



death before birth

Report to the Human Tissue Authority on disposal of pregnancy remains (less than 24 weeks' gestational stage)

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Death before Birth: Understanding, informing and supporting the choices made by people who have experienced miscarriage, termination, and stillbirth

This page introduces the 'Death before Birth' (DBB) research project to provide context to this report. Further details of the project can be found at deathbeforebirthproject.org.

Project team

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Overall project aim

To examine the law surrounding the disposal of the remains of pregnancy and the ways in which it is interpreted, and to examine the narratives of women and those who support them, focusing on metaphor as a commonly-used resource for expressing the inexpressible.

Project objectives

The research undertaken for this report meets the following DBB project objectives:

- **Objective 1:** Determine the socio-medical and legal contexts within which decisions about the disposal of the remains of pregnancy following miscarriage, termination, and stillbirth are made.
(Objective to be met by performing a content analysis of trust and partner organisations' protocols)
- **Objective 2:** Investigate how professionals supporting women who have experienced pregnancy loss interpret 'Guidance on the disposal of pregnancy remains following pregnancy loss or termination' (Human Tissue Authority, 2015) and how this Guidance impacts on their work.
(Objective to be met through the use of semi-structured interviews)

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Foreword

Caroline Browne
Head of Regulation, Human Tissue Authority

During 2014, miscarriage and the disposal of fetal remains had been the subject of increased levels of media controversy and public scrutiny: there had been scandals regarding the disposal of fetal ashes by crematoria in Scotland and the disposal of fetal remains by hospitals across the UK, followed by a call for a change in the legal status of fetal remains.

It was the Channel 4 Dispatches programme aired in March 2014 that exposed the poor practices of some hospitals, which were routinely disposing of fetal remains by incineration without any reference to the wishes of the parents. A ministerial statement stating that incineration was not an acceptable method of disposal prompted the Chief Medical Officer to ask the Human Tissue Authority (HTA) to develop new national guidance and to consider how compliance with it might be monitored.

Although the treatment of fetal remains was a topic we had touched on in our guidance, for example in our code of practice on disposal, it was not something we had focused on before. So, our starting point was to identify an expert group¹ and explore with them some fundamental questions to determine a way forward. We asked:

- What do we mean by the terms ‘fetal remains’ and ‘products of conception’?
- Should products of conception and fetal remains be able to be incinerated? If so, are there ways in which incineration can be considered ‘sensitive’?
- Should the guidance apply equally to termination of pregnancy and miscarriage?
- Should large quantities of fetal remains be able to be cremated/buried together?

There were a number of points on which everyone agreed. Women define their pregnancy according to their own circumstances, values, understandings and beliefs. The group agreed that any attempt to categorise the pregnancy presents a risk that health professionals may view the pregnancy differently from the woman involved. Furthermore, if the mode of disposal were to be linked to types of pregnancy or pregnancy loss, some women may find themselves being denied certain choices.

We agreed that the woman should be central; there should be no distinction between fetal tissue and material where fetal tissue is not present; and the gestation of the pregnancy should not be a factor. We also agreed that the guidance should apply equally to miscarriage and termination of pregnancy.

There were two points on which there was disagreement: whether incineration should be permitted in any circumstance, and whether incineration could ever be considered to be ‘sensitive’. In the end, this conflict was impossible to resolve. We relied on the current legal framework, which is that, in law, pregnancy remains (including fetal tissue) of less than 24 weeks are part of the woman – so tissue from the living for the purposes of the HT Act and the Cremation

¹ The group included representatives from the Royal College of Nursing, Royal College of Obstetricians and Gynaecologists, Royal College of Midwives, Miscarriage Association, Sands, Institute of Cemetery & Crematorium Management and the British Pregnancy Advisory Service.

Regulations. Therefore, cremation of pregnancy remains was, and remains, at the discretion of crematoria.

The HTA Guidance places the woman at the centre; it applies regardless of gestational stage and whether or not there is discernible fetal tissue (hence the use of the term pregnancy remains throughout). It provides for three different modes of disposal, with cremation and burial as the default methods. However, because the woman, her needs, as well as her wishes, are central and the choices she is offered must be able to reflect her own individual circumstances, values and beliefs about her pregnancy, incineration remains an option where the woman herself chooses this, or where she leaves it up to the hospital, or cannot make a decision. In these cases, hospitals can set their own parameters for when incineration might be appropriate, for example giving consideration to the gestation of the pregnancy.

We published interim guidance in May 2014, which set out the direction of travel. Then, in the autumn of that year, we were approached by Dr Sheelagh McGuinness, who invited me to attend a meeting to discuss a research project that was in the early stages of development looking at death rituals for the unborn.

I attended the meeting happy to advise on the legal position and provide information about our guidance. However, listening to the discussion, I soon saw the potential for the project to include research that would be extremely valuable to the HTA in assessing whether our new guidance (i) was being implemented; (ii) was known about by women; (iii) was fit for purpose. I am grateful that the project team saw this too, and agreed to extend the scope of the project to include this new line of enquiry. A very fruitful and exciting collaboration resulted, with the HTA acting as a key project partner and committing to using the outcomes of the project to inform its policy and guidance on the disposal of pregnancy remains.

This report marks a key stage in this very important work: for the HTA because it provides the first reliable information we have about the take up of our guidance, and, I believe, for clinicians in this area, because it brings to the fore some important emerging themes about the current approach to the disposal of pregnancy remains and how we still haven't got it right:

- Whilst it is promising that 44 of the 81 responding NHS trusts with maternity services had revised or created new policies after the publication of the HTA's guidance, it appears that few hospitals are routinely offering all the options recommended, with most tending to offer information on one only (shared cremation being the most common). This is contrary to the guidance, which stresses the importance of choice, and, as noted in the report, is out of line with current thinking on consent for treatment, which is moving towards the idea of shared decision making and more active participation by patients in determining their options.
- There is unease in some quarters about incineration remaining an option for disposal. Of particular interest to the HTA is that it is not considered to be problematic for hospitals to provide fewer options than recommended in our guidance (i.e. by excluding incineration). This is an interesting point, which warrants careful consideration, particularly as the lack of availability of incineration may conflict with a woman's view about the status that her pregnancy remains should be accorded. In essence, the conviction held by some that a fetus is a potential human being and therefore comparable in status to a living person, may bring a hospital, or its staff, into potential conflict with women who would prefer

incineration to burial or cremation. Linked to this is the question of whether incineration can ever be considered capable of being made 'sensitive'.

