

Coronial investigation of stillbirths consultation: Birthrights response

12th June 2019



Question 1: Do you think coroners should have a role in investigating stillbirths? Please Provide Reasons.

No.

Birthrights believes that the bereaved family, in particular the mother or individual parent who was pregnant, should remain at the heart of any investigation into a stillbirth. While we understand the positive intent behind these proposals, we have significant concerns about the unintended consequences of this step, particularly in terms of women and families having informed choice about what happens following the tragedy of a stillbirth.

Birthrights wants to emphasise that healthcare providers, Government and wider society should always listen to families whose lives have been changed forever by stillbirth, and we entirely accept that many families have felt that the current investigations and procedures for investigation have been inadequate and carried out in a defensive manner. Birthrights recognises that addressing these concerns is a major driver behind the development of these policy proposals, however as drafted the policy fails to put families at the centre. As such, we are concerned it may cause additional distress to families at an already traumatic time.

The consultation states that these powers “could give parents an authoritative and transparent account of what happened to their baby”, which is what most parents who have suffered the tragedy of a stillbirth understandably want. However, Birthrights is concerned that it may be misleading and simplistic, at least in some cases, to suggest that there is one “authoritative” and full version of the truth, that can be uncovered through rigorous independent scrutiny. For example, it may be that one or two offhand comments from healthcare professionals led to a woman feeling uncomfortable about seeking timely help when she experienced reduced fetal movements. These nuances can be lost in an adversarial, legal process and indeed the process can inhibit full transparency. Alternative processes, such as open disclosure, when conducted in a highly skilled way, might better achieve the policy objectives outlined, but unfortunately alternative options have not been considered as part of this consultation process.

Birthrights can only envisage a very carefully constructed and restricted role for coronial powers to investigate stillbirth, as a final resort. A coronial inquest, with appropriate safeguards for parents, could become the final layer of investigation (in an already profoundly traumatic process) for those families who consent to it. As it stands, the proposed policy has neither safeguards for parents nor any provision for families to consent to, or decline, coronial involvement, and Birthrights is not aware of any practical precedent for safeguards which could effectively meet these needs.

The Impact Assessment (IA) for the consultation states that the policy proposal aims to “generate maximum lessons learnt” from investigations into stillbirths (consultation document p9). This is not the same as a proposal which puts families at its centre.

The consultation document and IA are also silent on how the processes proposed by the Government would interact with investigative processes recently introduced under the Perinatal Mortality Review Tool and Healthcare Safety Investigation Branch. The IA

Footer for references

states: “This is not something that is known with certainty at this stage” (IA p17), despite the Government being asked repeatedly about this during the pre-consultation period. It is vital to understand how these processes are expected to interact, in order to understand the full impact on families and healthcare professionals.

Birthrights are strongly of the view that we should not impose a system of stillbirth investigation that could actually remove informed choice from families. Such a system would be highly unlikely to guarantee satisfaction for all families and would not lead to wider learning overall. More likely, a mandatory imposition of coronial powers in **all** cases of term stillbirth would undermine trust in healthcare and justice provision, and add to some families’ distress.

Birthrights thinks it is highly likely that there will be significant equalities impacts from these policy proposals. These include negative impacts on women from Black and Minority Ethnic groups, who are more likely to experience stillbirth.¹ We know that women facing the most complex multiple disadvantage include disproportionate numbers of women from these backgrounds as well as younger women. We know that they have worse experiences of maternity care², including after stillbirth³, and often fear and distrust public services.⁴ We are very concerned that mandatory engagement with the coronial system – especially without adequate support – will increase the risk of fractured, distrustful relationships with public services and substantially increase the trauma of many families. It is extremely disappointing to see that no equalities analysis has been carried out to date. No further work should be done without this vital part of the impact analysis.

The NHS, like other public bodies, is subject to the Human Rights Act 1998, and as such must provide rights respecting care to all women and pregnant people, including upholding the principle of bodily autonomy and ensuring informed consent is obtained. Birthrights strongly recommends that in order to meet the objectives of system-wide learning and to “enhance” the involvement of bereaved parents (consultation document p5), we must have a system to investigate stillbirth in which autonomy, choice and consent is paramount.

The experience of an inquest can be profoundly traumatising for a family and also for frontline staff members who have been with the family at the time of their stillbirth. It is unlikely that many families and frontline staff will have awareness of what it will be like

¹ Draper, E, Gallimore, I, Kurinczuk, J, Smith, P, Bobby, T, Smith, L & Manktelow, B (2018). *MBRRACE-UK Perinatal Mortality Surveillance Report, UK Perinatal Deaths for Births from January to December 2016*.

² McLeish, J and Redshaw M (2019). 'Maternity Experiences of mothers with multiple disadvantages in England: A qualitative study'. *Women and Birth*, 32(2),178-184; Birth Companions and the Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages*; Thomson, G and Balaam, M (2016). *Birth Companions Research Project: Experiences and Birth Outcomes of Vulnerable Women*. University of Central Lancashire; Redshaw, M and Henderson, J (2016). 'Who is actually asked about their mental health in pregnancy and the postnatal period? Findings from a national survey' *BMC Psychiatry*, 15(1), 322; Birthrights and Birth Companions (2019 forthcoming) '*Holding it all together: Rights issues experienced by women facing disadvantage during pregnancy, birth and postnatal care*'.

³ Redshaw, M and Henderson, J (2018). 'Care associated with stillbirth for the most disadvantaged women: A multi-method study of care in England' *Birth*, 45(3), 275-285.

⁴ Birth Companions and the Revolving Doors Agency (2018) *Making Better Births a reality for women with multiple disadvantages*. Available at: <http://www.revolving-doors.org.uk/file/2333/download?token=P2z9dlAR>

to go through the inquest - the stress, pressure and huge emotions that they might feel - until they arrive in the court room on the very first day. If this proposal is taken forward, families must be given realistic information about what is involved in coronial investigation, time to consider this properly during what is already a hugely difficult time (with any necessary support provided), the opportunity to make an informed decision about whether they want coronial investigation, and support throughout the process.

