Written Evidence submitted by Bolt Burdon Kemp

Women's Health Strategy: Call for Evidence

Who we are

Bolt Burdon Kemp is a firm of solicitors. We specialise in acting for those who have suffered serious injury as a result of medical negligence, personal injury or abuse. The firm is based in London, but represents clients nationwide. We are recognised as leading specialists in these fields of law.

We have a dedicated and growing team of solicitors whose passion lies in raising awareness of healthcare inequalities and effecting positive change for affected women. Our women's health team's primary role, is to investigate and conduct civil claims brought by women who are injured as a result of medical negligence. Our expertise is in the recovery of financial compensation for those avoidably harmed in claims encompassing, for example, gynaecological cancers, maternal birth trauma and resultant infertility.

Our firm has partnered with leading charities in the women's health sector including Birthrights and The MASIC Foundation. Their respective work supports women who have often suffered harm in a medical setting, campaigning and funding research into improving women's healthcare and respect for human rights during pregnancy and childbirth. Our charity partners' goals align with those of our firm in improving the lives of seriously injured women (or preventing harm coming to them altogether).

The writer, Olivia Boschat, is an Associate Solicitor in our firm's Medical Negligence department.

Terms of reference

With reference to the remit of this call for evidence, and in our capacity as experts in the area of medical negligence, we hope to assist by addressing the following three core issues:-

- Placing women's voices at the centre of their health and care
- Improving the quality and accessibility of information and education on women's health

- Understanding and responding to the impacts of COVID-19 on women's health

Our evidence: our clients

Every year our firm receives hundreds of enquiries from women of all ages, races and backgrounds with concerns about the standard of medical treatment they have received. The complaints we receive from women who have experienced medical negligence span the entire NHS healthcare system from initial presentation at their GP, through to Gynaecology, Obstetrics, Radiology, Oncology and more. Whilst we cannot represent all complaints received (due to the facts of their case, the time limits relevant to their case and such other factors), a significant proportion are justified and as such, common themes distinct to women begin to emerge.

We are witnessing increasing numbers of health related enquiries from women owing, we believe, to heightened awareness of healthcare inequality in the general population. Certainly in the last 12 to 18 months, we have seen complaints arising from women whose healthcare experiences have been even more unsatisfactory during the pandemic – not least because they have been prevented from accessing vital support.

The nature of the claims we conduct and the complaints we receive include the following:-

- Failure to obtain informed consent from expectant mothers with regard to birthing decisions;
- Stillbirths and neonatal deaths - sometimes associated with maternity scandals such as those seen at East Kent and Shrewsbury and Telford NHS Trust in recent years;
- Delayed referrals for female only conditions such as endometriosis and menopause;
- Negligent failures to diagnose or treat maternal birth trauma including anal sphincter and/or vaginal tears;
- Delayed diagnosis or misreporting of cancers including breast, cervical and other gynaecological cancers;

It is noteworthy that as a result of these failings, infertility or reduced fertility is a common outcome for many women of reproductive age. Accordingly, an overarching feature of the cases we conduct include assessing the impact of medical negligence upon a woman's fertility. Where it is established that a woman's fertility has been adversely affected, the civil law recognises that a claimant may be entitled to claim the costs, on a private basis, of surrogacy or IVF. Whilst this is a necessary and reasonable means of compensation for those affected, this comes at a considerable cost to the NHS and ultimately, the taxpayer. Whilst not the thrust of our firm's submission, it is perhaps appropriate to highlight the enormous costs associated with injured babies which can regularly coincide with the provision of substandard maternity care during pregnancy and birth.

It is our view that by investing time and resource into better education and the prioritisation of women's health, not only do women benefit, but this will translate into fewer examples of needless harm and negligence claims. In turn, this will ease the financial burden placed upon an already stretched NHS system. This must be achieved by eradicating healthcare inequality for women and not by restricting access to justice when things do go wrong.

