the issue requires a detailed investigation.

The organisation should send an acknowledgement within 3 working days, then within 20 days either a response about their decision or an explanation of the delay and a revised time frame.

Stage 3: Ombudsman
If not satisfied with the response to a Stage 2 complaint the complainant can appeal to the Scottish Public Services Ombudsman (SPSO) Post: Freepost SPSO Freephone 0800 377 7330 or call 0131 225 5300

Email: ask@spso.org.uk Website: www.spso.org.uk Online form: www.spso.org.uk/contact-us.

If they decide to take on the case a complaints handler is appointed to investigate and give a reply. The decision of the SPSO is final.
The Patient Advice and Support Service (PASS) is an independent service, delivered by the citizen's advice network. It "advises those who wish to raise concerns, make a complaint, and give feedback or comments about an NHS treatment or service." It does not provide legal advice but "PASS Advisers provide free specialist support, both via our advice line and through face-to-face appointments in local citizens advice bureau." www.patientadvicescotland.org.uk 0800 917 2127. They can help someone to prepare a complaint and support them through the process.

Wales

The process for raising concerns or complaints in NHS Wales is called 'Putting Things Right'. There is an information leaflet about the process available here. It suggests first talking to the staff involved but "If this does not help, or you do not want to speak to the staff, you can contact the health board or trust's complaints team." There are links to each Health Board's complaints information on this webpage NHS Wales complaints and concerns: Putting Things Right and these give details of how to raise a complaint. Often, they have a form to complete but it's not essential to use these.

Once a complaint has been received by the complaints team, they are expected to acknowledge it within two working days and respond to the majority within 30 working days. If they cannot respond within that time they should explain why and say when they will respond.

If the complainant is not happy with the response, they can request a review by the Public Services Ombudsman for Wales 0300 790 0203 www.ombudsman-wales.org.uk Llais Wales is an independent advocacy body "which provides free and confidential complaints advocacy and support." Telephone: 02920 235558
Email: enquiries@llaiswales.org Contact details for local Llias teams are here.

Northern Ireland

The process is set out in the NI Department of Health's document Guidance in Relation to the HSC Complaints Procedure - April 2019. This states that "The HSC Complaints Procedure has been developed around four key principles:

- openness and accessibility – flexible options for pursuing a complaint and effective support for those wishing to do so

- responsiveness – providing an appropriate and proportionate response
- fairness and independence – emphasising early resolution in order to minimise strain and distress for all
- learning and improvement – ensuring complaints are viewed as a positive opportunity to learn and improve services."

Each local Health and Social Care Trust has a Complaints Manager whose role includes advice and assistance with the complaints process. Information about these should be freely available (e.g. on a website) but there is a list of the contact details for each Trust at the bottom of this webpage. The Complaints Manager or their team can assist a complainant to put their complaint in writing. Alternatively, complaints can be made directly to a care provider to a senior member of staff or the Chief executive of the Trust. The Patient Client Council is an independent public body that offers advice and information about the complaints process by phone or email as well as advocacy services to help people with all the stages of informal or formal complaints, including making a submission to the ombudsman. Their service is independent, confidential and free, so they may be a good first port of call.

A complaint to a Health and Social Care Trust should be acknowledged within two or three working days of being received, and a full response should be provided within 20 working days. If the complaint will take longer to investigate, the complainant should be told and given an explanation of why this is.

If the complainant is not satisfied with the response they can refer it to the Northern Ireland Public Services Ombudsman (NIPSO). This can only be done once the Health and Social Care Trust has provided a response.

We hope that this information is useful to anyone who wants to make a complaint or is supporting someone who wishes to do so. The AIMS Helpline (helpline@aims.org.uk) can also provide information and support for making a complaint about the maternity services, although we cannot make a complaint on your behalf.

[1] Editor's note: Integrated care boards (ICBs) replaced clinical commissioning groups (CCGs) in the NHS in England from 1 July 2022

The British Intrapartum Care Society (BICS) conference 2023

by the AIMS Campaigns Team

The British Intrapartum Care Society (BICS) was initially set up in 2018 by a group of obstetricians but is for anyone involved in intrapartum care including obstetricians, anaesthetists, midwives, doulas, GPs and neonatal specialists, as well as service users.

AIMS attended the 2-day conference, which was to share research and learning and to promote standardised best practice for intrapartum and maternity care throughout the UK. There were oral presentations, workshops and opportunities for networking at a conference dinner.

AIMS was represented by 3 volunteers who displayed a poster, designed by our own Physiology-Informed Maternity Services (PIMS) group, titled ‘AIMS Campaign for Physiology-Informed Maternity Services’. They also had a stand set up where attendees were able to come and see what AIMS was all about, read some of the materials available and chat about using our resources or volunteering for AIMS.

The conference was a fantastic opportunity to not only attend the various presentations and participate in the workshops, but also to enable AIMS volunteers to network with other birth workers across the country and promote the work of AIMS.

AIMS volunteer, Jo Dagustun (on the left), with a conference delegate, sharing the Maternity Continuity Network's poster. Jo is also a co-creator of the AIMS poster.

How can digital consultations best be used in maternity care??

by Dr Georgia Clancy and Professor Catrin Evans

Since the publication of Better Births in 2016, maternity services in England have been undergoing changes. Overseen by the Maternity Transformation Programme, the aim has been to create safer and more personalised care. To achieve these goals, the Maternity Transformation Programme developed 10 core work streams. One of these workstreams was 'harnessing digital technology'.[1] In recent years the Covid-19 pandemic accelerated this digital policy imperative. One of the most commonly reported Covid-related changes to maternity services has been an increase in the use of digital (remote) consultations. In particular, the use of telephone or video-calling.[2],[3] As digital clinical consultations have become more widespread in maternity services, national guidance has quickly been developed. However, the ways in which digital consultations can best be used remains unclear. A particular concern is to ensure that the increased use of digital consultations is safe and does not lead to inequalities in care.

