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Availability of Less Invasive Prenatal, Perinatal and Paediatric Autopsy will Improve Uptake Rates; A Mixed Methods Study with Bereaved Parents

Celine Lewis,[1,2] Megan Riddington,[3] Melissa Hill,[1,2] Owen J Arthurs,[4] John C Hutchinson,[5] Lyn S Chitty,[1,2] Charlotte Bevan,[6] Jane Fisher,[7] Jenny Ward,[8] Neil J Sebire[5,9]*

[1] North East Thames Regional Genetics Service, Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK.

[2] Genetics and Genomic Medicine, The UCL Great Ormond Street Institute of Child Health, London, UK.

[3] Department of Psychological Services, Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK.

[4]Department of Radiology, Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK.

[5] Department of Histopathology, Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK.

[6] Stillbirth and neonatal death charity (Sands), London, UK.

[7] Antenatal Results and Choices (ARC), London, UK.

[8] The Lullaby Trust, London, UK.

[9]The UCL Great Ormond Street Institute of Child Health, London, UK.

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Running title: Parental uptake of less invasive autopsy

*Corresponding author:

Professor Neil Sebire: neil.sebire@gosh.nhs.uk

Department of Paediatric Pathology, Camelia Botnar Laboratories, Great Ormond Street Hospital, London WC1N 3JH.

Tel: 0207 829 8663

Abstract

Objective: To investigate whether less invasive methods of autopsy would be acceptable to bereaved parents and likely to increase uptake.

Design: Mixed methods study.

Setting: Bereaved parents recruited prospectively across seven hospitals in England and retrospectively through four parent support organisations.

Sample: 859 surveys and 20 interviews with bereaved parents.

Methods: Cross-sectional survey and qualitative semi-structured telephone interviews.

Main Outcome Measures: Likely uptake, preferences, factors impacting decision-making, views on different autopsy methods.

Results: Overall, 90.5% of participants indicated they would consent to some form of less invasive autopsy (either minimally invasive autopsy (MIA), non-invasive autopsy (NIA) or both). 53.8% would consent to standard autopsy, 74.3% to MIA and 77.3% to NIA. Regarding parental preferences, 45.5% preferred MIA, 30.8% preferred NIA and 14.3% preferred standard autopsy. Participants who indicated they would decline standard autopsy but would consent to a less invasive option were significantly more likely to have a lower

educational level (OR: 0.49; 95% CI: 0.35-0.70; p=0.000062). Qualitative findings suggest parents value NIA because of the lack of any incision and MIA is considered a good compromise as it enables tissue sampling whilst easing the parental burden associated with consenting to standard autopsy.

Conclusion: Less invasive methods of autopsy are acceptable alternatives for bereaved parents, and if offered, are likely to increase uptake and improve parental experience. Further health economic, validation and implementation studies are now required to assess the viability of offering these in routine widespread clinical care.

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Keywords: autopsy, post-mortem, less invasive, fetal, perinatal, prenatal, consent, preference, uptake.

Tweetable Abstract: Mixed-methods UK study finds less invasive methods of autopsy are acceptable alternatives for bereaved parents, and if offered, are likely to increase uptake and improve parental experience.

Introduction

Consent rates for autopsy in the prenatal, perinatal and paediatric setting have dropped significantly in the United Kingdom (UK) [1-3] Western Europe [4, 5] and the USA [6, 7] in the past 30 years. This is despite evidence that autopsy helps to establish the cause of death and can provide additional clinically significant information and influence future pregnancy management in 30–40% of cases.[8, 9]

Dislike of the invasiveness of the procedure, desire to protect the baby or child from harm and religious objections have all been identified as parental barriers to standard autopsy.[10] In order to address these concerns and improve uptake rates, a number of less invasive techniques have been developed and evaluated recently.[11] A large prospective trial reported that MRI based imaging techniques along with other ancillary investigations (non-invasive autopsy or 'NIA') had around 95% concordance for major diagnoses with conventional autopsy for fetuses, but was less accurate for newborns and children (85% and 54% respectively).[12] MRI combined with targeted laparoscopic examination and biopsy of visceral organs (minimally invasive autopsy or 'MIA') may be an alternative as it combines the advantages of both imaging and tissue sampling, and it has been estimated that >90% of significant histology findings from standard perinatal autopsies could be detected using a minimally invasive approach, although further evaluation is required.[13]