1. Placing women's voices at the centre of their health and care

Evidence on women's voices not being listened to within the health and care system

I have represented a number of mothers who have suffered injuries as a result of negligent care during pregnancy, birth and post-nataly. A common theme in these cases is that they do not feel listened to. Birthing plans for women are very important and the antenatal process of discussing birth preferences plays a crucial part - a time for women to ask questions and make informed choices. Too often, I have acted for women who have not been given the information they have asked for relating to, for example, the risk of third and fourth degree tears. Women have also been pressured into a vaginal delivery despite their preference for an elective C-section. By failing to give women the full information on birth risks and options antenataly, women cannot provide informed consent as is the legal requirement pursuant to the landmark ruling in *Montgomery v Lanarkshire Health Board* [2015] UKSC 11.

Furthermore, all too often I hear from mothers who have not been afforded sufficient time to digest the information and the material risks, and decide what is best for them. Women are particularly vulnerable during pregnancy and birth. Whilst childbirth is natural and common in the NHS, on an individual level, it can be frightening and make women very anxious if they are not given the full picture, risks and all. They must be the central point of the process.

I have represented women who following childbirth have been left with life-changing injuries as a result of negligence. In the weeks following childbirth, women have told me that their injuries have been trivialised. The women did not appreciate that what they experienced was not normal, and because they were not listened to by the medical professionals, they felt abandoned and left to manage their pain and discomfort alone and without the treatment and support they needed. Childbirth is physically and emotionally momentous. Any concerns expressed by a woman before, during and after childbirth should be genuinely listened to.

A case example:

I represented Sarah* following the birth of her first baby. Despite Sarah asking questions during the antenatal appointments and asking to avoid instrumental delivery, she was told that she would be able to choose between a C-section or forceps delivery *only* if the labour stalled or she needed intervention. She was not told of the risks of more severe tears associated with forceps delivery. She was also not told of the increased risk of a C-section during the second stage of labour. Ultimately, she was unjustifiably pushed towards a vaginal delivery by those tasked with her care.

Sarah's labour did slow and when she asked for a C-section she was told this was not a feasible option. Her baby was eventually delivered with forceps. Sarah suffered a third degree perineal tear which was not correctly recognised or repaired. Her concerns over the next fortnight were dismissed and she was told that the incontinence she was suffering from was normal. Sarah's voice was not listened to. She suffered the most severe form of maternal birth trauma – trauma which she was not aware could even happen. She was either given the wrong or woefully inadequate information before the birth, leaving her unprepared and unable to make an informed decision about her treatment. Sarah had to undergo multiple surgeries to repair her physical injuries and she is now no longer incontinent, however she is left with permanent pain, scars and psychological damage. Negligence was established.

*alias to protect my client's identity

Evidence of women's voices not being listened to in relation to specific conditions or types of interaction

I represent several women who have suffered a delay in diagnosis of gynaecological cancers because symptoms were negligently misdiagnosed or worse still, dismissed. For example, too often women presenting with post-coital bleeding are not referred on for further investigations leading to delays in diagnosing cervical cancer.

I have seen first-hand how life-changing a delay in diagnosis of cervical cancer can be to a woman, and her fertility. I have seen through our firm's work that a woman's young age often means her symptoms are dismissed as something less sinister than cervical cancer, because it is a less likely cause. This problem is compounded by the consequences of losing fertility at a young age before having or completing a family. The consequences for women who need treatment which will affect their long term fertility (either through surgery, treatment or medication) can be catastrophic. Decisions have to be made (often in haste) about egg harvesting and freezing and discussions with family and partners have to take place, long before they are at the life-stage where they want to take those decisions.

Following a Freedom of Information Request made by Bolt Burdon Kemp to the NHS in September 2017, our firm found that women are almost a third more likely to receive a wrong medical diagnosis than men[1]. This is a result of the system's failings and must be addressed. We hope that our contributions will assist in furthering this agenda.

Taboos and stigmas in healthcare related to gender, and the barriers to open discussion

Bolt Burdon Kemp funded research conducted by Censuswide between 22.05.2019 – 28.05.2019, with 2,008 general respondents aged 16+ in the UK. The survey was conducted from a nationally representative sample of UK adults. Quotas were applied to nationally representative proportions for age, gender and region.

Our survey found almost 1 in 10 women (7%) said they have no-one to talk to about any issues they might have regarding their reproductive health. 1 in 10 do not feel heard or believed when they talk to doctors about their reproductive health[2].