The ARM@DA project[4] explored the use of digital consultations in maternity care. As a realist review,[5] the aim was to understand when, where, and for whom digital consultations could be used to ensure safe, effective and acceptable care. To do this, the project carried out a review of the existing evidence on digital consultations. It also conducted consultations with stakeholders (service users, community organisations and maternity healthcare professionals).

What we found

The study found that there are some key factors to consider in order for digital consultations to work well. The first was the organisational infrastructure and resources provided to support digital consultations, for example, healthcare professionals need to have access to the necessary technology (e.g. digital devices and WiFi) when working onsite and in the community, appropriate workspaces in which to conduct digital consultations (e.g. private and quiet), and NHS systems set up to support hybrid care. This can impact how digital consultations are put into practice and how staff respond to the change.

The second consideration is training and support for staff. This can help to optimise safety, uptake and sustained use of digital consultations. This means providing ongoing access to clinical, administrative and technical support to keep things running smoothly. It is also important to communicate with staff about how and why they could be using digital consultations, as well as providing guidance to aid decision-making.

Third is providing personalisation and flexibility for women. This is so that digital consultations can better adapt care to meet individual needs and life circumstances. Key here is supporting choice and empowerment, and meeting individual needs. This can help digital consultations to be viewed as a valuable addition to traditional maternity care.

Fourth is recognising some of the challenges a diverse population of women might face in accessing digital consultations and what can be done to overcome these challenges. For example, increasing women's knowledge of maternity services can help them to navigate care more easily. Supporting those who face language and communication barriers can facilitate access to services. It is also important to consider the best way of interacting with service users if they have limited access to digital resources.

Finally, the review found that relationship-focussed connections are central to delivering quality digital care. Managing relationships and building rapport between professionals and service users digitally can be difficult. Evidence shows that digital consultations can be used most effectively and safely when the relationship between the woman and health professional is already established. This can provide women with a sense of support, comfort and control in their care (potentially including at-home monitoring), in turn, improving satisfaction and clinical outcomes.

The size and complexity of the maternity care system means that there is no one-size fits all approach to using digital consultations in maternity care. However, based on our findings we have developed some 'CORE' implementation principles:

- **C** Create the Right Environment, Infrastructure and Support for Staff
- **O** Optimise Consultations to be Responsive, Flexible and Personalised to Different Needs and Preferences
- **R** Recognise the Importance of Access and Inclusion
- **E** Enable Quality and Safety through Relationship-Focused Connections

As part of the ARM@DA project we have developed a free e-learning resource based around these CORE principles. The e-learning resource is suitable for anyone interested in best practice principles for digital consultations, but particularly healthcare professionals. Access it here: www.nottingham.ac.uk/helmopen/rlos/practice-learning/midwifery/telehealth/armada/index.html

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The ARM@DA project: The ARM@DA project was led by Professor Catrin Evans at the University of Nottingham. Dr Georgia Clancy was the research fellow on the project. ARM@DA was supported by colleagues from the University of Nottingham, University of Sheffield, University of Bradford and the Nottingham Maternity Research Network.[6] The project also drew on the expertise of a range of stakeholders including maternity healthcare professionals, service users and third sector organisations (Sister Circle and the National Autistic Society). For more information about ARM@DA please visit the project website[4] or follow @ARMADA_Project1.[7]

This work is supported by the UK National Institute for Health Research (NIHR), Health and Social Care Delivery Research (HSDR) Programme, grant number: NIHR134535. The views expressed are those of the authors and not necessarily those of the NIHR or the UK Department of Health and Social Care.

[1] *NHS England. Maternity Transformation Programme, www.england.nhs.uk/mat-transformation*

[2] *Jardine J, Relph S, Magee LA, et al. Maternity services in the UK during the coronavirus disease 2019 pandemic: a national survey of modifications to standard care. BJOG 2020 2020/09/30. DOI: 10.1111/1471-0528.16547*

[3] *Sanders J, Blaylock R and WRISK Study Team. Users' experiences of COVID-19 maternity service changes (Version 2). 2020*

[4] *The ARM@DA project (2024) A realist inquiry into maternity care at a distance https://armada-project.co.uk*

[5] *WONG G. Realist reviews in health policy and systems research. Evidence synthesis for health policy and systems: a methods guide. World Health Organization, 2018*

[6] *Nottingham Maternity Research Network: www.nottsmaternity.ac.uk*

[7] *Follow the ARM@DA Project on Twitter: https://twitter.com/Armada_project1*

MBRRACE-UK Reports – Shocking Racial and Socioeconomic Inequalities Continue and Even Widen

By Catharine Hart

Author Bio: Catharine Hart studied biology at the University of York and later trained as a midwife at the University of East Anglia. She lives with her family in Suffolk and is an AIMS volunteer and a member of the Campaigns Team.