Birthrights is especially concerned about the impact of the following:

- Families may have no understanding that if coronial powers are granted, this will mean that the decision to have a post-mortem no longer rests with them and is now up to the coroner. The consultation states that the coroner will have “legal custody” of the baby’s body (para 70). This is likely to be a very distressing situation for some families, both in terms of the loss of decision-making authority and as a descriptor of coronial powers. It may significantly impact the time that they can spend with their stillborn baby after birth and could adversely affect whether a family are able to bring their stillborn baby home for a short time following the stillbirth. It could also adversely impact families from some religious backgrounds where burial should take place as soon as possible. The IA recognises that 72% of responses to a survey by the Stillbirth and Neonatal Death charity (SANDS) “were concerned or very concerned about the fact that coroners do not require parental consent to order a post-mortem” (pg 13) and Birthrights is very concerned that this does not seem to have been taken into account in the policy development.
- Birthrights has heard the experience of being at an inquest described as a “legal circus”. Families and care providers have described situations where lawyers were talking over them, and the whole dialogue and work of the day was focused on legal procedure. These parents felt lost, isolated and ignored and as though they were merely a “post-script” to the work of the court. If this policy is pursued, families would need significant support before, throughout and after the process. Families would also need mental health support and although we recognise perinatal mental health is a priority within the NHS Long Term Plan, we also know that to date mental health support in the perinatal period has been patchy, with those groups most in need of support less likely to be asked about their needs or provided with support.⁵
- Birthrights is deeply concerned that these proposals make no provision for the parents of the stillborn baby to receive legal aid so that they might be properly represented in Court. The NHS Trust and any other interested party will have a number of experienced lawyers representing them, both in preparation for the hearing and during the entire hearing itself. This would be a complete imbalance of power towards the state and a real disparity of arms, which is made even more significant if the parents have not consented to the inquest happening in the first place. In addition, the proposals make no provision for language support for women and families who need it.
- The lack of legal representation for the mother or individual parent who has given birth compounds the serious issue that it will be the entire medical record of the person who has given birth which will form the bulk of the evidence at the hearing. Many families will be completely unaware of this and may not realise beforehand that they

⁵ Redshaw, M and Henderson, J (2016). 'Who is actually asked about their mental health in pregnancy and the postnatal period? Findings from a national survey' *BMC Psychiatry*, 15(1), 322

will need to answer detailed questions about their own medical records and decisions during pregnancy, labour and birth.

- These proposals offer no safeguards around the questioning of the person who has given birth, and as it stands, their whole medical record is open for questioning from the coroner and from the lawyers of other parties. This could include extensive questions around the choices a person had made antenatally, which were lawful but may have been outside of recommendations from healthcare professionals, as well as questions around unlawful behaviour (such as taking recreational drugs). Again, the IA is silent on the impact of enabling coroners to use the medical records of a person who is not the subject of the inquest. Mandating the use of an individual's medical records against their will could be considered a breach of their Article 8 rights to private and family life under the European Convention of Human Rights, if the full disclosure exceeds what is necessary or proportionate given the objective it is seeking to achieve. We are not aware of any precedent elsewhere for this intrusion into an unwilling woman's privacy or for practical safeguards which might effectively protect women from invasive and distressing questioning.
- An inquest would mean that a person who had given birth to a stillborn baby would have their past medical history, including that which may be irrelevant to the stillbirth and deeply private, laid bare in a public court room. This could include such matters as mental health, substance abuse, previous involvement with safeguarding and abortion. These proposals offer no suggestion that there would be any reporting safeguards put in place, nor that the government would strongly recommend these. In an international climate of condemnation of women for their choices around pregnancy, reproductive rights and antenatal care, this opens the door to sensationalist media coverage of an inquest which may vilify the lawful choices and lifestyles of grieving parents.
- From a procedural perspective, many families may not be aware of the time that an inquest will take and the delays which can inevitably accompany coroner listings, especially given the large caseload for coroners within the UK. Birthrights is aware that the view of some clinicians frequently involved in inquests is that the coroners' system is "in crisis" for those cases which are already being investigated, without adding another layer of very complex cases.

Birthrights recognises that the state and healthcare providers will want to learn further about the causes of stillbirth in order to continue to reduce the UK rate of stillbirth. Birthrights believes that the good intentions of such learning would become unsafe, if it would occur at the expense of grieving families who have no wish to become the means of such learning.

Erosion of trust in the Government and in healthcare providers would be a high a price to pay for any learning gained by potentially forcing traumatised families to submit to a painful judicial process.

This could be exacerbated by erosion of trust within healthcare systems as well: as the IA recognises, introducing judicial processes "could undermine existing working relationships between the various parts of the system currently involved in investigations of stillbirths" (consultation document p19).

Birthrights' position is that if properly safeguarded, coronial investigations and hearings might have a limited place in providing a further layer of independent scrutiny when

families consent, and when earlier investigations have been poorly managed and inadequate. Nevertheless, this would require significant safeguards to be introduced, as discussed above, and Birthrights is not aware of any practical precedents which would be likely to provide the degree of reassurance required. Coronial powers to investigate stillbirth present a raft of procedural and ethical concerns of their own, and are not a universal panacea to resolve the shortcomings in procedure and independence in all current term stillbirth investigations.

Question 2: Do you consider that coronial investigations of stillbirths would achieve the policy objectives set out in paragraph 41? Are there any other policy objectives that we should consider in improving the systems for determining the causes of stillbirths and delivering better services?

No.

The policy objectives in paragraph 41 of the consultation document are as follows:

- To provide an independent assessment of the facts and causes of the stillbirth being investigated;
- To provide for transparent investigations which give parents an opportunity to express their views on the circumstances leading to the stillbirth of their baby and keep them engaged and informed throughout the process; and
- To contribute to system-wide learning about the causes of stillbirths and the circumstances leading to them, with a view to contributing to the wider health-system efforts being made to improve maternity outcomes.

Birthrights accepts that a coronial inquest can provide an independent assessment of the facts and causes of a death of a child or adult and could offer the same level of independence to an inquest into a stillbirth.

Birthrights has grave concerns as to whether coronial investigations of stillbirths could meet the second and third objectives. Birthrights also notes that in the IA, the “policy proposal is [...] to generate maximum lessons learnt and recommendations” (p9), which is not the same as any of the objectives above, in tone or practice.