Infertility is not discussed openly in our society. For many it has connotations of shame. Fertility funding is often woefully substandard and inconsistent across the country. Many Trusts only offer one IVF round for women unable to conceive naturally because of funding barriers, compared to NICE recommendations that women under 40 should be offered three

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[1] Trust me I'm a doctor? The rise in misdiagnosis claims | Bolt Burdon Kemp

[2] How do women feel about their reproductive health? | Bolt Burdon Kemp

full cycles if they have been trying for more than two years. IVF funding largely depending on a woman's postcode is clearly unsatisfactory – NHS support of this nature should be applied uniformly, on a national basis, to eradicate this inequality.

Women suffer significant injuries and changes to their bodies during childbirth, whether negligently caused or not. Faecal and/or urinary incontinence, prolapse, perineal tears and maternal mental health issues are not uncommon yet all of these conditions remain taboo. Many women do not know that these are all possible risks and consequences of childbirth.

Practitioners in healthcare need to avoid tiptoeing around women and tell them the truth about childbirth so that they can understand the process and know what to expect. Expectant parents can then digest this information over time in the lead up to birth and make informed decisions.

Post-nataly, more support needs to be given to women to reassure them during their recovery. Failing to give women the requisite support contributes to maternal mental health conditions.

2. Improving the quality and accessibility of information and education on women's health

In addressing this core theme, we submit two examples of where we consider improved education and information accessibility would improve healthcare outcomes for women.

a) Cervical screening – The barriers

Cervical screening is an exceptionally important tool in preventing cancer before it develops. Despite this, too many women fail to engage and suffer tragic consequences as a result.

There are understood to be many reasons for reduced engagement in cervical screening rates including embarrassment, age, cultural norms and lack of awareness. Sadly, the increase in screening brought about by the death of Jade Goody appears now to have diminished.

We believe that improving the quality and accessibility of reliable information and education in dispelling the myths around cervical cancer and the screening process will save lives. This is because we know that the later the diagnosis of cervical cancer or indeed of identifying precancerous cells, the worse the outcome. Being diagnosed later significantly reduces the chances of successful treatment, a good quality of life and sadly reduces the overall chances of survival.

Focusing on cultural barriers in particular, we believe more work must be done to target those women in ethnic minority communities.

In multicultural towns and cities across the UK, cultural and language barriers mean that new ways must be found to target and reach those women who have so far been unable or unwilling to engage in cervical screening.

Dr Laura Marlow from University College London conducted research[3] into cervical cancer screening and looked at the barriers faced by ethnic minority women. Dr Marlow found that ethnic minority women felt that there was a lack of awareness about cervical cancer in their community and several did not even recognise the terms '*cervical screening*' or '*smear test*'. A misconceived low risk of cervical cancer was influenced by beliefs around sex outside of marriage and some women felt a diagnosis of cervical cancer might be considered shameful in their community. Some also reported that they would be reluctant to attend their GP surgery for a smear out of embarrassment when it would be likely that they would bump into someone from their community there.

The origins of these obstacles almost exclusively relate to poor quality education and information dissemination.

What can be done?

Where resources are sparse and time is limited for medical professionals, there is no single answer to the problem. However, we consider even modest changes could make a big difference. Our proposals include:-

- Improve outreach in ethnic minority communities where there is a perceived stigma attached to screening, to educate and reform popular opinion.

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[3] https://srh.bmj.com/content/41/4/248

- Where potential language barriers exist, providers should consider sending translated copies of their invitation / advice letters. This would make consultations and continuation of patient care more efficient and both patient and professional can ensure important details have been fully understood.

- Cervical Screening information to be available in a variety of languages.

- Providers to consider holding information evenings for community or faith groups and/or drop-in clinics and helplines.

- To improve training for medical professions involved in screening. This will mean they are better equipped to sensitively interact with patients who can better understand the importance of cervical screening and return next time.

- To encourage women to bring a friend or a family member to a consultation if their language skills are limited or where this does not cause embarrassment.

- Providers to offer out-of-hours or weekend screening thus reducing the necessity for women to seek time off work. This is likely to be a particular barrier to those in lower paid employment many of whom will belong to the BAME community.