- Midwives were most concerned about how conversations with parents are conducted – how the options are explained, the language used, and the information that is available for them to help them reach the decision that is right for them. This brings us back to the core aims of the project – to understand how language and metaphor are used by parents and how their care can be enhanced by the ability of clinicians, whatever their role, to listen and respond in an appropriate way.

The report contains a number of recommendations, all of which aim to provide further clarity for women. One, about the meaning of 'sensitive incineration' and its legitimacy as a mode of disposal, is for the HTA to consider and we will be doing just that.

In February 2018, month 18 of the project, the project team will host a conference to bring together academics and members of our user groups to discuss research, translation of findings, and future activities. In keeping with the aims of the project, a key feature will be a plenary panel discussion led by bereaved individuals.

In the meantime, the Ministry of Justice will continue to work on bringing pregnancy remains within the scope of the Cremation Regulations and we may be preparing to operate in a new regulatory landscape as far as the disposal of pregnancy remains is concerned. We will continue to work with the project team and partners in the months ahead to ensure that the care of any woman who suffers pregnancy loss, for whatever reason, places her views at the centre of the decision about the disposal of her pregnancy remains.

Report to the Human Tissue Authority on disposal of pregnancy remains (less than 24 weeks' gestational stage)

Executive summary

Report summary & objectives

This report provides an overview of preliminary findings from a research investigation into the extent to which the Human Tissue Authority Guidance (2015) has been incorporated into hospital policies for the management and disposal of the remains of pregnancy. The research also examined the extent to which those providing care to women – particularly, midwives working in hospitals and members of the funerary industry – were aware of the HTA Guidance, and considered whether or not they were incorporating it within their practice. The purpose of this report is to communicate the results of this research to the Human Tissue Authority with the aim of informing their future revisions to the HTA Guidance. However, the report will be of interest to other stakeholders involved in the disposal of the remains of pregnancy and in the support of those who experience pregnancy loss.

The research was conducted among trusts from across the four regions of NHS England. Three methods were employed: (1) examination of the HTA Guidance and guidance from other organisations to discern standards for disposal of pregnancy remains; (2) collection and analysis of a sample of trust documentation related to the care of women who had experienced miscarriage or termination for reasons of fetal anomaly (TOPFA); (3) qualitative interviewing of a small sample of bereavement care providers in hospitals within NHS England and professionals in the funerary industry in order to assess their perceptions of the HTA Guidance.

The research was conducted by academics from the Universities of Birmingham and Bristol as part of a larger project, 'Death before Birth', funded by the Economic and Social Research Council (UK) [see: deathbeforebirthproject.org].

Key findings*

- Generally, women are being offered some choice for disposal of pregnancy remains.
- Trust policy on disposal of remains of pregnancy is often unclear or internally inconsistent.

Key recommendation to HTA:

- There is confusion about what sensitive incineration means and whether it is a legitimate option for disposal of pregnancy remains. The Human Tissue Authority could provide a statement which clarifies the legitimacy of this disposal method.

Key general recommendations:

- That there be a move towards a standardised approach to provision of information about options for disposal of pregnancy remains. This could be achieved with specific patient information leaflets on disposal and standardised consent forms like those provided by Sands for post mortem. Such an approach could help ensure that women are being provided with a range of options for disposal of pregnancy remains.
- That consideration be given as to whether disposal of remains of pregnancy be integrated into miscarriage care pathway, potentially within the meaning of treatment and as such discussed as part of the consent process.

* The limited scale and parameters of the research mean that these findings should be treated as suggestive of more wide-spread policies and practice, but not as concrete evidence pertaining to *all* NHS England trusts or *all* bereavement care providers and funerary professionals.

I. Introduction

This report provides an overview of the findings for the first two work packages of the 'Death before Birth' project. Our primary aim was to examine the extent to which Human Tissue Authority Guidance on the disposal of pregnancy remains (2015) had been incorporated into hospital policies for management and disposal of pregnancy remains among trusts belonging to NHS England. We also wished to examine the extent to which those who were providing care to women were aware of the HTA Guidance and incorporated it into their practice.

To assess the minimum expectations for how remains of pregnancy should be treated/disposed of, we analysed the most recent versions of key guidance in this area. We then examined a sample of hospital trust documentation to find out whether hospital policies reflected expectations set out in the HTA Guidance. Finally, we interviewed a range of professionals working in this area to find out what their views were of practice and, specifically, the extent to which they were aware of official HTA Guidance.

Our analysis is focused on pregnancy loss that occurs prior to 24 weeks' gestation as different rules apply for stillbirth. Our investigation of hospital documentation focused on trusts within NHS England and did not take into account private health care providers (such as private hospitals or independent sector clinics).

Stage 1: Overview of key guidance on the disposal of pregnancy remains

As a starting point, we examined four guidance documents in order to assess current expectations for management and disposal of pregnancy remains. Our aim was to assess the extent to which the expectations set out in the Human Tissue Authority Guidance (2015) were reflected in updated codes of practice from other organisations.

The following documents were examined:

- 'Guidance on the disposal of pregnancy remains following pregnancy loss or termination' (Human Tissue Authority, 2015);
- 'Managing the Disposal of Pregnancy Remains: RCN Guidance for Nursing and Midwifery Practice' (Royal College of Nursing, 2015);
- 'The Sensitive Disposal of Fetal Remains: Policy and Guidance for Burial and Cremation Authorities and Companies' (Institute of Cemetery & Crematorium Management, 2015);
- Chapter 20: Funerals and Sensitive Disposal in *Pregnancy Loss and the Death of a Baby: Guidelines for Professionals* (4th Edition) (Stillbirth & Neonatal Death Charity, 2016).