With respect to the second objective, coronial inquests certainly provide transparent investigations by nature of the fact that they are held in public. The entirety of a pregnant person’s medical records will become the main evidence in the hearing and will be laid bare to the public (and potentially to the media as well). At the end of the hearing, the medical records of the person who gave birth, and all of the evidence which has been given about those records, will become a matter of public record. Birthrights strongly believes that many bereaved families will not have envisaged, and will not want, this level of scrutiny of their private lives in the public domain, particularly at an already traumatic time.

The second objective speaks of giving parents; “an opportunity” to “express their views” but a coronial inquest will not achieve that. A mandatory investigation into all term stillbirths will instead compel parents to attend and to give evidence in a witness stand. This is an entirely different situation in law and removes all elements of informed choice for parents within a context where there is no parity of arms.

The second objective further speaks of keeping parents “*engaged and informed*” throughout the process but Birthrights asserts that there are currently huge question marks over how this could be achieved. Who is going to keep parents informed if they are given no legal aid to be represented at the hearing and in any preparatory hearings?

Who is going to support the parents throughout the court process? The consultation event attended by Birthrights revealed that services to support parents who have suffered a stillbirth are poor in certain areas of the UK, and especially lacking in Wales. The coronial investigation will be a lengthy process and these proposals are silent on how parents will be supported throughout. Any investigation into a stillbirth, but most especially an inquest, could intrude on and reduce families’ time to be with and to grieve with their stillborn baby; often removing their ability to take their stillborn baby home or bury their baby in accordance with their religion. The proposals do not reflect any awareness of the real risk that the prolonged process and judicial nature of a mandatory coronial inquest could actually add to and prolong the family’s grief. It also fails to recognise that support services for women and families who have experienced a stillbirth may fall away whilst the investigative processes are still ongoing, compounding distress.

With respect to the third objective, Birthrights accepts that there is the possibility for some learning about the causes of stillbirths to arise from a coronial inquest. This is extraordinarily difficult to quantify and there are certainly no guarantees of learning at this stage.

Birthrights believes that the possibility of wider learning needs to be balanced against the very clear and obvious risks that the introduction of mandatory coronial investigations would bring.

With respect to wider learning, Birthrights disputes the premise that the best possible route to wider learning about the causes of stillbirth, automatically lies outside of the NHS. Birthrights also questions what the planned routes are for disseminating learning: it is not clear how learning will be disseminated beyond the immediate Trust involved, and whilst we recognise that there is a requirement to respond to a Report to Prevent Future Deaths, we understand that there is no process for validating whether bodies have acted on recommendations.

Birthrights is aware that in some parts of the UK (for example Bristol), when families consent to post mortem tests, their regional healthcare providers are able to carry out and pay for an extensive array of paediatric pathology tests which don’t immediately pertain to the cause of death but can be enlightening as to the cause of a stillbirth. In reality, a coroner would likely not order, nor would a coroner’s court pay for, similar tests, because they don’t immediately pertain to a cause of death. Certain regional NHS healthcare providers are already offering a consent-based service, which includes a fuller level of detail, including tests and examinations which the coroner would likely not order. These extensive levels of testing and round-table discussions between clinicians can provide a fuller level of answers to parents in a far less stressful environment than a court hearing.

In respect of any other policy objectives which the Ministry of Justice should consider, Birthrights submits that the following policy objectives should also be considered:

- To sustain and improve public trust in state healthcare providers
- To enshrine Human Rights Law principles within all systems of investigation into stillbirths
- To prioritise finding and delivering the fullest possible answers to parents.

- To establish and sustain timely, open, and respectful dialogue between clinicians and families in the event of a stillbirth.
- To build, sustain and promote a *Climate of Continuous Learning* (in order to keep this policy in line with Better Births).

Birthrights believes that whilst independence is a key objective in any policy on the investigation of stillbirths, trust is also key. Birthrights submits that any objectives to have greater independence must be balanced by an intention to re-build and/or to sustain trust in maternity and healthcare systems. Enshrining Human Rights Law principles into all investigations about stillbirths is one route to achieving this. Birthrights proposes that if the focus is on independence of the process to the exclusion of re-building trust between the NHS and families, such a shift in process could ultimately increase divisions. If all term stillbirth investigations are mandatorily moved into the justice system, not only may trust in both the state and healthcare providers be lost, there may no longer be an incentive for NHS providers to rebuild it.

Trust will be an especially pertinent issue for women and parents who have already had negative experiences of dealing with state/government functions or with statutory services. These may also be the people who map on to area of greatest socio-economic deprivation, or BAME families, where stillbirth rates are highest.

Birthrights strongly believes that unless there is a very high probability that the implementation of these proposals will be a significant and meaningful contribution to system wide learning and to reducing stillbirth, whilst also respecting and meeting the needs and rights of grieving families, then the proposals will not be likely to meet all of the policy objectives set out in paragraph 41.

Question 3: Do you agree with the proposal about ascertaining who the mother of the stillborn baby is and the baby's name if they have been given one? Do you think there is anything else that should be considered?

No.

Birthrights only agrees with the proposal of ascertaining who the mother of the stillborn baby is and the baby's name if the mother has given her express informed consent to the holding of an inquest into the stillbirth of her baby.

Birthrights can envisage a situation where a grieving mother or birthing parent could be subjected to a further layer of trauma and feel castigated by being forced to attend at an inquest and give evidence about themselves, their pregnancy, their birth and their medical record. If a mother or birthing individual desperately wished to grieve in private and to attend only the investigation offered by their local healthcare providers, then their decision should be respected.

Question 4: Do you agree with the proposal about ascertaining how it was that the baby was not born alive? Do you think that there is anything else that should be considered?

No.

Birthrights strongly believes that explorations of a woman's or birthing person's lawful and legitimate choices during pregnancy and birth should be excluded from coronial scrutiny.

Birthrights strongly submits that such an exception should be written into any legislation, otherwise there is a real risk that women and individuals giving birth will be called to account during an inquest for their lawful rights, choices and behaviour during pregnancy and childbirth.