- MBRRACE-UK Saving Lives Improving Mothers' Care Report 2023
- MBRRACE-UK Perinatal Mortality Surveillance State of the Nation Report 2023
- MBRRACE-UK Perinatal Confidential Enquiry: A comparison of the care of Asian, Black and White women who have experienced a stillbirth or neonatal death
- A comparison of the care of Black and White women who have experienced a stillbirth or neonatal death
- A comparison of the care of Asian and White women who have experienced a stillbirth or neonatal death
- SANDS Listening Project: Learning from the Experiences of Black and Asian Bereaved Parents

Image: MBRRACE-UK

MBRRACE-UK Saving Lives Improving Mothers' Care Report 2023

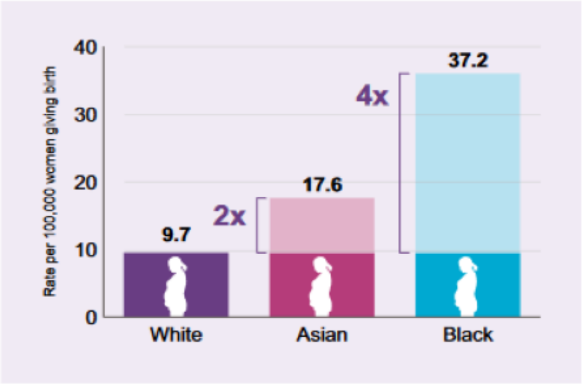
Last year's annual MBRRACE (Mothers and Babies: Reducing Risk through Audit and Confidential Enquiries)[1] report into maternal death in the UK was published in October 2023, reporting on the women and birthing people who died in the UK and Ireland between 2019-2021. The current system of confidential enquiries began in 1952, initially reporting on deaths every three years;[2] this is the tenth report published since MBRRACE began to report annually[2]. The story behind each woman who died is looked at in detail, so patterns can be recognised and real lessons learnt to prevent these tragic events occurring again. The full report is available here,[3] with infographic[4] and lay summary[5] versions also available.

In 2019-21, 572 women died during and up to the first year after pregnancy; 241 of these deaths occurred during pregnancy or up to six weeks after birth. This is out of 2 066 997 women giving birth in the UK and is an increase on last year's figures, but this increase is not statistically significant and includes deaths from the COVID-19 pandemic. Thankfully, the maternal mortality rate in the UK remains low, a rate of 11.7 women per 100 000 pregnancies. However, the government's target to reduce maternal mortality by 50% by 2025 compared to 2010 levels will likely be missed.

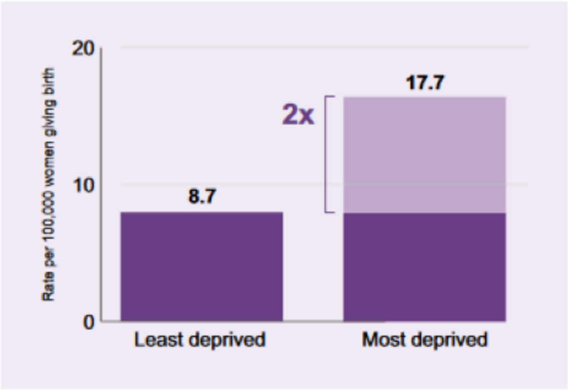
COVID-19, cardiac disease and blood clots were the three joint highest causes of death overall (each responsible for the deaths of 33 women). Blood clots remain the highest cause of death during pregnancy and up to 6 weeks postnatally. The death rate from obstetric haemorrhage has increased, although this is not statistically significant and deaths from eclampsia or pre-eclampsia have also now increased to nine women (a significant increase compared with five women who died from this cause in 2015-17). Seventeen women's deaths were associated with epilepsy, including from SUDEP (Sudden Unexpected Death in Epilepsy), an increase in recent years and nearly double the rate from 2013-15, also noted in previous MBRRACE reports.[6] The authors state that this increase is associated with changes in the guidance around prescribing epilepsy medications, which would likely have affected pregnant women. The report recommends more personalised care, including a good understanding of each woman's individual circumstances, when discussing the benefits as well as risks of medication, for example, echoing previous recommendations from MBRRACE.[6]

Inequalities in Maternal Mortality

Ethnic group



Living in more deprived areas



Images: MBRRACE-UK

Stark racial inequalities in maternal mortality unfortunately still persist, although they are decreasing slightly. The shocking statistic that Black women in the UK were five times more likely to die during or in the year after pregnancy, compared with White women, was highlighted by MBRRACE in 2019, although racial disparities were known about before this.[6]

This report shows that Black women still remain nearly **four times** more likely to die (3.7), compared with White women. This is also not the only racial disparity, with Asian women also having around **twice** the risk, compared with White women. 25% of the women or birthing people who died were born outside of the UK (where place of birth was recorded), although the death rates for those women born in the UK was not significantly different from those born outside of the UK.

This report clearly shows stark effects of social inequalities of health, with women in the most deprived areas still around **two times** more likely to die. 12% of the women who died had multiple severe disadvantages recorded – especially mental health issues, domestic abuse and substance use. The authors note that this should be thought of as a "minimum" as many of these factors aren't reported or recorded. Only 53% of the women who died received the "recommended" number of antenatal care appointments. The proportion of women who died who had involvement with social care was 21%, a figure which has increased in recent years. There was an intersection of medical and social problems, compounding the risk factors for some of the most vulnerable women, who were often disengaged from health services. The risk of disjointed working was highlighted, with failures of communication between teams. Vulnerable women were not listened to, received inappropriate care and felt exposed and scrutinised. Mental health continues to be a significant factor, with 10% of women or birthing people's deaths directly caused by mental health related issues. Suicide remains the leading cause of death in the postnatal period, with mental health causes overall accounting for **39%** of deaths in this time period. It is clear that further action is needed on mental health issues and really *wholescale* action to address the needs of the most vulnerable women.[7]

Concerningly, this report only takes us up to, but not into, the cost-of-living crisis, so even more widening disparities in death rates may be expected next year.[8] A shocking **89%** of all the deaths occurred postnatally (an increase from last year's figure of 86%), emphasising the need for increased resourcing for postnatal care, especially since it is already recognised as being under-resourced. [9],[10]

Deaths from direct causes have only decreased by 1% since 2010 (excluding deaths from COVID-19) and the authors state that "There was evidence of a maternity system under pressure in the care of many women who died".[3] It is vital that all healthcare professionals are given the training and resources to be able to keep up-to-date in their practice and have the skills to care for women with complex mental, physical and social care needs. Unfortunately, there are currently restrictions being put on the authors of the report, including that all recommendations must be 'cost neutral'. This undermines the integrity of the report and prevents the authors from making many recommendations for real change, which would require increased investment.