Stage 2: Document sampling process

Initially, we created an online questionnaire² which was distributed to bereavement midwives in individual hospitals with maternity services. Hospitals were sampled purposefully to achieve geographical distribution across four NHS England regions and include a variety of types of hospitals (district, teaching, specialised, etc.).³ While distributing the questionnaire an effort was

² Online questionnaires included an option to upload electronic versions of trust policies or guidelines on the disposal of pregnancy remains. The invitations to the questionnaire in a form of a link were sent to bereavement midwives, however, on occasion, they were forwarded to somebody else within the hospital (research midwife, labour matron, gynaecology nurse, etc.).

³ Palinkas, L. A. *et al.* 2015. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health and Mental Health Services Research*, 42: 533-44.

made to include hospitals with A&E departments but no maternity services. Such hospitals tend to be found in cities where there is also a nearby hospital with maternity services, often a specialised women's hospital. However, staff contacted in these hospitals:

- a) insisted that women suspecting miscarriage would be more likely to go to nearby hospitals with maternity services; and
- b) reported no knowledge of existing policies for disposal of pregnancy remains.

As a result, hospitals with A&E departments but no maternity services were not included in the sample for questionnaire distribution.

The response rate was low (24 responses from 92 requests to complete). Given the unsatisfactory response rate⁴ we decided to submit Freedom of Information (FOI) requests to trusts. We submitted FOI requests to 105 trusts spread across all four NHS England regions. FOI responses included trust guidelines and policies, consent forms, and patient information leaflets (PILs). Trusts were sampled purposefully to accommodate the following criteria: provision of maternity services, variety of types of hospitals that provide maternity services (general, teaching, district, specialised), and geographical distribution across all four NHS England regions.

Between November 23rd 2016 and March 31st 2017 we received responses from 83 trusts, of which 5 reported that they had no maternity services.⁵ In addition to these 78 FOI responses we included documentation provided by 3 trusts in response to the questionnaire. This gave us a total sample of documentation from 81 trusts of which we closely analysed 54. The decision to focus more closely on a smaller subsample that reflected geographical distribution of all received documents was motivated by time constraints.

Of the documentation returned:

- 44 trusts had revised or created policies after the publication of the 2015 HTA Guidance;
- 22 made explicit mention of the HTA Guidance.

Documentation that does not take the HTA Guidance into account usually refers to one or more of the following as baseline for their policy:

- NICE. 2012. Clinical Guideline 154. Ectopic Pregnancy & Miscarriage;
- RCN. 2007. Sensitive disposal of all fetal remains;
- RCOG. 2005. Disposal following Pregnancy Loss before 24 Weeks of Gestation (Good Practice No. 5);
- Sands. 2007. Pregnancy loss and the death of a baby: Guidelines for professionals (3rd edition). London: Sands.

⁴ Many questionnaires were returned incomplete, the respondents frequently claimed inability to answer the questions regarding the policy for disposal of pregnancy losses. Few questionnaires were submitted with relevant trust policies or guidelines, which motivated a change in data collection strategy towards the FOI requests.

⁵ These trusts were contacted following details available on the NHS website in November 2016 stating that they have Maternity Services. These details proved out-of-date for these 5 trusts.

Breakdown of trust responses					
NHS England Region	South	London	Midlands & East	North	Total
Number of FOI responses from trusts with maternity services	22	12	20	24	78
Documentation returned with questionnaires	1	0	1	1	3
Analysed	13	7	13	21	54
Policy/guideline updated after 1 st of April 2015	13	6	11	14	44
Mention Human Tissue Authority Guidance (March, 2015)	8	3	4	7	22

Stage 3: Assessment of professionals' perceptions of HTA Guidance

Semi-structured interviews were conducted with:

- Bereavement care providers in hospitals within NHS England (8 bereavement midwives, 2 gynaecology nurses, 1 bereavement nurse, and 1 mortuary care manager);
- Professionals in the funerary industry (5 funeral directors, 8 bereavement service managers, and 2 officers at national funeral care institutions).

Interviewed professionals were employed in a range of roles that involved the responsibility for providing bereavement care following pregnancy loss. This demonstrated that there are many possible organisational strategies for offering such bereavement care within either healthcare or funerary settings. The sample of interviewees reflected the geographical subdivision of NHS England (North, Midlands and East, London, and South of England).

The interviews focused on two main themes:

- The provision of bereavement care to parents following pregnancy loss with a focus on the choices offered for sensitive disposal of pregnancy remains; and
- The levels of familiarity that the professionals had with the HTA 'Guidance on the disposal of pregnancy remains following pregnancy loss or termination' published in March 2015.

While the interviews produced rich and nuanced collections of data, patterns clearly emerged, as detailed below.

- **Knowledge of the HTA Guidance:** Relatively few interviewees had first-hand knowledge of the HTA 'Guidance on the disposal of pregnancy remains following pregnancy loss or termination'. Of those who were familiar with its contents, most were hospital staff members who participated in revising hospital policies, or professionals engaged in shaping industry policies. Many pointed to other hospital employees (such as mortuary managers) who could always be consulted when doubts arose regarding the permitted disposal methods.
- **Understanding of the HTA Guidance:** When the main points of the HTA Guidance were recapitulated to the interviewees, most hospital bereavement care workers

contended that their hospitals were already compliant with these recommendations, which in most cases signified offering some (rather than all) of the choices mentioned in the HTA Guidance [further details below].

- **Attitude to sensitive incineration:** Among the funerary industry professionals, there was a pronounced unease about the option of sensitive incineration being offered at all, although they were not averse to parents organising the disposal themselves.

II. Expectations for handling & disposing of pregnancy remains

The focus of our analysis here is on four guidance documents for disposal of pregnancy remains following miscarriage or termination of pregnancy prior to 24 weeks' gestation listed on page 7. We started with the Human Tissue Authority Guidance (2015) and then examined the extent to which the other documents reflected the expectations for disposal of remains set out in the Human Tissue Authority document.

What follows is a summary of four key expectations set out in the Human Tissue Authority Guidance (2015) on how pregnancy remains should be managed, the options that should be available to women, and how information should be communicated. Generally all of the other guidance reflected these standards with the exception of the ICCM approach to sensitive incineration.