A coronial hearing intended to provide more answers and detail to parents in respect of why their baby was stillborn, could become a hearing where the bereaved parents feel that they themselves, their lifestyle and their lawful decision-making outside of guidance or recommendations, is effectively on trial.

A key driver to these proposals (evidenced in the first paragraph on page 3 of the consultation) appears to be the need to learn lessons around the quality of care and treatment offered and given to pregnant people who then have a stillborn baby. We are concerned that little thought appears to have been given to the way in which these proposals, as currently drafted, could open the door to scrutiny and criticism of women and individual's medical history, including any illegal activity or past experiences of safeguarding and her lawful choices in reproductive health, pregnancy and birth.

Birthrights recognises that the intention of the legislation may not be about the choices that a woman or individual makes in pregnancy. Nevertheless, the disparity of legal support between families unable to pay for representation and NHS Trusts will put women at a significant disadvantage, particularly if they have made decisions which fall outside standard care guidelines (despite these being legal decisions for a woman to make in line with her human rights). Birthrights is also acutely aware that policing and criticism of women's lawful choices still happens too often within maternity care and in other related spheres (such as health and social care), not to mention the media. This is all the more relevant as other countries with strong ties to the United Kingdom are taking steps to erode women's rights in reproductive health and bodily autonomy.

An inquest will fail to be a trustworthy process for parents to go through if they are not only compelled to be part of it (i.e. if their consent is disregarded - see answer to question 10) but are also concerned throughout the proceedings that they may personally be at risk of criminal or statutory investigation/prosecution.

Question 5: Do you agree with the proposal about ascertaining when foetal death occurred or was likely to have occurred and when the baby was stillborn? Do you think there is anything else that should be considered?

No.

Birthrights only agrees with the proposal of ascertaining when foetal death occurred or was likely to have occurred and when the baby was stillborn if the following procedural and ethical safeguards are met:

- The parents have given their express informed consent to the holding of an inquest into the stillbirth of their baby, having been given sufficient information about what this is likely to involve, how it relates to any other investigative processes being offered or undertaken, and time and any support required to reflect and come to a decision.

- There are appropriate procedural safeguards in place so that during the giving of evidence, a woman's or birthing person's choices during pregnancy and birth are excluded from coronial scrutiny.
- There are appropriate media reporting restrictions in place for the inquest hearing.

Question 6: Do you agree with the proposal about ascertaining where foetal death occurred or was likely to have occurred and where the stillborn baby was delivered? Do you think that there is anything else that should be considered?

No.

Birthrights only agrees with the proposal of ascertaining when foetal death occurred or was likely to have occurred and when the baby was stillborn if the following procedural and ethical safeguards are met:

- The parents have given their express informed consent to the holding of an inquest into the stillbirth of their baby, having been given sufficient information about what this is likely to involve, how it relates to any other investigative processes being offered or undertaken, and time and any support required to reflect and come to a decision.
- There are appropriate procedural safeguards in place so that during the giving of evidence, a woman's or birthing person's choices during pregnancy and birth are excluded from coronial scrutiny.
- There are appropriate media reporting restrictions in place for the inquest hearing.

Birthrights respectfully proposes that any new legislation should use the phrase: "where the stillborn baby *was born*" as opposed to "delivered". "Born" is factually accurate and demonstrates respect and sensitivity to the individual who has actually given birth.

"Delivered" does not reflect the factual reality of the situation that the woman or pregnant person is giving birth and this language does not reflect the rights and responsibilities of UK service users and service providers.

Question 7: Do you agree that as part of their findings coroners should identify learning points and issue recommendations to the persons and bodies they consider relevant? If not how do you think that coroners should disseminate learning points?

Yes.

Birthrights believes that maternity care and all investigations within and around it, should operate in a climate of continuous learning.

Birthrights supports the overarching idea that coroners could, if possible, identify learning points and issue recommendations to relevant bodies.

Birthrights asks whether "relevant persons" is intended to include the bereaved parents or family of the stillborn baby? If so, is the government proposing that a coroner, who is not a medical professional nor the actual maternity or healthcare provider for the parents, should issue learning points on medical issues to parents? This would appear to be wholly outside the coroner's role and a dangerous blurring of lines between judicial

recommendations and individualised healthcare recommendations given by a medical professional.

Birthrights asks what weight the coroner's recommendations are intended to have and what processes will be in place to ensure that they are followed up?

Birthrights would also like to see the detail in the proposals for the actual process by which any lessons will be disseminated and shared. The proposals are silent on how this process would take place and it is difficult to comment further without there being a clear process already laid out. There is a risk that coronial investigations could result in similar recommendations emerging from more than one investigation if learning is not disseminated appropriately.

Question 8: Beyond identifying learning points in individual cases, do you think coroners should have a role in promoting best practice in antenatal care?

No.

Birthrights is unclear what is specifically being suggested by this proposal and ask what is specifically meant by the phrase: "best practice in antenatal care"? Birthrights is concerned that this is a suggestion that a coroner should make pronouncements outside of their remit as independent members of the judiciary, and cross over into promotion or advocacy for particular schools of thought on medical issues. This would be highly inappropriate, and counter to the legal position (set out in *Montgomery v Lanarkshire Health Board* [2015] UKSC 11) which requires healthcare practitioners to support women to make personalised decisions. Coroners should not be given a public health remit as a result of these proposals.

In order to be appropriately supported to carry out investigations of stillbirths, coroners require a complete, up to date, understanding of current case law and evidence around antenatal and intrapartum care. Birthrights has significant concerns over whether this is likely given the pressure that the coroners court systems are already under.

If these proposals were to go ahead, Birthrights contends that the following additional training for all members of the judiciary would be required in order that they are fully conversant with the following legal and factual issues:

- Human rights in childbirth law and how it pertains to antenatal care
- All common law in relation to bodily autonomy, informed consent and mental capacity in healthcare
- How principles of human rights and common law can be enshrined in antenatal and intrapartum care
- The concept of continuity of carer and the conclusions of Better Births (2016) and the MBBRACE report (2018)
- Forensic and testimonial evidence with respect to continuity of carer in antenatal care
- All relevant NICE guidelines on antenatal and intrapartum care including the quality of any evidence relied upon to produce those guidelines

- An understanding of how NICE and other guidelines are created and their status in law.