To date, only a few small studies have been conducted in high-income countries (UK and Belgium) to assess attitudes of bereaved parents [14-16] towards less invasive autopsy, with findings suggesting a potential increase in uptake (18%-99%). Research on the hypothetical acceptability of MIA has also been conducted in low- and middle-income including countries in Africa and Asia, where acceptability of MIA on a relative was 73%.[17] Successful implementation of less invasive methods will require evaluation to assess performance and acceptability amongst key stakeholders. The aim of this study was to answer the question "are less invasive methods of autopsy acceptable to bereaved parents, likely to increase uptake and if so, by how much?"

Methods

This study was funded through an NIHR HTA project (14/168/06) and approved by London-Bloomsbury Research Ethics Committee (16/LO/0248). The funder played no role in conducting the research or writing the paper. Further detail about study methods are provided (Appendix S1). There was no core outcome set for the study.

Parent involvement

The aim of parent and public involvement in the study was to ensure the research aims were parent focused and credible, ensure the study materials were acceptable to the target audience, and offer personal insight to help interpret the study findings. Bereaved parents and parent advocates from support organisations were involved as co-applicants in the funding application and took part in the initial design of the study including the recruitment strategy. They were also involved in the development of the research as co-producers of the survey, interview guide and participant information sheet. Parent advocates were on the study steering committee which monitored the study progress and interpreted the data. In May 2018 we held a dissemination meeting which was attended by parent advocates to present the findings and check the validity and interpretation of the data.

Study setting

Participants were recruited 1. retrospectively through four parent support groups and 2. prospectively through seven hospitals across England.

Study design

This was a mixed-methods study comprising 1) a cross-sectional survey with bereaved parents, and 2) qualitative telephone interviews with survey responders.

1. Cross-sectional survey with bereaved parents

The survey (Appendix S2) was developed specifically for this study and co-designed with an advisory team comprising a clinical psychologist, pathologist, radiologist, fetal medicine consultant, genetic counsellor, social scientist, parent advocates and three bereaved parents who had imput into the questions and wording used to describe the three methods of autopsy. We also drew on a survey developed by Breeze et al. [16] exploring parental views towards autopsy and a systematic review on factors associated with uptake [10]. The survey was made available online (Survey Monkey Inc, Palo Alto, California, USA) as well as in paper format. At the end of the survey participants could either remain anonymous or provide contact details if they wished to take part in an interview.

2) Semi-structured telephone interviews with survey responders

A topic guide (Appendix S3) was co-designed with input from the advisory team, the aim of which was to explore the findings from the quantitative survey in more depth. The topic guide explored: parents' experience of being approached about standard autopsy (for those for whom a coronial autopsy was not required) including reasons for accepting or declining; their views towards NIA and MIA including perceived advantages and potential concerns or limitations of the procedure; and their preference for standard autopsy, MIA, NIA or no autopsy including the reasoning behind their preference. The same descriptions of autopsy

used in the survey were given during interviews. Interviews were digitally recorded and transcribed verbatim.

Recruitment

We recruited participants both retrospectively and prospectively to address a potential bias that bereaved parents from support organisations have differing views to bereaved parents from the general population.

Retrospective recruitment

Bereaved parents were recruited retrospectively through UK support organisations between June-September 2016. Anyone who had experienced the pregnancy loss (either through miscarriage, termination of pregnancy for a fetal anomaly or stillbirth), or a neonatal or infant death was eligible to take part irrespective of whether they had been offered an autopsy or an autopsy was requested by the Coroner's office. No time limit was set on how long ago the loss occurred.

Prospective recruitment

Between September 2016 and December 2017 (study end date) we prospectively recruited bereaved parents who were ≥18 years of age and had experienced a loss (as above). . Participants were recruited by a member of the healthcare team (e.g. obstetrician, bereavement midwife, intensive care consultant) following discussion of autopsy examination, irrespective of whether they consented or declined. In February 2017 the protocol was amended to include bereaved parents who had not been offered the option of an autopsy examination.