1. Notwithstanding pregnancy tissue and fetal remains prior to 24 weeks' gestation being regarded legally as tissue of the pregnant woman, all guidance noted that there was good reason to have special procedures in place for handling and disposing of such material. The guidance variously noted that it was important that such material be disposed of 'sensitively' and 'with respect'.
2. All guidance emphasised the importance of good communication and provision of information to women regarding disposal options.⁶
3. With the exception of ICCM⁷, all Guidance emphasised the importance of women being made aware of the full range of options available for disposal of remains of pregnancy:
 - a. Hospital-arranged cremation [shared/individual];
 - b. Hospital-arranged burial [shared/individual];
 - c. Hospital-arranged incineration (HTA, 2015; RCN, 2015; Sands, 2016) ['sensitive', separate from other clinical waste];
 - d. Possibility for making private arrangements;
 - e. Burial outside a cemetery/burial ground [usually burial in private garden];
 - f. Knowledge of all options for disposal even if not locally available (RCN, 2015), understanding of all options (HTA, 2015).
4. Guidance also included recommendations about aspects of the service including:
 - a. Possibilities for parental attendance;
 - b. Whether ashes would be returned;
 - c. Costs.

⁶ Miscarriage Association has produced guidance for healthcare professionals on 'Talking about sensitive disposal of pregnancy remains: Caring for women and their partners experiencing pregnancy loss', www.miscarriageassociation.org.uk/for-health-professionals/learning/talking-about-the-sensitive-disposal-of-pregnancy-remains/ (Accessed May 3rd 2017).

⁷ The ICCM's 2015 guidance states that 'disposing of these babies [fetal remains] with clinical waste is now considered unacceptable' in 'The Sensitive Disposal of Fetal Remains: Policy and Guidance for Burial and Cremation Authorities and Companies', <http://www.iccm-uk.com/iccm/library/Fetal%20Remains%20Policy%20Updated%20Sept2015%20.pdf> (Accessed August 27th 2017). Incineration, according to HTA 2015 Guidance, was acceptable only when 'the woman makes no choice, or does not want to be involved in the decision, or does not express an opinion within the stated timescales'. All of the guidance emphasised that burial and cremation should be available '*regardless of whether or not there is discernible fetal tissue*' (our emphasis).

III. Findings

The findings presented here are based on:

- a. Detailed analysis of 54 sets of trust documentation (from across the NHS England regions);
- b. Preliminary analysis of the interviews detailed above.

It should be noted that most trusts submitted multiple policies with sections on the disposal of pregnancy remains, e.g. policies on different management of miscarriage, policies on termination of pregnancy, policies on management of pregnancy loss in labour ward, etc. These policies sometimes had different review dates, as a result of which they may have contained inconsistent information regarding the disposal of pregnancy remains. When calculating numbers of trusts where certain practice was found, consistent policies from one trust were counted as one while impossibility of finding an answer within submitted documents was counted as zero or 'unclear'. This has impacted the numerical values presented in this section insofar as they cannot be consistently represented as percentages. Instead, they represent an indication of intensity of a given practice.

(1) Interpretation of 'sensitive' and 'respectful' handling/disposing of fetal material

Documentation from every trust set out clear procedures for the handling and disposal of pregnancy remains. Remains were usually stored either individually or in individual compartments of a larger container. Clear procedures were outlined for labelling and recording where remains were kept and linking the remains to the woman; this included details such as specifications for the sorts of containers that were to be used and the rules on where the remains should be stored. Some policies also provided guidance on particular staff members accompanying remains to the mortuary and the final disposal site (if not on hospital grounds).

Quite often there was a linkage between 'sensitive' and 'respectful' disposal and a limitation on the range of choices available for disposal; most commonly this meant not offering incineration. Sensitive disposal of pregnancy remains under 24 weeks' gestation was often interpreted as providing a service similar to the disposal requirements for stillbirth (i.e. burial or cremation), including keeping a non-statutory register of funerals/services [see further on services in III.4].

(2) The importance of communication and information

Trust documentation emphasised the importance of responding to the needs of the woman who has experienced the pregnancy loss and being led by the woman's expectations of what should happen to the pregnancy remains. Generally, trust policies emphasised that, as far as is possible, the discussion of what happens to the remains should be responsive to the needs of the particular woman, and that the woman's final decision should be respected. This is best summarised in the following statement in the RCN Guidance:

The critical issue in supporting best practice is in respecting a woman's choice, based on the understanding that this is her pregnancy loss – regardless of the circumstances of that loss – and that she is best placed to determine how the remains should be managed.⁸

⁸ 'Managing the Disposal of Pregnancy Remains: RCN Guidance for Nursing and Midwifery Practice' (Royal College of Nursing, 2015) 5.

However, there is evidence to suggest that trust policies are also very much guided by the view, first expressed in Polkinghorne 'Review of the Guidance on the Research Use of Fetuses and Fetal Material', that:

On the basis of its potential to develop into a human being, a Fetus is entitled to respect, according it a status broadly comparable to that of a living person. Thus, the relevant categories of ethical significance are 'alive' and 'dead', and the category of 'pre-viable' used in the Peel Report, is not of ethical significance.⁹

This approach emphasises the importance of respectful treatment and handling of fetal tissue because the fetus is valuable in and of itself. In other words, the needs or views of the woman from whose body the tissue had come are not the only concern while providing care following pregnancy loss. Numerous trust policies evidenced a potential conflict between the default hospital approach to disposal and the views of a woman about what should happen to the pregnancy remains and the status that this material should be accorded.

Hospital staff that offer bereavement care following pregnancy loss agreed that being able to make choices is paramount to parents' regaining a sense of control after an unanticipated loss. However, there are numerous opportunities for parents to make choices outside of selecting the disposal method. As a result, availability of fewer choices for disposal than suggested by the HTA 2015 Guidance does not tend to be considered as a serious impediment in providing care following a pregnancy loss.

Consent process

The HTA, RCN, ICCM, and Sands all emphasised the importance of women being afforded the possibility not to have to make a decision about disposal. There was variation in how the trusts we examined dealt with this:

- No requirements to decide and no information on disposal provided;
- No requirement to make a decision but information on disposal provided;
- Some trust consent forms offered women the possibility to 'opt out' of making a decision about disposal (usually only for women undergoing termination of pregnancy).

In cases where the woman did not make a decision regarding the method of disposal and the trust had a provision for such a situation, communal cremation was the most frequent disposal method.