MBRRACE-UK Perinatal Mortality Surveillance State of the Nation Report 2023

This latest MBRRACE-UK perinatal report[11] was published in September 2023 and presents the annual confidential enquiry into perinatal deaths (stillbirths and neonatal deaths – deaths in the first 28 days of life) for the year 2021. An infographic version is also available here.[12] Unfortunately, the overall stillbirth and the neonatal death rates both increased this year, for the first time in seven years, to 3.54 per 1000 births (compared with 3.33 in 2020) and 1.65 per 1000 live births (compared to 1.53 in 2020).

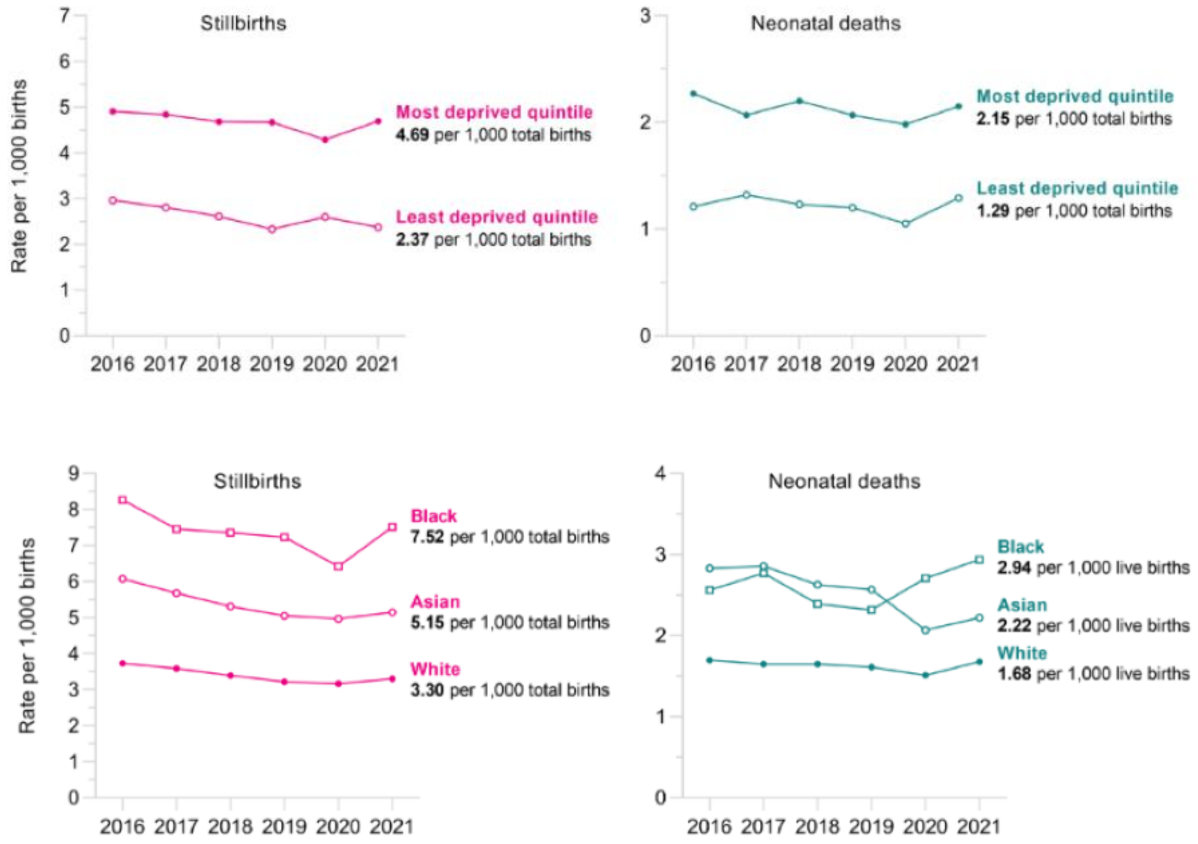
The overall perinatal mortality rate was 5.19 per 1,000 total births (compared with 4.85 in 2020). These year-on-year increases are thought to be related to the “direct and indirect effects of the COVID-19 pandemic”.[13]

There are variations in these rates between the devolved nations, with Scotland having the lowest stillbirth rate (3.27 per 1000 births) and Northern Ireland the highest (4.09 per 1000 births). There was also quite wide variation in the rates between different individual units, even after adjusting for the type of care available (e.g. intensive care etc.). Babies born preterm (before 37 weeks) make up over 70% of both stillbirths and neonatal deaths. The cause of death remains unknown for around one third of stillborn babies.

Effects of ethnicity and deprivation

As in previous perinatal reports, large disparities in the rate of stillbirth or neonatal death remain between ethnic groups. Black babies have the highest rate of stillbirth or death in the first month of life compared to babies of all other ethnicities, with more than **double** the rate of stillbirth and just under double the rate of neonatal death compared with their White counterparts. Asian babies also have around 50% higher rates of both stillbirth and neonatal death. These differences increase with social deprivation.