Whilst less relevant to education, we are also supportive of the expansion of the current trial of HPV home testing kits as this is likely to help tackle the embarrassment barrier.

b) Late Diagnosis of Endometriosis and Menopause

In 2019, as part of our firm's commitment to improving the lives of women and their healthcare experiences, we collected responses from over 2,000 women regarding their views on common misconceptions and misinformation in reproductive health. Our survey found that when British people attended their doctor in respect of their reproductive health, almost twice as many women than men had to go back to the doctor because their issue was not resolved to their satisfaction in the first visit. This includes over one in ten women (12%) who have had to go back to the doctor three to five times over the past five years after being unable to resolve their issue in the first visit. It is clear that women in the UK are living with unresolved reproductive issues for much longer than they need to.

As part of this research, we spoke to Dr Anne Henderson, Consultant Gynaecologist and founder of 'Gynae Expert'. She reported that misconceptions about reproductive health can even extend to how doctors treat their patients, including medical misdiagnosis. *"In women of reproductive age, one of the most commonly mismanaged conditions is endometriosis. For later on in life, the most commonly mismanaged condition is the menopause, and specifically the perimenopause."*

This rings true in light of the enquiries we regularly receive from women questioning whether the delay in their receiving an accurate diagnosis had caused them avoidable pain and suffering.

When it comes to the management of endometriosis, a condition that affects 1 in 5 women and often has a genetic element (so family history is important), the average time from presentation to diagnosis is a shocking *7.5 years* – and this has not improved over time. Whilst difficult to diagnose, these years can be miserable for a sufferer. We often see a woman's ability to work and engage in normal day-to-day activities hugely affected. Furthermore, repeated presentations to medical settings strain the system.

Similarly, our research found that spending on products for menopause is a significant expenditure for women over the age of 45. "*Menopause care is a crisis,"* said Dr Henderson, noting that the perimenopause is one of the most grossly mismanaged conditions when it comes to reproductive health. GPs will often overprescribe peri-menopausal women antidepressants when, in fact, these women should be offered Hormone Replacement Therapy.

It is therefore our strongly held view that better training and education *within* the medical profession would result in the earlier diagnosis of debilitating, often neglected, female only conditions such as endometriosis and menopause.

3. Understanding and responding to the impacts of COVID-19 on Women's Health

The impact of Covid-19 on expectant mothers cannot be underestimated.

Many women had to attend key antenatal appointments and scans alone. These women lost the opportunity to share the joy of scans with their partners, but even more concerning, many found themselves alone when they received distressing news about the wellbeing or viability of their baby. These women were then burdened with the responsibility of communicating sometimes devastating news to partners after appointments. Over the last 12 months, our team has spoken to a number of women who have been told that their baby has sadly passed away in the womb without their birthing partner present.

Women have been denied the opportunity to have the support of a birth partner at a critical time; one that was made even more stressful due to the threat of the virus.

During the pandemic, women have had to undergo the early stages of labour alone in hospital triage areas and labour wards, with partners only permitted to join them before delivery.

Childbirth can be a frightening experience, particularly for first-time mothers. Women can feel vulnerable and overwhelmed. High pain levels, fear for their own health and their child's health can prevent the most confident women advocating for themselves or being able to take informed decisions about treatment options; this is when having a birth partner is crucial. The absence of a partner during this time will have had a far reaching impact on the experience for many women and babies across the country.

To this end, our team have spoken to women who have endured labour alone, which is frightening enough when there are no complications. However, when things do go wrong, women have told me how they felt out of control. They did not understand what was happening and they had no one to advocate for them. Once again, women are bearing the brunt of negative outcomes when it comes to maternity care. The sooner this is addressed, the better.

COVID-19: A Positive Consequence?

Notwithstanding the above, one of the few positives that have emerged out of the pandemic is that employers appear to be more receptive to a more flexible approach to the working day. For anyone with caring obligations this has been a benefit. We hope that this flexible and home working approach can be adopted on a more permanent basis by employers to help anyone with caring responsibilities to balance work and home life. This will also benefit women who are less able or confident to work full time in an office because of, for example, childbirth complications or menopause.

By way of example, our client Linda* was unable to work in an office following a medical negligence claim which left her with faecal incontinence. Unfortunately her employment was terminated because of her injuries, but if she had been allowed to continue to work from home she may have been able to continue working and benefiting her family and the economy. We hope that the shift towards flexible / remote working is one that is adopted by more employers for the benefit of all.

*alias to protect client's identity

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