2) Semi-structured telephone interviews with survey responders

A sub-set of survey responders who had indicated their willingness to take part in an interview, were purposively sampled to ensure a range of demographics and preferences towards types of autopsy. Potential participants were contacted by email or telephone and invited to take part in a telephone interview. Interviews were conducted by either MR or CL between November 2016 and May 2017.

Data Analysis

For the quantitative survey data, frequencies were used to summarise the findings around acceptability, likely uptake, preferences and decision-making factors. A Chi-squared test and independent samples t-test was used to determine significant associations between variables. A McNemar test was used to identify statistically significant changes in proportions when comparing likely uptake of standard autopsy, MIA and NIA. Likert scales were dichotomized before analysis. For participant characteristics, where small numbers occurred, categories were dichotomised e.g. ethnicity was collapsed into White v Other. Two-sided 95% confidence intervals were estimated. Surveys were excluded if data were missing for the questions on acceptability, likely uptake and preferences (questions 1-7). Quantitative data were analysed using SPSS 22 (IBM, Chicago, IL, USA) and $p<0.01$ was considered as significant.

For the qualitative data, free-text comments and interviews were combined into one data set for analysis. We used a thematic analysis approach whereby themes were derived both inductively and deductively from the data [18]. Qualitative data analysis was facilitated using Nvivo version 10 (QSR International, Pty Ltd) software.

Results

Survey Participants

In total 938 surveys were returned; 870 through retrospective recruitment (655 through Sands, 108 through ARC, 81 through Lullaby Trust, and 26 through Child Bereavement UK) and 68 through prospective recruitment. Seventy-nine were excluded due to missing data (79 from the retrospective recruitment and 0 from prospective recruitment) leaving 859 for inclusion in the analysis. Of those, 51% (439) left free text comments for qualitative analysis. Due to the nature of the retrospective recruitment, it is not possible to calculate a response rate. For the prospectively recruited participants, 23 participants actively declined to take part at the time of discussing the study (feedback from health professionals suggests this was due to the sensitivity of the subject matter and timing of the approach), and 160 passively declined (study packs were taken home and not returned) (30% response rate). The majority (83.2%) had been approached about autopsy (7.4% had not been approached, 2.1% couldn't remember and in 7.4% of cases a coroners' autopsy was required). Just under half (48.6%) of those who had been approached consented to a standard autopsy. Survey responder demographics are presented in Table 1 and experience of loss in Table 2.

Quantitative Results

Likely uptake of standard autopsy, MIA and NIA

Overall, 90.5% (777) of participants indicated they were likely to consent to some form of less invasive autopsy (either MIA, NIA or both). In total, 53.8% (462) indicated they were

likely to consent to a standard autopsy, 74.3% (638) were likely to consent to MIA and 77.3% (664) were likely to consent to NIA (Table 3).

Participants who indicated they would decline standard autopsy but would consent to a less invasive option (excluding those who were not sure for either) were more likely to have a lower educational level (59.1% A level and lower v 40.9% degree and above, OR: 0.49; 95%CI: 0.35-0.70; p=0.000062). There was no significant difference in age, gender, country of birth, ethnicity, religious faith, which faith, recruitment method or experience of loss. (p>0.01 for all). A McNemar's test with continuity correction indicated that people were more likely to consent to a less invasive autopsy than standard autopsy (90.5% v 53.8% respectively, $X^2(1)=102.68$, $p=3.9x10^{-24}$). Similarly, people were more likely to consent to MIA rather than standard autopsy (74.3% v 53.8%; $X^2(1)=57.47$, $p=3.4x10^{-14}$) and NIA rather than standard autopsy (77.3% v 53.8%; $X^2(1)=95.56$ $p=1.44x10^{-22}$).