We also examined the documentation for details of the extent to which the consent process for histology and post mortem took disposal into account. Generally, these policies included details for disposal of pregnancy remains although there was variability about the extent to which disposal was specifically mentioned on the consent form. There was variation in practice as to what happened to any blocks, slides, or residual tissue samples. Approaches included: blocks and slides maintained as part of the woman's medical record, returned to woman/funeral director for burial or cremation¹⁰, sensitive incineration.

⁹ 'Review of the Guidance on the Research Use of Fetuses and Fetal Material' (HMSO, London, 1989) 20. The Polkinghorne report is explicitly mentioned in the RCN Guidance, 2007. This could account for why this approach is reflected in trust policies.

¹⁰ See further the Institute of Cemetery & Crematorium Management's 2009 guidance 'The Disposal of Body Parts (Blocks and Slides)': 'Cremation of samples is only acceptable where the samples in question relate to one deceased

Record keeping

All the trusts analysed had clear procedures in place for recording what happened to the remains. The importance of documentation and record-keeping was emphasised in case the woman later changed her mind about not wanting to know what happened to the remains.

Patient information leaflets (PILs)

Pregnancy losses may occur in a number of different settings both within and outside of hospitals. The lack of information provided in the PILs meant it was difficult to evaluate the level of information and support being offered to women. For example, of the trust documentation we examined, only one trust included specific information for ambulance staff about what should happen to pregnancy remains.

Within hospitals pregnancy loss may occur in A&Es, Early Pregnancy Units (EPUs) within Gynaecology, and Labour Wards in Maternity Services. None of the interviewees had in-depth knowledge of A&E procedures for miscarriage. EPUs do not always have designated bereavement staff; many gynaecology nurses are aware of the need for sensitive communication and appropriate bereavement care, although the issue of sensitive disposal was rarely foregrounded by the interviewees.

The lack of information in the patient information leaflets meant it was also unclear what advice was being offered to women who miscarried at home or returned home to miscarry. The documentation provided in response to the FOI did not always provide information on the guidance given to women who are miscarrying outside of a hospital setting. However, where this was mentioned we found that documentation suggested that the following advice should be offered to women in this situation who contacted the hospital:

- 8 trusts provided the option of bringing the remains to hospital for disposal;
- 3 trusts recommended the remains be disposed of in the toilet; two specifically advised that remains be 'flushed down the toilet'.

NICE recommends expectant management of miscarriage as a first-line management strategy for early losses.¹¹ This means that more women miscarry at home than in hospital, which is why providing them with clear information on the disposal options is of crucial importance for their care. **It would therefore be worthwhile to consider including disposal of pregnancy remains as part of treatment within NICE guidelines.** The absence of clear action-guiding trust policies places a burden on staff and could mean that women are not being given appropriate care and support.

individual, and it is the desire of the relatives of the deceased that the samples are cremated. The cremation of such samples may only take place in accordance with the Cremation Regulations 2008. The cost of carrying out such cremations should be determined locally. Consideration must be given to the handling of glass residues after cremation, and the use of trays is recommended. It is also advisable to consult with cremator manufacturers to ensure the cremations are carried out in the most safe and environmentally friendly way. Bulk cremation of samples is not acceptable. It should be made clear to hospital authorities that crematoria cannot accept samples in bulk, and that samples can only be accepted for cremation in accordance with the Cremation Regulations 2008 and subject to the above guidance.' <http://www.iccm-uk.com/iccm/library/BodyPartsPolicy.pdf> (Accessed August 29th 2017).

¹¹ See 'Ectopic pregnancy and miscarriage: Diagnosis and initial management in early pregnancy of ectopic pregnancy and miscarriage', <https://www.nice.org.uk/guidance/cg154/evidence/full-guideline-pdf-188402077> (NICE 2012) (Accessed August 29th 2017).

Furthermore, given how many early pregnancy losses are confirmed in emergency departments and Early Pregnancy Units, including pregnancy loss bereavement care pathways in the policies and guidelines of these departments could contribute to improving the quality of care beyond strictly clinical procedures.

(3) Options available for disposal of remains of pregnancy

Hospital-arranged disposal

Shared cremation was the most common method for disposal of pregnancy remains. Many hospitals confined individual cremation to later gestational stages or to situations where the parents requested an individual cremation. Similarly, the default approach to burial tended to be shared burial at earlier gestational stages.

Availability of cremation and burial by trusts				
	Routinely available	Exceptionally available	Not available	Unclear
Cremation	48	3*	3	–
Burial	25	18*	9	2

*Exceptions include: at cost; for cultural or religious reasons; for recurrent miscarriage; if parents have a burial plot already; later gestational stages.

Availability of incineration by trusts				
	Available	Explicitly 'no incineration'	Not mentioned	Unclear
Incineration	15	12	26	1

Incineration, where available, was generally only allowed in particular circumstances such as pregnancy losses that occurred at early gestational stages or where there were no identifiable fetal remains; for terminations of pregnancy (for non-medical reasons); in situations where the woman did not want to make a decision; or for disposal of any tissue and organs remaining following histology and post mortem.

Most of the trust documentation analysed evidenced *some* choice being offered although overwhelmingly not to the extent advocated in the official HTA Guidance. It was possible to find the following patterns:

- Women were not explicitly offered information on *all* potential hospital-arranged options (i.e. cremation, burial, incineration);
- Trusts tended to offer explicit information on one option for disposal (usually shared cremation);
- Often patients were advised to speak with a member of staff if they did not wish this form of disposal to take place. What advice they were offered at this point is unclear [see discussion regarding action-guiding trust policies];
- Some trusts provided information about other options available locally 'if requested' by the patient (although generally not incineration);
- Very few trusts provided information on options that were not available locally;

- There was inconsistency both within and between the trusts examined on how information was provided; PILs did not generally contain information on disposal;
- Trust policies were often internally inconsistent about the range of available options for disposal.