Without this, coroners would not be in a position to properly investigate stillbirths. Birthrights has experience with other investigatory bodies and regulators where advice given by expert witnesses has not always been legally accurate, and it is vital that this risk be removed in any coronial processes.

Question 9: Is there anything else that you would like to see come out of a coroner's investigation into a stillbirth? What other determinations should be made?

Birthrights would wish for coroners to be able to specifically note any areas where adherence to, respect of and understanding of an individual's human rights could have been improved.

Where a coroner has reached a decision that aspects/absences of clinical practice was a reason for the stillbirth, Birthrights would like to see a coroner give a strong recommendation for updated training to take place, and if necessary that such training should be given by highly qualified external providers. This is also the case where aspects of managerial, practice management or legal failings are identified.

Question 10: Do you agree that no consent or permission from the bereaved parents or from anyone else should be required for a coronial investigation into a stillbirth to be opened? Please give your reasons.

No.

Birthrights do not agree that no consent should be sought from the bereaved parents.

Birthrights' position is that for women and families to obtain real benefit from the granting of coronial powers to investigate stillbirth, then they must truly remain at the heart of the process and their consent must therefore be sought before an investigation can be opened.

Consent and legal personhood

The entire system of maternity care provision during pregnancy in the UK is predicated on women or pregnant individuals having the final say with respect to all decisions about their body, their unborn baby within them, and their care. Birthrights submits that a stillborn baby, remains within that symbiotic relationship with its mother/parent that exists during pregnancy, and should continue to be treated as such - the final decision continuing to rest with the mother or pregnant parent.

Birthrights are aware that some respondents to this survey may seek to make the argument that a stillborn baby is almost indistinguishable from a baby who was born, breathed independently for a short while and then died, and that both babies should therefore be treated identically in terms of coronial powers. We also recognise that this may not be a meaningful distinction for parents.

However, Birthrights submits that within current personhood law in the UK these two babies are actually very different legally, and therefore should be subject to distinct differences in rules regarding coronial powers.

A baby who has drawn breath and lived independently of its mother/birthing parent even for a very short time, has been granted personhood in UK law and thus has all of the

legal rights of any alive person living in the United Kingdom. UK law deems them to have been independently alive. A foetus, a baby who does not and cannot live independently from the person who has carried it, does not have the legal rights of personhood which stem from being able to breathe independently. Any decisions in respect of a foetus or baby who is not able to live and breathe independently always require the pregnant person's consent. Even where a woman or pregnant individual lacks capacity to make informed decisions on their own about their body, their wishes and preferred decision cannot be simply bypassed by a court and still carry significant weight as part of the totality of the evidence.

To wholly bypass the principle of informed consent with respect to coronial investigations of stillbirths could not only exacerbate the grief and trauma of parents, but crosses into the legal territory of giving personhood to babies who have never lived independently, purely because they have reached a particular gestation. Birthrights does not believe the Government intends to row backwards on the law of bodily autonomy and give legal rights to some unborn babies that supersede the rights of women and pregnant individuals.

In difficult and complex areas of law, legal boundaries are still drawn. Those boundaries remain in place until Parliament changes them. Current UK law draws one such line at 24 weeks of pregnancy and another such line at babies who are able to breathe independently of their birthing parent. Birthrights strongly submits that any new coronial powers must be drawn up in the context of these existing legal boundaries – for example by treating investigations into stillbirths as a separate category of investigation from investigation of deaths – and should not be drawn so as to suggest unborn babies from 37 weeks have legal personhood.

Birthrights notes that even in the case of babies who were able to live independently, if only for a short time, their death does not result in an automatic referral to a coroner. This is because if a medical professional is able to sign a death certificate citing natural causes, there is not automatic need for an inquest. The situation is different for stillborn babies as they do not and cannot receive a death certificate because they have never been independently alive. This significant difference about death certificates underlines that current UK law draws a crucial distinction in personhood between independently alive babies and babies who are stillborn.

The IA describes a desire to avoid “unjustifiable differentiation between coronial powers in investigating neonatal (and other) deaths and stillbirths” (p7). This is deeply concerning. Birthrights strongly believes that to seek to treat inquests into stillbirths as almost indistinguishable from inquests into the death of a baby undermines a key pillar of UK maternity care, as to who should make decisions for babies who are not independently alive beyond the womb.

Consent and impact on bereaved families

Birthrights strongly submits that the consent of parents is a vital safeguard to ensure that the bereaved parents are able to be truly engaged and informed throughout the process and to optimise any possible learning opportunities.

Birthrights submits that it is crucial to recognise that coronial inquests may not feel like a safe and appropriate way of investigating stillbirth for all women or individuals who have given birth. Some families may view a coronial investigation as exacerbating their grief. We are very concerned that mandatory engagement may in some cases do more

harm than good, especially in the absence of legal and other support. As stated under question 1, we know that women facing disadvantage experience higher rates of stillbirth, have worse experiences of maternity care⁶ including after stillbirth⁷ and often fear and distrust public services.⁸ We are very concerned that mandatory engagement with the coronial system – especially without adequate support – will increase the risk of fractured, distrustful relationships with public services and substantially increase the trauma of many families. It would be wholly detrimental to their wellbeing and to building greater trust with state bodies, to force them into what could be a harrowing inquest process, for the sake of “learning opportunities”, if they do not wish to give consent.

Birthrights submits that the laudable objective of increasing learning opportunities should never take precedence over the health, welfare and support of bereaved families. Birthrights questions the ultimate value of any such learning points gleaned from a process that families have not wanted and which may have contributed to their trauma.