Women in the most deprived areas have around **twice** the rate of stillbirth and neonatal death, compared with those from the least deprived areas. It is very concerning that inequalities along both the lines of ethnicity and socioeconomic deprivation widened in 2021, with increases in the stillbirth and neonatal death rates for babies of Black, Asian and White ethnicities and babies from the most deprived areas, as seen in the graphs below. There is currently a national target to reduce stillbirth and neonatal mortality rates by 50% by 2025, compared to 2010 levels.[13] It is clear that these disparities must be addressed urgently if there is to be any chance of meeting this target.



Images: MBRRACE-UK

MBRRACE-UK Perinatal Confidential Enquiry: A comparison of the care of Asian, Black and White women who have experienced a stillbirth or neonatal death

The focus of these two reports was to investigate differences in the quality of care provided to Black, Asian and White women and birthing people who all sadly experienced the loss of a baby during late pregnancy (stillbirth) or a neonatal death in the year 2019. There are two separate reports – a comparison of the care of Black and White women and a comparison of the care of Asian and White women, all of whom experienced a stillbirth or neonatal death. The aim was to find out whether care guidelines were followed, if improvements in care could have prevented these outcomes and what lessons can be learned to help prevent these outcomes for Black and Asian women in the future.

These reports are based on medical records and "the women's voice is rarely heard in the notes".[14] The authors also acknowledge that they don't have access to information about specific care environments or cultures, which could mean that issues such as racism at a policy or organisational level cannot always be picked up on.

A comparison of the care of Black and White women who have experienced a stillbirth or neonatal death

This report looked at the care of 36 Black and 35 White mothers and babies. The main report is available here[15] with a lay summary[16] and infographic version[17] also available. For the year 2019, babies of Black or Black British ethnicity have a 124% increased rate of stillbirth and 43% higher rate of neonatal death, compared with White babies. Black women or babies were much more likely to have significant issues identified with their care (84%, compared to 69% of White women or babies), although the authors suggested that improvements in care might have made a difference to the outcomes of the mother or baby in similar proportions of women from both groups.

Issues found in the care given included poor record keeping, with inconsistency in the recording of ethnicity, nationality and citizenship status. Identification of language needs and interpreter provision was judged "inadequate across all ethnic groups".[15] *None* of the women who required interpreters was provided with one throughout their care (this also includes the Asian women in the second report) and there was inappropriate use of family members and healthcare professionals for interpreting. Many complex social risk factors were not recorded, especially in White women.

Although some aspects of access to care and engagement (late booking, follow up of non-attendance) was similar between Black and White women, Black women were more likely to be disengaged or experience barriers to accessing some specific aspects of care. For example, oral glucose tolerance tests weren't offered to over 20% of eligible Black women (compared with 3% of White women). None of the Black women was offered a high dose of Vitamin D as is recommended. Around 50% of all parents experienced sub-optimal neonatal care, with similar rates for Black, Asian and White parents. There were also issues around information giving, including that only 47% of Black women were documented as having been given information about reduced fetal movements, compared with 58% of White women. Some women reported not being given clear information about their care or what services were available. This led to some women stopping medication without a full discussion, disengaging with services and not attending appointments.[18]

A comparison of the care of Asian and White women who have experienced a stillbirth or neonatal death

This report looked at the care of 34 Asian and 35 White mothers and babies. The main report is here,[19], with a lay summary[20] and infographic version[21] also available. For the year 2019, babies of Asian ethnicity were at 57% increased risk of stillbirth and 59%

increased risk of neonatal death, compared with White babies. The authors thought that improvements in care might have made a difference to the outcome of the baby for 26% of Asian and 49% of White women and the outcome of the mother in 59% of Asian and 69% of White women. There were similar issues found with recording ethnicity or citizenship statues and interpreter provision as in the other report although more language barriers were identified in Asian women. The report noted that Asian women were more likely to decline antenatal screening for chromosomal conditions (35%, compared to 6% of White women). There may be many reasons for this which the report doesn't really go into. AIMS supports the recommendation to provide more information about antenatal screening tests, including translated information to overcome language barriers, as long as this is unbiased information and women are truly supported in their decisions, free from any coercion. All women have the right to accept or decline any aspect of care and this shouldn't be seen as a "problem", as long as any refusal is an "informed refusal".

Fewer episodes of good care were recognised for Asian women, compared to their White counterparts and more of their care was graded poor. Oral glucose tolerance tests were again highlighted as an example of racial bias in care and were not offered to 22% of Asian women, compared with 3% of White women. There was a failure to offer the correct dose of Vitamin D to 90% of Asian women. Although fewer social risk factors were recorded for Asian women, this could also be because they were not recognised or under-recorded.[22]

This is the first confidential enquiry to take place since the national Perinatal Mortality Review Tool (PMRT)[23] was introduced in 2018. Compassionate and sensitive care at this time can help families come to terms with these devastating losses. However, unfortunately less than 10% of the reviews were graded as good quality. Problems included not enough multidisciplinary team input and the reviews not directly addressing parents' questions or concerns. Language barriers were evident, with no parents at all who experienced language barriers being recorded as having concerns or questions about the care they had received. Most bereaved parents had appointments to review their care, but not all received a letter afterwards. Black parents were less likely to receive a letter addressed to them than White parents and complex medical language was used in these letters, despite the fact that exactly the same letter was sent to the parents as to the GP. AIMS is glad to hear that the panel recommend that women's and families voices are now actively sought in conducting these reviews and given the chance to talk about what they have been through.