The lack of information of available options runs counter not just to the expectations from national Guidance set out in Section II. It also potentially runs counter to the Supreme Court decision in *Montgomery v Lanarkshire Health Board*.¹² The judgment in this case emphasised the importance of patients being made aware of *all* treatment options available to them. However, this raises a question of the extent to which disposal should be considered part of the treatment process. It could be argued that choice of the disposal option belongs to the part of care pathway as it may affect the woman's wellbeing following pregnancy loss. Furthermore, framing disposal as a part of care would impact the possibility of including information about all forms of disposal within a standardised bereavement care pathway.

Cremation/burial

There was variation in whether hospital-arranged cremation included both shared and individual options. The latter was most often offered for later gestations, where there were identifiable fetal remains, or where there were cultural/religious expectations. Burial was offered less often, with a similarly diverse range of options including shared/individual burial, limitations on gravestones, variation in costs. Most of the NHS professionals interviewed worked at hospitals that offered a choice of either cremation or burial although there were instances where trusts would only cover the cost of one particular disposal method [see further on costs in section III.4].

Sensitive incineration

Some trusts do not offer sensitive incineration for pregnancy losses (n=12); where this was available it was almost always limited to specific circumstances (e.g. earlier in pregnancy, where there was no identifiable fetal tissue, or only for tissue samples remaining following histology or post mortem, on request, or where a woman did not want to decide on the disposal method).

This evidences a clear gap between about the day-to-day reality of trust practices and the expectations contained in the HTA Guidance (2015), the RCN Guidance (2015), and Sands Guidance (2016) that women be provided with information on *all* disposal options. It may be that incineration is generally felt to be an inappropriate way of disposing of fetal remains (e.g. documentation suggested that incineration was incompatible with treating fetal remains with dignity). The lack of availability of sensitive incineration is particularly problematic where it may conflict with the view of the woman about the status that the fetal material should be accorded.¹³

Many hospitals do not have an incinerator on site, and thus supervising the sensitivity of the procedure conducted off-site is hindered. Following a number of controversies in the last two

¹² [2015] UKSC 11.

¹³ 'Guidance on the disposal of pregnancy remains following pregnancy loss or termination' (Human Tissue Authority, 2015) 7. Documentation on termination for non-medical reasons did not fall within the remit of our FOI request; however, in the documentation returned it is clear that several trusts (n=9) operate a policy of solely offering cremation or burial for remains in this situation. See also section III.4 on details of the services which may often accompany these burials/cremations.

decades, there is also a general perception of incineration as a socially unacceptable method of disposing of fetal remains. Some hospital staff interviewed expressed discomfort about discussing sensitive incineration as an option of disposal following pregnancy loss, instead calling it 'hospital cremation', which highlights the difficulties of clear, unbiased communication following pregnancy loss. Many staff are unable or unwilling to explain the difference between sensitive incineration and cremation to grieving parents, especially when there are many other questions that require parental decisions (e.g. histopathology/post mortem, memory-making, etc.).

Numerous interviewees have suggested that cremation, either shared or individual, at a local crematorium may often be an option that is likely to be deemed (by parents and general public) as more dignified (and therefore superior) to sensitive incineration. It was clear from the interviews with people in the funerary industry that sensitive incineration was not considered a desirable disposal method for pregnancy remains, unlike either cremation or burial. Many interviewees mentioned recent scandals revealing that fetuses from early pregnancy losses were incinerated despite parents being informed that they would be cremated. When referring to these events, the emphasis was often placed on the fact of incineration as an inappropriate disposal method rather than the parents having been misinformed, which further highlights a generally unfavourable attitude to this option of disposal. Such an attitude was generally more pronounced among funerary industry employees than among NHS staff.

Another possible explanation for the limited number of trusts where incineration was offered is the statement in the 2015 HTA Guidance that '[c]remation and burial should always be available options for the disposal of pregnancy remains, *regardless of whether or not there is discernible fetal tissue*.'¹⁴ The FOI request we sent included a question about any changes in the policy for the disposal of pregnancy remains after the publication of the HTA 2015 Guidance.

- N=4 trusts previously offered incineration for products of conception or where there was no identifiable fetal tissue;
- N=1 trust responded that 'work is underway to seek ways of providing cremation to all pregnancy tissue'.

In other words, despite the explicit permission in HTA Guidance to offer sensitive incineration as a legitimate method of the disposal of pregnancy remains, some trusts misinterpreted this point.

Private arrangements

All the trusts examined acknowledged the possibility for private arrangements to be made. However, there was variation in the level of information and support offered to those who chose to arrange their own disposal process. As mentioned above, options for disposal were not always included in PILs; this means it is impossible to tell from documentary analysis alone the extent of the information being provided to patients.

Home burial

On the basis of the documentation provided there was some uncertainty over the facilitation of home burial. Approximately half of the trusts examined provided explicit information on requirements for home burial, however, there was reticence amongst a minority of trusts about the practice.

¹⁴ 'Guidance on the disposal of pregnancy remains following pregnancy loss or termination' (Human Tissue Authority, 2015) 5.

- N=26: provided explicit information on home burial; of these:
 - N=1: provided information on home burial for early losses but prohibited it for later losses
 - N=2: provided such information on request only and advised staff not to make 'unsolicited offers' to take the remains away
- N=4: had policies which discouraged or prohibited home burial/bringing the remains home;
- N=24: provided either no information on home burial or unclear documentation;
- One trust in our sample reported it returned remains 'impregnated with seeds' to facilitate home burial. There was no mention that seeds would be added to the remains on the patient information leaflet.

Timelines

As mentioned in Section II, the HTA recommends that trusts provide clear timelines for when decisions should be made regarding disposal of pregnancy remains. The HTA suggests an upper limit for storage of 12 weeks, after which time the trust should dispose of remains in accordance with its default policy. Information about both timelines and default disposal method should be provided to women.

Where detailed, there was variation in the timescale allowed for women to make a decision regarding disposal. Twenty-nine of the trusts clearly outlined timescales within which decisions should be made regarding disposal (a minimum of 10 days/ a maximum of 3 months); these trusts also provided information on what would happen to the remains in the absence of consent.

Analysis of the documentation from 25 trusts did not provide any information on timescales or on what would happen to the remains in the absence of consent. Some of the documentation analysed seemed to mandate that a decision be made by the woman. In practice, according to the interviewees, very few parents do not make this decision, which may suggest that this provision has relatively little bearing on trust practices.