Birthrights notes that current evidence clearly demonstrates that not all families would wish to have an inquest into their stillbirth. The IA itself recognises that 72% of responses to a survey by the Stillbirth and Neonatal Death charity (SANDS) “were concerned or very concerned about the fact that coroners do not require parental consent to order a post-mortem” (p13). The MBRRACE perinatal surveillance report published in 2018 sets out that “There has been a small increase in the rate of consent for post-mortem for stillbirth from 47.2% in 2014 to 49.4% in 2016”⁹. That is, fewer than 50% of families consent to post-mortem examination of their stillborn baby, yet this policy is predicated on a 100% post-mortem rate. This suggests more than half of families could experience their stillborn baby undergoing post-mortem investigations against their will and be forced into an inquest that they did not wish to endure. The perinatal surveillance report recommends that “All parents of babies who die should be provided with unbiased counselling for post-mortem to enable them to make an informed decision”,¹⁰ highlighting the importance of choice for families. It is inappropriate to sacrifice this choice in favour of “maximum learning” (IA p9). which could further undermine trust between state health and judicial bodies.

Birthrights believes that if there could be a guarantee of further learning, clearer answers for parents, and a positive experience for families, then arguments around dispensing with consent in coronial investigations into stillbirth might be acceptable. However, there are far from any such guarantees and a forced judicial hearing for unrepresented

⁶ McLeish, J and Redshaw M (2019). 'Maternity Experiences of mothers with multiple disadvantages in England: A qualitative study'. *Women and Birth*, 32(2),178-184; Birth Companions and the Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages*; Thomson, G and Balaam, M (2016). Birth Companions Research Project: Experiences and Birth Outcomes of Vulnerable Women. University of Central Lancashire; Redshaw, M and Henderson, J (2016). 'Who is actually asked about their mental health in pregnancy and the postnatal period? Findings from a national survey' *BMC Psychiatry*, 15(1), 322; Birthrights and Birth Companions (2019 forthcoming) '*Holding it all together: Rights issues experienced by women facing disadvantage during pregnancy, birth and postnatal care*'.

⁷ Redshaw, M and Henderson, J (2018). 'Care associated with stillbirth for the most disadvantaged women: A multi-method study of care in England' *Birth*, 45(3), 275-285.

⁸ Birth Companions and the Revolving Doors Agency (2018) *Making Better Births a reality for women with multiple disadvantages*. Available at: <http://www.revolving-doors.org.uk/file/2333/download?token=P2z9dlAR>

⁹ Draper, E, Gallimore, I, Kurinczuk, J, Smith, P, Boby, T, Smith, L & Manktelow, B (2018). *MBRRACE-UK Perinatal Mortality Surveillance Report, UK Perinatal Deaths for Births from January to December 2016*.

¹⁰ *ibid*

parents that have not consented to this process could result in them suffering considerably more trauma.

Question 11: Do you agree that the coroner's duty to hold an inquest should apply to investigations of stillbirths? Please give your reasons?

No.

Birthrights does not agree that the existing coronial powers and duties to hold an inquest should be extended to cover stillbirths as set out in the proposals.

Existing coronial powers are in place to enable enquiries and investigations into the death of a person who had been legally alive.

Stillborn babies are tragically never able to live/be alive in a legal sense of personhood. Consequently, stillbirths must have rules governing their investigation which are distinctive from the powers of investigation into the death of a legally alive person.

To do otherwise would risk eroding a central premise of United Kingdom law, that the foetus does not have legal personhood until it lives independently of its mother/birthing parent, and thus a foetus does not have legal rights.

In the current global climate of erosion of women's reproductive and bodily autonomy rights around the world, in favour of foetal personhood, it is vital that the Government do not appear to begin to grant foetal legal rights as an unintended consequence of these proposals.

Creating a new and distinctive set of coronial powers that permit a coronial enquiry and investigation, subject to informed consent from the bereaved parents and supported by appropriate safeguards addressing the issues raised here, is the only acceptable solution compatible with human rights principles.

Such a new and distinctive set of powers would enable an additional layer of scrutiny and additional opportunity for learning to be available to those families who request it, whilst maintaining the clear legal distinction between babies who were legally alive outside of the womb and those who were not.

Question 12:

Do you agree with the proposals for the links and sequencing between coronial and non-coronial investigations? Please give your reasons.

No.

Birthrights submits that the links and sequencing between the proposals for coronial investigations and existing non-coronial investigations are not currently clear nor well-reasoned.

The consultation document states that there are currently "Several well-established processes in place for investigating the causes of stillbirth" (p5, para 3). Birthrights questions how 'well-established' many of these processes are. There has been significant recent change in processes and bodies involved in investigating stillbirth, and change is still occurring through the Health Service Safety Investigations Bill. This involves the development of significant skills resources as well as new processes. Birthrights questions

whether now is an appropriate time to introduce a new layer of process and investigation, especially when the Government is unable to articulate how all the difference processes would interact and avoid undermining each other or trust in healthcare institutions.

It is vital that any investigative mechanisms are trusted and enable families to find out as much as they can / wish to about what happened to their baby. Birthrights accepts that at present there can be unacceptable delays and parents do not always feel that they receive full answers. We recognise that national review programmes such as MBRRACE-UK *Perinatal mortality and morbidity confidential enquiries* and the Royal College of Obstetricians and Gynaecologists' Each Baby Counts programme have identified that there is scope to "improve the **quality** of investigations into the circumstances that have led to avoidable stillbirths occurring" (consultation document p14, para39. Our emphasis). Birthrights also acknowledges that the proposals for coroners to investigate stillbirths are intended to achieve greater independence and separation from the NHS and are supported by some bereaved families. However, much more thought needs to be given to how the different investigative processes interact and the implications for families, before any decisions are made to move investigations into stillbirth wholesale into the judicial system. At present, it is not clear from the proposals how these systems interact or what this would mean for families or health professionals, which is deeply concerning.

Birthrights suggests there may be opportunities to build on existing processes. For example, Birthrights asks what evidence is available on the investigations already carried out by the Healthcare Safety Investigation branch on intrapartum stillbirths at term? Is there current information on how well the HSIB investigations conducted to date have contributed to learning? What is the feedback from families who have been through the process? Birthrights notes in particular that whilst coronial inquests are conducted in public, the HSIB investigations involve evidence and recommendations for improvement only being shared with the family, the organisation and the clinicians who were involved in the case (consultation document p11, para 18). This provides a layer of privacy to grieving families as to their own medical records and choices during pregnancy, which they would lose in a coronial court hearing.