Acceptability of standard autopsy, MIA and NIA

Regarding acceptability of the three options, 77.3% (664) thought standard autopsy was acceptable, 86.3% (741) thought MIA was acceptable, and 87.3% (750) thought NIA was acceptable (Table 2). A McNemar's test with continuity correction indicated that people found MIA more acceptable compared to standard autopsy (86.3% v 77.3% respectively, $X^2(1)=24.53$, $p=7.3x10^{-7}$) and NIA more acceptable than standard autopsy (87.3% v 77.3% respectively, ($X^2(1)=26.54$, $p=2.5x10^{-7}$). There was no statistically significant difference between those who found NIA or MIA more acceptable (p=0.21).

Preferences for different options

When asked to choose between the different options, 45.5% (n=391) preferred MIA, 30.8% (n=265) preferred NIA, 14.3% (n=123) preferred standard autopsy, 7.7% (n=66) had no strong preference and 1.6% (n=14) would not choose any of the options. No significant associations were found between participant characteristics, recruitment method or type of loss with preference for the different options ($p>0.01$ for all).

Factors associated with decision-making

'To understand why it happened' and 'to understand if it might happen again"' were the items most frequently cited as extremely important by survey responders when making decisions about autopsy. Factors rated least important were 'my religion's views about autopsy' followed by 'concern it would delay funeral arrangements' (Table 4).

Interview participants

For the interviews, 36 participants were contacted following their initial voluntary expression of interest and 20 consented and took part (56% recruitment rate); 18 were female. Interview participant characteristics are presented in Table S1. Interviews lasted between 27 minutes and 1 hour 30 minutes.

Qualitative findings

Here we summarises the overall themes that emerged from the qualitative analysis around acceptability of standard autopsy, MIA and NIA. A detailed description of key themes along with supportive quote can be found in Appendix S4.

Standard autopsy

Acceptability of standard autopsy was linked to comments around the thoroughness of the procedure, associated with "taking all steps possible", and one which "gives the best chance of determining the cause of death" or identifying information that would be relevant for future pregnancies. For some parents, the need for answers and gain some level of "closure" outweighed the concerns they held about the invasiveness of the procedure. However, for many parents, the invasiveness was perceived to be too traumatic to consent to the procedure. Babies and children were often positioned as special cases. The acceptability of standard autopsy for this "tiny", "fragile" group was called into question by parents, and alternative options sought that would minimise parental burden and safeguard the dignity and respect of the child.

Non-invasive autopsy

NIA was acceptable for most parents primarily because the lack of incision enabled the child to "rest in peace" and put parents "more at ease" consenting to the procedure. NIA was viewed as a more "comforting" choice for parents, one that would not contribute further to the "distressing thoughts" and "guilt" that many were already experiencing. Moreover, because there were no incisions to the body, parents felt it would enable them to participate in rituals around death such as washing, holding and dressing their babies before the funeral, found to be important in moving forward. Nevertheless, some participants raised concerns about the completeness of the information that NIA could gather and acknowledged that it might be unsuitable in certain circumstances. Other parents stated that they were prepared to accept a reduced chance of finding an answer if it meant their child would not be cut.

Minimally invasive autopsy

MIA was considered to be a "good compromise" as it overcame some of the limitations of NIA but enabled tissues samples to be taken without requiring large incisions to the body. Thus it allowed parents to balance their need for thoroughness and answers whilst easing the parental burden by protecting the baby or child from further "harm". Nonetheless, for some parents, MIA was still perceived as invasive and any level of invasiveness remained intolerable. In addition, some parents raised concerns as to whether there was a risk that conditions might not be detected and whether it could reach the same level of diagnostic yield as standard autopsy. The importance of research to compare both approaches was discussed.

Parental views about research participation

The vast majority (87.9%; n=58) of prospectively recruited parents were glad to have been asked to take part in this study, 12.1% (n=8) were unsure and none regretted it.

Discussion

Main Findings

This is the largest UK study exploring parental views, preferences and hypothetical uptake of less invasive autopsy. The findings suggest the potential for a significant overall increase, which could be as high as 90%, if less invasive methods were available. However, in practice uptake will depend on availability and effectiveness of different methods of autopsy in specific circumstances, and would need to be further investigated following implementation.