(4) Disposal arrangements

There was variation across the trusts examined regarding the manner in which cremation/burial was conducted. Most funeral directors and bereavement service managers interviewed agreed that all pregnancy losses, irrespective of the stage of gestation, deserve the same care and dignity as the remains of a person who has lived and died. As such, cremation/burial was often accompanied by a funeral-like service.

The services offered (both as outlined in the documentary analysis and as described by those interviewed) shared the following aspects:

- Pregnancy remains in coffins or coffin-like containers would be transported to the cemetery or crematorium chapel in an appropriate vehicle, either by a funeral director or a designated member of the bereavement team;
- Irrespective of whether bereaved families were present, a short service would be held, often with a piece of music and/or a few words from the funeral director or a member of the chaplaincy team;

- Often services would have explicitly religious overtones (e.g. services described included blessings, Bible readings, and/or prayers);
- The coffin(s) would be placed on the catafalque during the service, followed by an act of committal (closing of the curtain around the coffin(s) or slight lowering of the coffin(s) into the catafalque);
- The funeral services, especially those unattended by parents, would usually be short, in some cases less than 5 minutes' duration.

For non-viable fetuses (NVFs) a non-statutory register would be kept, not infrequently in perpetuity; often this non-statutory register only contains case numbers and dates of funerals rather than identifiable information (these case numbers can be matched with information held by the trust although for a limited time [25-50 years], as trusts are not required to maintain patient records indefinitely).

Parental attendance at burial/cremation

A key difference between these services and those for a previously living person was that parents were not always able to attend the actual cremation or burial service, particularly if this was a shared cremation or burial. Many of the trusts examined held general services of remembrance on a monthly, biannual, or annual basis. However, there was much more variation in whether parents could attend the actual cremation or burial:

- N=18: parental attendance allowed for *all* cremations/burial (regardless of whether shared or individual);
- N=11: parental attendance allowed in certain circumstances*;
- N=5: parental attendance not allowed at all;
- N=20: unclear based on the information provided.

*E.g. for later gestational stages only, for individual cremations or burials but not shared cremations or burials, attendance allowed for burial or cremation but not both, attendance allowed only at certain locations.

Some trusts provided parents with information on where and when the cremation/burial would take place even if they did not facilitate attendance.

Ashes

The ICCM recommends that 'hospital[s] must inform parent(s) that on occasion, ashes might not be recovered from individual cremation' and that 'hospital[s] must inform parents that ashes from shared cremations, where a number of babies are placed in a single container are not individually identifiable and that they will be scattered or buried within the garden of remembrance with their location being registered'.¹⁵ Analysis of the documents provided by trusts evidenced variation in practice. To the extent that these expectations were met, we found:

- N=16: offered ashes where available from both shared and individual cremations;
- N=6: offered ashes for individual cremations only but offered information about what would happen to ashes from shared cremations~;

¹⁵ 'The Sensitive Disposal of Fetal Remains: Policy and Guidance for Burial and Cremation Authorities and Companies' (Institute of Cemetery & Crematorium Management, 2015) 6.

- N=6: stated that no ashes were offered (from either individual or shared cremation) with no further information;
- N=5: offered no ashes but provided information about what would happen to ashes from cremations~;
- N=18: did not mention ashes in their documentation;
- N=3: did not provide cremation as a disposal option.

~Usually the location where the ashes would be scattered or buried.

Interviews with bereavement services managers and crematorium managers clearly demonstrated that producing no ashes, even after individual cremations of an early-stage pregnancy loss, occurs very infrequently. Although at times the amount of ashes recovered is very small, a skilled cremator operator is almost invariably able to produce them. When asked about the pattern of informing parents of the impossibility of recovering ashes, the interviewees tended to explain that it usually resulted from an unwillingness or fear to disappoint parents in cases where an error had been made by the cremator operator leading to a lack of ashes.

Costs

It was unclear how costs were being met within the majority of the trusts examined. The following is a breakdown of the information that could be garnered from the trust documentation provided:

- N=26: hospital covered the cost of at least the default disposal option;
- N=1: hospital covered the costs for earlier stage losses but applied a charge for disposal of later stage losses;
- N= 20: provided no information on costs;
- N=7: other*.

*Other here includes: costs covered by donations; through a charitable organisation; where crematoria do not charge.

Generally group or individual cremation (depending on gestational stage) was the default option identified in the documentation. Crematoria often do not charge for disposal of NVFs although there may be a charge for collection of ashes. Burial was usually mentioned as incurring a cost either to the hospital or to the parents.

IV. Best practice

Our research has highlighted that the extent of compliance with the HTA Guidance is variable but the review of trust documentation did illustrate examples of best practice. This section draws together those examples, taken from different trusts within NHS England, which could be used to inform the drafting of standardised documentation to assist in compliance.

Our analysis of documents provided by trusts as well as interviews with professionals who care for people who have experienced pregnancy loss indicated a need for a more standardised bereavement care pathway.

(1) Best practice

The following key elements of best practice are detailed in the HTA Guidance:

1. All staff involved in discussing disposal of pregnancy remains should be aware of trust policies and able to discuss the different options, including their practical aspects.
2. All trusts should advise women of the options of cremation, burial, sensitive incineration, or making their own arrangements. Where a hospital cannot provide a particular option, they should still advise women of that option and who they can approach if that is their disposal method of choice.
3. Trusts should be explicit as to whether hospital-arranged cremations or burials are shared or individual. If shared, they should advise women of their options if they would prefer an individual cremation or burial.
4. Policies should be sensitive to different beliefs, cultures, values, and religions.
5. Women should be provided with written and verbal information on disposal options, including what happens if the woman does not wish to make a choice, or no choice is made within a maximum of 12 weeks. This information should include details of who to contact if a particular method of disposal is desired by the woman.
6. Trusts should record the decision made, how, when, and where the remains were disposed, or (if the remains were collected) the date of collection.
7. Remains for disposal should be sealed in individual containers or packages with identification labels. Remains for sensitive incineration should be stored and incinerated separately to clinical waste.