There may also be opportunities to build on emerging best practice around approaches such as open disclosure,¹¹ which use round-table meetings, 'safe space' concepts and open discussion, keeping the bereaved parents at the heart of the discussion. These processes are not judicial in nature. While a coroner's court does not technically apportion blame or decide upon criminal/civil liability, it is often a very confrontational, overwhelming experience for families and frontline health care providers. Invoking coronial powers is an attempt to achieve greater independence, but given the length and judicial nature of the process involved, Birthrights asks whether such a perception of independence will come at the expense of an additional layer of trauma to families?

Birthrights invites the Government and healthcare trusts to also consider alternative ways in which they can and should improve current investigative services. Human rights-based communications skills training for all healthcare providers, enshrining a

¹¹ See, for example, Iedema, R, Sorensen, R, Manias, E, Tuckett, A, Piper, D, Mallock, N, Williams, C. and Jorm, C. (2008). 'Patients' and family members' experiences of open disclosure following adverse events'. *International Journal for Quality in Health Care*, Volume 20(6), 421-432, <https://doi.org/10.1093/intqhc/mzn043>.

climate of transparency and continuous learning, and an “opt out” to an automatic debriefing service are just three examples of many immediate steps that could be taken.

Birthrights submits that one of the key concerns highlighted by inquests into child and adult deaths is a failure of clinicians to engage and communicate effectively and respectfully with the bereaved family. Birthrights believes that an absence of dignified, human rights based, compassionate communication is at the heart of many instances of inadequate care, including stillbirths. A focus on resolving this issue is crucial and a complete change of investigative process will not provide an automatic solution.

Birthrights is not convinced that, for many families, the best solution to greater independence and further learning on the causes of stillbirth, lies in moving the entire process of investigation of stillbirths to a mandatory investigation in the public arena of an inquest court.

Question 13: Do you think coroners should have the same powers in relation to evidence, documentation and witnesses in stillbirth investigation as well as ordering medical examinations as they do for death investigations now? Please give your reasons.

No.

Birthrights strongly submits that explorations of a woman's or birthing individual's choices during pregnancy and birth should be excluded from coronial scrutiny.

A coronial inquest into the death of a stillborn baby will be markedly different from the inquest into a deceased person in one particular respect - the key witness evidence and key medical records in a stillbirth inquest will be from a person who is still alive and making plans for life after the inquest - the woman or individual who gave birth. This person will very likely be grieving and, at the same time, tentatively hopeful to resume their life beyond the inquest. They might include considering more pregnancies in the short to medium term future.

Birthrights strongly submits that careful restrictions should be written into any legislation, to protect the woman or birthing parent of the stillborn baby from certain avenues of questioning, including from certain lines of questioning by another grieving parent, who may be representing themselves if they are estranged from the woman or person who gave birth.

Birthrights asserts that without such protections on witness evidence and questioning, there exists a real risk that women and individuals giving birth will be called to account during an inquest for their rights, choices and behaviour during pregnancy and childbirth.

A coronial hearing which is intended to provide more answers and detail to parents in respect of why their baby was stillborn, could become a hearing which blames the woman or person who gave birth and where the bereaved parents feel that they themselves, their lifestyle and their lawful decisions in pregnancy, possibly outside of standard guidance or recommendations, are effectively on trial.

A key driver to these proposals (evidenced in the first paragraph on p3 of the consultation and the reference to “maximum learning” on p9 of the IA) appears to be the need to learn lessons around the quality of care and treatment offered and given to pregnant people who then have a stillborn baby. Birthrights is concerned that little thought appears to have been given to the way in which these proposals, as currently drafted, would open

the door to scrutiny and criticism of women's and individual's medical history, including illegal activity or past experiences of safeguarding, and lawful choices in reproductive health, pregnancy and birth.

Birthrights recognises that the intention of the legislation may not have been about the choices that a woman or individual makes in pregnancy. Nevertheless, the disparity of legal support between families unable to pay for representation and hospital Trusts will put women at a significant disadvantage, particularly if they have made decisions which fall outside standard care guidelines (despite these being perfectly legal decisions for a woman to make). Birthrights is also acutely aware that policing and criticism of women's lawful choices still happens too often within maternity care and in other related spheres (such as health and social care), not to mention the media. This is all the more relevant as other countries with strong ties to the United Kingdom are taking steps to erode women's rights in reproductive health and bodily autonomy.

An inquest will fail to be a trustworthy process for parents to go through if they are not only compelled to participate, attend and give evidence (if there is consent disregarded - see answer to question 10), but also remain concerned throughout the proceedings that they may personally be at risk of criminal or statutory investigation/prosecution. Such a process could not be suggested to 'enhance' the process for grieving parents, and instead could add an additional layer of trauma and fear to their pain.

Question 14: What, if any, other powers should coroners exercise to aid their investigations into stillbirth?

Birthrights strongly recommends that coroners who investigate stillbirths should have adequate powers within their coronial procedural rules to enable them to put reporting restrictions in place on the media. Inquests are usually held in public but there are a number of reasons why it could be in the interests of justice for the hearing not to be reported on in detail until the coroner has made their finding and given their conclusion.

Inquests are exceptional by way of the sensitive subject matter of the proceedings. The death of a baby or child or an investigation of a stillborn baby are even more so. As drafted, the current proposals suggest that the woman's or birthing individual's medical record is likely to form the bulk of the evidence in the hearing and they may well face extensive questioning on the details of it and the choices and medical issues they have faced. Under the current proposals, this questioning could even come from another parent if the parents are not in a relationship and are separately represented or separately representing themselves. Birthrights can envisage situations where for the parents and/or care providers at the time of the stillbirth, giving evidence at an inquest will be harrowing.

Birthrights submits that extensive consideration must be given to the impact on the grieving family and on the wider public, in having private aspects of medical notes and personal, lawful, decision-making around birth, become compulsorily public as the key evidence in an inquest. There is a significant need to ensure that reports of inquests do not end up as narratives of blame in media reporting in the wider domain. Coroners must have powers to restrict the reporting of these matters so as to enable to grieving family the greatest opportunity to resume a private and family life to some degree, after the hearing has been concluded.

For a family or parent to be hounded by the media, seeking a sensationalist article, during the time that they are giving evidence about the stillbirth of their baby or after the

conclusion of the hearing, cannot ever be in the public interest, not in the interests of justice.