SANDS Listening Project: Learning from the Experiences of Black and Asian Bereaved Parents

SANDS interviewed 56 Black and Asian bereaved parents for this report,[24] to learn about their experiences and what they feel needs to improve. Around half the parents felt they had received worse care or were treated differently because of their ethnicity. More than half felt that healthcare professionals didn't listen to them; in some cases this was linked to racism or stereotyping. The report concludes that the voices of some Asian and Black parents go unheard.[22] There were examples of good, personalised care with staff advocating for those in their care. However, there was also poorly coordinated care, which led to delays and errors with serious consequences. Parents felt they weren't always given the information about safety and risk which they needed. Some parents felt anxious when their ethnicity was highlighted as a risk factor, but this didn't lead to enhanced care. Most bereaved parents who were involved with a review or investigation described negative experiences with complex and ineffective processes and a lack of transparency. Some parents described mistakes during reviews (e.g. incorrect paperwork) which was not only extremely upsetting but stopped them getting answers about why their baby had died.

Discussion

Whilst some examples of good care were highlighted, these reports also sadly show women and families in the most distressing of situations, being treated with little empathy or kindness, unable to advocate for themselves or their babies or to give informed consent, receiving translation by untrained family members, and having a lack of control over their own decision making. They have also suffered significant barriers to care and poor care including racial discrimination and bias, which is likely to have unfortunately contributed to poor outcomes and experiences.

How can decisions be truly informed and true consent given where there are language barriers and also cultural barriers around complex medical language and procedures? Maternity services need to communicate with all women and birthing people they serve, effectively, in a format that is accessible for each person. Lack of interpretation services clearly impacts women's ability to understand their care and make informed decisions (or informed refusals!) and AIMS supports the recommendation to improve this alongside recommendations to improve recording of ethnicity, nationality and language needs and social as well as medical risk factors. All women need to be provided with unbiased, personalised information, including about the significance of their ethnicity on risk levels in a sensitive and respectful way. However, it is unclear how the recommendation to ask women about their “citizenship status” would help end racial disparities. All pregnant women in the UK are entitled to maternity care, regardless of their immigration status for example,[25] although some may be charged for care.[23] Healthcare professionals need to carry out any recommendation to ask about immigration or citizenship status sensitively, with the aim of building relationships, rather than increasing fear.

AIMS has long campaigned for *equitable* maternity services, where *all* service users receive the same levels of care, to mitigate, as far as possible, these inequalities in outcome and experiences. Yet, unfortunately, in the UK disparities along the lines of ethnicity and socioeconomic status continue. As Professor Jacqueline Dunkley-Bent (International Confederation of Midwives) urges us, the time to act is now because “every preventable death is one too many”.[26] The findings of these reports remain truly shocking. In 2021, the UK perinatal mortality rate increased for the first time in seven years and inequalities by ethnicity and deprivation have not only continued but actually increased. Although not statistically significant, we are now also seeing a rise in maternal mortality. All of the reports reviewed here urge policymakers to ensure equity for all service users, but it is clear we are a long way from this. Not only are Black and Asian mothers significantly more likely to die during or soon after pregnancy, with Black women in particular still nearly **four** times more likely to die, there continue to be inequalities in baby loss and baby death for Black and Asian babies too.[3] Those in the most deprived areas are still also twice as likely to die during or after pregnancy or experience a stillbirth or baby death, compared with those in the least deprived areas.

There is evidence that a caseload model of midwifery and continuity of carer might have mitigated some of these outcomes, including the rates of stillbirth and preterm birth.[27], [28] In 2019 the NHS Long Term Plan stated that 75% of women from Black, Asian and other ethnic minorities and the most deprived areas should receive continuity of carer by 2024.[29] However, this target was placed on hold in 2022 due to staffing pressures. As Jo Dagustun, our Campaigns team volunteer, has written “the cost of not making this service transformation, across a range of outcomes, is simply too high for us to accept”.[30] AIMS continues to campaign[31] for continuity of carer to be fully implemented for all, as key to a safe, personalised and equitable maternity service.

All birthing women, people and babies deserve an equal chance of survival; where ethnicity is associated with increased risks, care needs to be enhanced, along the principles of “proportionate universalism”.[32] The government must set out and fund long-term plans aimed at eliminating these inequalities in pregnancy loss and baby deaths. Specific targets with timeframes are very much needed here, as recently recommended by the House of Commons Women and Equalities committee.[33] As a first step, AIMS believes that, as a minimum, the Government must urgently implement the Women and Equalities committee recommendation to increase the annual budget for maternity services to £200–350 million, as also recommended by the Health and Social Care committee[31] and endorsed by the Ockenden report.[34]

This year's confidential enquiry is to be welcomed as one of the first to highlight the role of caregivers and the healthcare system in contributing to these disparities. None of these reports can give us the whole answer to the question "why is this happening?", but hopefully can add a piece to the jigsaw. Rather than just focussing on "risks inherent in Black and Brown women's bodies",[35] the 2023 confidential enquiry suggests other social and structural causes for these disparities instead. Unfortunately, systemic bias in the maternity services, poor practice and racial discrimination from some healthcare professionals may have contributed to the devastating outcomes and disparities discussed here. AIMS is glad to see system-wide issues being taken into account with the recommendation for the role of racism or discrimination to be explicitly considered whenever maternity policies are formulated or investigations into care are taking place.