(2) Staff awareness

Policies

Many different staff across a range of Hospital departments may be involved in advising women about the disposal of pregnancy remains. This may include temporary staff employed to cover staff shortages. Where trusts have policies covering disposal of pregnancy remains that vary across departments due to e.g. different review dates, confusion is possible, particularly amongst temporary staff or those dealing less frequently with pregnancy loss. Some trusts avoid this by employing one policy covering all circumstances of miscarriage and termination of pregnancy as well as options for disposal. One of these policies also cross-referenced relevant information leaflets, forms for completion etc., and included them as appendices so they could be readily available. The policy made use of a contents page at the front of the document to allow particular information to be easily located.

Staff

One trust dealt with pregnancy loss and disposal primarily in its gynaecology department. Therefore, whilst its policy on disposal of pregnancy remains applied to all staff, it stipulated that advice should be sought from the gynaecology department in the first instance. This is good practice as it ensures that, where possible, staff frequently involved in discussing disposal options will be involved and can fill in gaps in knowledge of those less frequently engaged in doing so.

(3) Information about disposal options

Provision of written information to patients is usually by way of patient information leaflets. Some trusts utilised different leaflets according to the circumstances of the loss, for example distinguishing between those who miscarry and those who have a termination of pregnancy. There were also examples of trusts dealing with disposal options in a separate leaflet to that dealing the medical management of the pregnancy loss, respecting the woman's right to choose whether she receives this information or not.

Best practice ensured that information given to women about disposal options included all options referred to in the HTA Guidance and matched that set out in the trust's disposal of pregnancy remains policy. Where trusts were not able to offer a particular option, they detailed where that option could be sought. Contact details were also provided for particular options. Best practice included setting out within the leaflet the timescales for making a decision and what would happen in the event of no decision being made. Some leaflets were also clear about whether the hospital or the woman would have to bear the cost of a particular disposal method.

Women miscarrying at home are often excluded from the disposal options available to those who miscarry within a hospital setting. A limited number of trusts stated explicitly that women should be advised to bring the remains to the hospital if they wished for the hospital to arrange disposal for them.

One trust had a patient information leaflet for those terminating their pregnancy and offered the same disposal options for those losing their pregnancy in some other way, including the option not to be involved.

One trust complied with the need for sensitivity to different cultural values and religious beliefs by requiring staff to check people's religious or cultural beliefs, instead of making assumptions as to what did or did not apply. Other trusts complied with this by offering exceptions to their default arrangements if, for example, a religion required a particular form of disposal (e.g. individual burial).

(4) Recording information

Consent forms

Many trusts use consent forms as a method of recording the woman's decision about disposal. Examples of best practice included consent forms which detailed what written information had been given to the patient about disposal, with one trust requiring this information be given and

the woman given time to read it before making a decision. The same trust indicated that consent should be sought in a quiet place.

Consent forms conforming with best practice listed all options for disposal, including contact details for particular methods and alternatives not offered by the hospital (for instance, the option to make individual arrangements). Other examples of best practice included giving women the option to attend the funeral service or not, or to be notified of the date of the service if they wished. Where the burial plot was shared, one trust's consent form was explicit about the implications of this in relation to the ability to place markers on the grave etc.

Several trusts provided space on the consent form to record that the woman had either not made a decision or did not want to discuss disposal, and included timeframes within which a decision must be made and how disposal would take place if no decision was made within that timeframe.

Another example of best practice was a trust that gave women electing a hospital-arranged disposal a 'cooling off' period of 4 weeks within which they could contact the hospital if they changed their mind about the method of disposal.

Checklists

Some trusts utilised checklists to be completed and stored in the woman's records confirming what information (written and verbal) about disposal options had been given, what decision had been made, what forms had been completed and tracking the storage and disposal of remains.

Storage of remains

One trust had a document setting out different protocols for storage and transfer of remains according to the method of disposal chosen, whether histological or post mortem examination was to be carried out and the location of the pregnancy loss. These protocols complied with the HTA Guidance and were indexed so information could be easily found.

V. Conclusion & recommendations

From the analysis we have undertaken it is clear that there is a range of good – and improving – practice, with regard to management and disposal of remains of pregnancy. However, it is also clear that there is variation in practice across England and indeed within trusts. It was difficult to draw firm data from the information provided because hospital trust policy was often internally incoherent. This usually resulted from different aspects of trust policy being updated at different times and/or consent forms and PILs being updated on an ad-hoc basis and not in conjunction with the policy to which they relate.

Our main findings are as follows:

- Women are being offered some choices, but not all, with regard to disposal of remains;
- There is inconsistency in terms of the range of information and support being offered to women;
- PILs often do not contain information about management and disposal of remains which means that the level of care and information a woman receives is dependent on those caring for her;
- It is not clear whether disposal of remains of pregnancy is discussed as part of the consent to treatment process, i.e. that women are made aware that their options for disposal might be shaped by the approach to treatment chosen.

Many trusts offering fewer choices than recommended in the HTA 2015 Guidance interpreted their policies on the disposal of pregnancy remains as compliant with the Guidance. This evidences some ambiguity in how key aspects of the HTA Guidance could be interpreted.

Recommendations:

- That there be a move towards a standardised approach to provision of information about options for disposal of pregnancy remains. This could be achieved with specific patient information leaflets on disposal and standardised consent forms like those provided by Sands for post mortem. Such an approach could help ensure that women are being provided with a range of options for disposal of pregnancy remains.¹⁶
- There is confusion about what sensitive incineration means and whether it is a legitimate option for disposal of pregnancy remains. The Human Tissue Authority could provide a statement which clarifies the legitimacy of this disposal method.

Possible actions:

- Trusts review their guidance to ensure that women are provided with information about all disposal options.
- PILs about miscarriage contain clearer information about options for disposal of pregnancy remains or trusts use a separate PIL that specifically details options for disposal.
- Trusts and crematoria review their policies on parental attendance at services to ensure that attendance is facilitated as far as is possible.
- Trusts provide clearer guidance on the advice that should be offered to women who miscarry outside of the hospital setting regarding options for disposal of pregnancy remains.

¹⁶ The development of a National Bereavement Care Pathway will be an important contribution to achieving this. www.sands.org.uk/professionals/projects-improve-bereavement-care/national-bereavement-care-pathway (Accessed May 3rd 2017).

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