Question 15: Do you think it is appropriate for coroners to assume legal custody of the placenta? If not, why not?

No.

Birthrights submits that there is strong argument that the placenta, as an organ of the person giving birth, legally belongs to them. It is organ of their body, dependent on being inside their body in order to function, and is grown by their body. Birthrights recognises the reasons as to why a coroner would need to have custody of the placenta in order to carry out coronial enquiries and an investigation, and we suggest that on such a sensitive issue, informed consent becomes vital.

Trust in the coronial process and in local healthcare providers is far more likely to be sustainable if the human rights principles of dignity, bodily autonomy and informed consent are adhered to in respect of any decisions around what should happen to the placenta.

A woman or birthing parent is far more likely to wish to engage with a coronial enquiry and to support and trust the process, if the need for the coroner to have the placenta is explained in a careful and dignified manner and her informed consent sought for custody to be granted to the coroner.

Question 16: Do you agree that coroners should not have to obtain consent or permission from any third party in exercising their powers, except where existing rules already provide for such a requirement? Please give your reasons.

Yes.

Birthrights is strongly of the view that the consent of the bereaved parents must be sought before any inquest of a stillbirth.

Please see the reasons set out in our answer to question 10 above.

Question 17:

We have no views on this question.

Question 18: If you answered “no” to both parts of the question above, which group of stillbirths do you think should be investigated?

Birthrights submits that whichever stillbirths should be investigated outside of the internal NHS systems and HSIB, those investigations should be strongly guided by the intentions, needs and choices of the bereaved parents.

Question 19: Do you agree that coroners should investigate all full-term stillbirths (ie all stillbirths in scope) Or do you think that a further distinction could be made within this category?

No.

Birthrights is strongly of the view that the consent of the bereaved parents should be sought before any inquest of a stillbirth. (For the reasons set out in detail in our answer to question 10 above).

Birthrights envisages that it will be very difficult in some cases to determine whether or not a stillbirth was at “term”, given the challenges of accurately dating a pregnancy. Birthrights submits that families should not be subjected to an arbitrary cut off, which may contribute to them feeling neglected, abandoned and ignored by healthcare and justice services.

Birthrights submits that there should be some degree of flexibility around the phrase “37 weeks” and families who have a stillbirth that falls just outside of that time period, and who consent to an inquest, should have the opportunity to request that the time period be widened to include their stillbirth for exceptional reasons. This would be in keeping with the current civil procedure rules around limitation periods for bringing a claim. There are time limits given for each type of claim to be brought in UK civil procedure law but there is also a procedure for asking for claims to be brought which fall outside of limitation if there are exceptional circumstances.

Questions 20; 21 – 27 (IA):

We have no views on this question.

Question 28 (IA): What impact do you think coronial investigations of stillbirths will have on investigation of stillbirths undertaken: (a) locally; and (b) by the Healthcare Safety Investigation Branch (HSIB)? Will the current investigation of stillbirths continue independently of coronial investigations or will some current activity be displaced or otherwise impacted by coronial investigations of stillbirth?

This is a question for the Government to answer and it is disappointing to see that, a year after Birthrights first asked how the proposals for coroners to investigate stillbirths would interact with current and new investigatory systems, there remains no answer. The Government needs to resolve this fundamental issue as a matter of urgency and before implementing any new policy in this area.

Question 29 (IA): Do you think the proposals in chapters 1 – 6 may have any further impact on a group with a protected characteristic? If so, please explain what these impacts would be and which groups would be affected.

Again, this is a fundamental question and it is extremely disappointing to see that no equalities analysis has been carried out before these proposals have been put out to consultation. No further work should be done without this vital part of the impact analysis. Birthrights believes it is highly likely that there will be significant equalities impacts from these policy proposals. These include negative impacts on women from Black and Minority Ethnic groups, who are more likely to experience stillbirth.¹² We know that women facing the most complex multiple disadvantage include disproportionate numbers of women from these backgrounds as well as younger women.

¹² Draper, E, Gallimore, I, Kurinczuk, J, Smith, P, Boby, T, Smith, L & Manktelow, B (2018). *MBRRACE-UK Perinatal Mortality Surveillance Report, UK Perinatal Deaths for Births from January to December 2016*.

We know that they have worse experiences of maternity care¹³ including after stillbirth¹⁴ and often fear and distrust public services.¹⁵ We are very concerned that mandatory engagement with the coronial system – especially without adequate support – could increase the risk of fractured, distrustful relationships with public services and substantially increase the trauma of many families. Birthrights suggests the lack of legal aid support is likely to disproportionately impact these groups, and no mention has been made of language support for women and families who speak no or limited English at any stage. We also think it is likely that families from some religious backgrounds which urge burial as soon as possible are likely to be disproportionately impacted by proposals which will inevitably introduce (probably significant) delay before families can make funeral arrangements. The Government must carry out a full equalities impact assessment before any further work is undertaken.

¹³ McLeish, J and Redshaw M (2019). 'Maternity Experiences of mothers with multiple disadvantages in England: A qualitative study'. *Women and Birth*, 32(2),178-184; Birth Companions and the Revolving Doors Agency (2018). *Making Better Births a reality for women with multiple disadvantages*; Thomson, G and Balaam, M (2016). Birth Companions Research Project: Experiences and Birth Outcomes of Vulnerable Women. University of Central Lancashire; Redshaw, M and Henderson, J (2016). 'Who is actually asked about their mental health in pregnancy and the postnatal period? Findings from a national survey' *BMC Psychiatry*, 15(1), 322; Birthrights and Birth Companions (2019 forthcoming) '*Holding it all together: Rights issues experienced by women facing disadvantage during pregnancy, birth and postnatal care*'.

¹⁴ Redshaw, M and Henderson, J (2018). 'Care associated with stillbirth for the most disadvantaged women: A multi-method study of care in England' *Birth*, 45(3), 275-285.

¹⁵ Birth Companions and the Revolving Doors Agency (2018) *Making Better Births a reality for women with multiple disadvantages*. Available at: <http://www.revolving-doors.org.uk/file/2333/download?token=P2z9dlAR>