For improvements to be implemented successfully, however, there also first needs to be an enabling environment for change, with good staffing levels, knowledge and infrastructure for example. It is also clear that wide scale, transformative changes are needed across the whole maternity system to fully address these issues, including embedding anti-racism in national policies and maternity curriculums[31] and improving diversity, especially at leadership levels.[32] Black and Asian women and birthing people must be the decision makers in their own maternity care and not just be "included in the conversation" but *centred* in redesigning the system, to serve *all* equitably. AIMS continues to campaign for these changes, as outlined in our position paper on racial inequalities in maternity services,[36] alongside others working in this area, including Five X More,[37] Birthrights,[32] The Motherhood Group[38] and the All Party Parliamentary Group on Black Maternal health.[39] As Dr Christine Ekechi, consultant obstetrician and gynaecologist, says - "Let's engage, advocate and demand change!".[26]

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Screening for twins: Why good guidelines matter

by Stephanie Ernst

Author Bio: Stephanie Ernst is a parent of monochorionic twins born at 31 weeks with Twin Anemia Polycythemia Sequence, and founder of the TAPS Support Foundation. As an advocate for changes to screening protocols for monochorionic twins and TAPS awareness, she has been published in several magazines and is a recognised speaker on issues like rare diseases, the involvement of patients in research, and breaking down communication barriers with medical professionals. She has also participated in research as a patient, a parent, and as an author and has spoken at several international congresses on what twin parents need. In her spare time, she cooks, reads, and hangs out with the coolest 10 year old twins ever (and her husband!).

Multiple pregnancies come with a lot of additional worries and risks, and I know that a lot of us ask questions about whether the increased screening and the discussion about the risks are essential. Why are we worrying people about something that might not happen and taking away the feeling of control that they have over their pregnancy? As advocates and activists, we know that there's often little clarity around the reasoning and that things are hidden behind walls of jargon and white coats. That's why it's essential to talk about the relevant guidelines, the quality of the evidence behind them, and where they may need to be updated. Guidelines provide a pathway for better care but can also fall short.

In this article, I'll refer to the Twin and triplet pregnancy NICE guideline [NG137][1] and draw additional information from the ISUOG Practice Guidelines: role of ultrasound in twin pregnancy.[2]

The NICE Guidelines

In 2019, the latest version of the Twin and triplet pregnancy NICE guideline was launched,[1] covering the care that should be offered to pregnant people during pregnancy. This was considered a comprehensive upgrade to previous guideline and utilised the voices of leading experts in twin pregnancy, those involved in the day-to-day care of twin pregnancies, and lay experts from multiple birth organisations.
Based on new evidence and the surveillance processes, there was a recognised need for these guidelines to be updated. As per the scope for the update:[3]

> **"The surveillance process also identified that the topic of intrapartum care related to multiple pregnancy should be added"**

And

> **"In current practice, a significant proportion of multiple pregnancy losses occur intrapartum, and the risk of adverse perinatal outcomes is greater in multiple than in singleton pregnancies."**

Multiple births are at a higher risk for perinatal mortality and complications (as evidenced by the MBRRACE report of 2021),[4] and the purpose of updating and improving the NICE guideline was to provide better guidance for those working with women with multiple pregnancies and improve outcomes.

This guideline emphasised establishing chorionicity (twin type)[5] early, providing evidence-based information on screening pregnancies appropriately, and referring to expert centres when complications appear.

One notable difference between the NICE and the ISUOG guidelines is the approach to screening and diagnosis. While both emphasise the importance of early identification and monitoring, the ISUOG guidelines provide more comprehensive recommendations for ultrasound assessment. ISUOG guidelines are developed in conjunction with a Clinical Standards Committee,[6] and are subject to rigid peer review, much like a scientific paper. These guidelines are structured differently to NICE Guidelines, with more input from scientific communities, without guidance from the community.

The NICE guidelines, although robust, lack the specificity required for managing twin and triplet pregnancies effectively. An example of this lies within the recommendations for screening for Twin Anaemia Polycythaemia Sequence (TAPS). While there are excellent recommendations in place for screening after laser surgery treating Twin-to-Twin Transfusion Syndrome (TTTS), the guidelines only recommend screening for TAPS when there is a size discordance (difference in size between twins) of 25% or more, cardiac compromise, abnormal umbilical artery or isolated polyhydramnios (polyhydramnios in just one twin).

Although cardiac compromise is present in around 69-72% of TAPS cases,[7] and around 50% of cases present with some size discordance, neither of these are considered primary diagnostic criteria for TAPS. And if we consider the recommendation to screen when isolated polyhydramnios is present, we only have to look at the differences between TAPS and TTTS – "TAPS is characterised by large inter-twin hemoglobin differences in the absence of amniotic fluid discordances".[8]

Relying solely on the NICE criteria to screen for this disease may lead to missed cases. It is known that TAPS presents with no symptoms to the parent,[9] and that routine doppler of the mid-cerebral artery (MCA) is the most accurate way of detecting it, and monitoring disease progression, leaving concern that following NICE recommendations may lead to delayed diagnoses and tertiary referrals for interventions.

Why good screening matters

Quality screening for twin and multiple pregnancies is crucial in ensuring the well-being of both parents and their babies. Recent studies, such as one published in the European Journal of Obstetrics & Gynecology and Reproductive Biology,[10] make it clear that multiple pregnancies come with increased risks, including a higher likelihood of preterm birth and low birth weight. (For more information on the risks within multiple pregnancy, refer to the earlier AIMS article, "Multiple Multiples", by Rebecca Freckleton.)[11] Early and accurate screening helps identify these risks, allowing healthcare providers to tailor their approach and provide the best possible care.

Another study, published in the Journal of Clinical Medicine,[12] emphasises the impact of multiple pregnancies on maternal mental health, highlighting the importance of screening not only for physical but also psychological well-being. Quality screening is like a proactive health check for expectant parents carrying more than one baby, helping healthcare professionals anticipate and address potential challenges earlier.

Screening during pregnancy is about potentially improving outcomes. Recent studies[12] emphasise the importance of expanding screening guidelines for twin pregnancies to include conditions like Twin Anaemia Polycythaemia Sequence (TAPS), Twin-to-Twin Transfusion Syndrome (TTTS), and Selective Fetal Growth Restriction (SFGR). These conditions can significantly impact the health of babies in multiple pregnancies. The ISUOG Practice Guidelines provides recommendations for ultrasound screening specific to twin pregnancies. Comprehensive screening for these conditions helps doctors detect and address potential issues early on, potentially saving lives and improving the overall health of babies. So, when it comes to screening during pregnancy, it's not just about routine - it's about being thorough and proactive to ensure multiples receive an appropriate standard of care, which can lead to better outcomes.

Updating Guidelines

The current NICE guideline leaves some gaps in screening for specific conditions in multiple pregnancies and does not provide detailed support for complications in monochorionic twins. These conditions can impact up to 25% of these pregnancies[13] and significantly impact the health of babies. The guideline falls short in giving clear directions to healthcare providers on how to screen for and address these potential issues early, leaving room for missed opportunities to improve outcomes for parents and babies. As we aim for the best care during pregnancy, we must advocate for guidelines that cover all bases, ensuring that every expectant parent receives the support and information they need to make effective decisions about their pregnancies.

NICE guidelines have been criticised for not fully addressing essential aspects of multiple pregnancies. These guidelines, while offering valuable information on general care during pregnancies with more than one baby, may not adequately support the screening for conditions like Twin Anemia Polycythemia Sequence (TAPS), Twin-to-Twin Transfusion Syndrome (TTTS), and Selective Fetal Growth Restriction (SFGR). We must continue to advocate for screening for these diseases, as they have potentially devastating short and long-term outcomes.

To the future

In conclusion, navigating multiple pregnancies' complexities can be exciting and challenging. The recent updates to the NICE guidelines represent a commendable effort to improve care for expectant parents of twins and triplets. However, our journey toward optimal care doesn't end with guidelines but involves an ongoing commitment to education and advocacy.

As highlighted, guidelines, including those from NICE, might sometimes fall short in addressing all essential aspects of multiple pregnancies. One area that stands out is the non-inclusion of routine TAPS screening, based on technically inaccurate diagnostic criteria as previously discussed in this article. On International TAPS Day, 3rd March

2024, we are drawing attention to the need to update screening guidelines worldwide. This is not only to accommodate the updates in research, but also so that parents and the wider community can be educated about the complications that can happen and make informed decisions about their care during and after pregnancy. Families have the right to all the information available, and to be actively involved in decision making processes. This is more than just a policy, it is now a matter of ethics.[14]

As advocates, it is empowering for us to be educated about the evolving evidence landscape and to actively participate in discussions around the need for updates to screening protocols. We need to recognise the gaps in the guidelines, not as criticisms, but as opportunities for improvement. By staying informed and engaged, we can contribute to the collective effort in building on and updating guidelines, ensuring that they encompass the latest evidence and provide comprehensive support for the unique challenges of twin and triplet pregnancies. It is up to us to proactively advocate for our well-being, fostering a healthcare environment that continually strives for the best possible outcomes for parents and babies in multiple pregnancies.

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What has the AIMS Campaigns Team been up to this quarter?

by the AIMS Campaigns Team

Written outputs:

- BICS (British Intrapartum Care Society) conference poster on our campaign for physiology-informed maternity services
- Updated position paper on Freebirth
- Birth Activists Briefing: Making a complaint about NHS services
- Report of Parliamentary Debate on Birth Trauma

Conferences and meetings attended:

- 8th November: Professor Mary Renfrew's Cross-sectoral Multidisciplinary Workshop in Belfast
- 16th & 17th November: BICS Conference in Cardiff
- 17th November: Wales Maternity & Midwifery Festival
- 18th November: ARM Hands off Midwifery! Power, Politics & Practice conference
- 22nd November: MBRRACE Stakeholder Meeting, online
- 30th November: NHS-E Maternity Transformation Stakeholders Council, in person
- 4th December: RCM Research Prioritisation project steering group meeting, online
- 8th December: International round-table of organisations supporting human rights in childbirth, online
- 14th December: MBRRACE-UK Perinatal Enquiry
- 15th December: Stakeholder meeting SBLCv2 evaluation, online
- 8th January: RCM Research Prioritisation project partners meeting, online
- 18th January: CHERISH project Stakeholder Advisory Network meeting

What else we have been reading:

- Butler S. E. et al 'Induction of labor and cesarean birth in lower-risk nulliparous women at term: A retrospective cohort study', Birth Issues in Perinatal Care, online version - January 2024
- Davies, S. 'Future Midwife: What the NMC proposals mean for the midwifery profession' - June 2023
- House of Lords Library report: Performance of maternity services in England - January 2024
- NHS England, GP six to eight week maternal postnatal consultation - what good looks like guidance - December 2023
- SANDS/Tommy's Policy Unit report: Better board oversight needed to save babies' lives - November 2023

What have we been watching:

- BBC Panorama programme on 29th January: Midwives under Pressure

Thanks to all the AIMS Campaigns Volunteers who have made this work possible. We are very keen to expand our campaigns team work, so please do get in touch with campaigns@aims.org.uk if you'd like to help.