Strengths and limitations

A major strength of this study is the large number of participants and the mixed methods approach which enabled corroboration of findings and a deeper understanding of the topic. Moreover, responses from prospectively recruited parents suggest that the majority of survey responders did not experience any adverse effect from taking part in the study. A further strength is that PPI was embedded from the outset; PPI input into the survey design was particularly important to ensuring the questions were clearly phrased and included the benefits and limitations of the different approaches. Whist there was a significantly larger number of participants recruited retrospectively than prospectively, there was no overall difference in preferences for autopsy between the two cohorts. Furthermore, we did not identify any differences in autopsy preferences across participant characteristics or loss experience despite the majority of survey responders self-selecting their ethnicity as White and well-educated. There was a greater proportion of responders who had experienced stillbirth over other forms of perinatal loss, but this mirrors the proportions of children, infant and perinatal mortality from recent national data. [19] Our sample does reflect national data in that 49% of parents had previously consented to a standard autopsy, which is comparable to the national average of 45% [3]. Not unexpectedly given the sensitive subject matter, there was a low response rate from parents recruited prospectively which may have biased findings (30%). Women with poorer emotional wellbeing may have been less likely to respond. However, this figure is comparable with a recent survey study of parental experience of autopsy following stillbirth where the response rate was 30% [20]. Online recruitment enabled us to recruit a much larger sample than was likely to have been possible prospectively, yet is subject to non-response bias as participants may have been more interested in or enthusiastic about the topic. Another potential limitation is that we

did not collect data on how long ago the loss occurred – time since loss may have influenced their views and preferences. Finally, the hypothetically high uptake of MIA and NIA seen in our findings may not concur with actual uptake in a real life scenario.

Interpretation

Having presented parents with information about the benefits and limitations of the different approaches, both MIA and NIA were clearly more acceptable (86% and 87% respectively compared to 77% for standard autopsy), a finding supported by the qualitative work, where less invasive approaches were preferable as they were considered 'kinder' to both parent and child. Whilst our findings support those of Cannie et al. [15] in that overall there was a preference for less invasive methods, 15% of participants still indicated a preference for standard autopsy as it was the most complete test available. This finding highlights that some parents will continue to opt for the method which can theoretically provide the most information and supports the importance of providing parents with a choice.

Consistent with our study, Henderson et al. found that women with lower educational attainment were significantly less likely to consent to a standard autopsy [20]. Our finding that survey responders from low educational backgrounds who would decline standard autopsy were likely to consent to a less invasive approach, highlights that the availability of less invasive autopsy opens up opportunities for this group that would otherwise be unavailable. Further research with this group to identify optimal ways of communicating about standard autopsy is also important.

The primary reasons why bereaved parents consented to autopsy in this study, namely to understand why it happened and if it would happen again, have also been identified as the main motivators in other studies [1, 16, 21, 22] supporting the importance of information to inform recurrence risk. However, unlike research conducted in low- and middle-income countries[17], in the current survey, religion was not found to be an important factor in decision-making. This is likely to be because of the small number of Muslim and Jewish responders. However, qualitative research with parents and religious leaders from these two religious groups has shown that the invasiveness of standard autopsy is a key reason why Muslim and Jewish families decline, along with the requirement to bury the body quickly, and that non-invasive approaches in particular, would be considered religiously permissible and much preferred.[23]

The findings from this study have significant implications for future clinical practice. Given the current low uptake rates for standard autopsy, and the reasons behind this, an alternative is required, both to provide the best care available for parents and families and for public health reasons including evaluating the quality of obstetric and neonatal care [24]. The broadening range of investigative strategies now available aligns with NHS England's goal of significantly improving patient choice by 2020 [25]. The major finding from this research is that there is likely to be a significant increase in uptake of post-death investigation if personalised and more acceptable approaches were routinely available. Several requirements must be put in place to make less invasive autopsy a viable alternative, including training of radiologists to interpret imaging results and pathologists to conduct image-guided biopsies, availability of scanning equipment, training for health professionals to offer less invasive autopsy appropriately, adapted consent procedures, and

guidelines for which method is most appropriate in which circumstances and clear information for parents to support them making informed choices [26].

Maintaining a sufficient level of health professional education and awareness with regards to autopsy options could prove to be a major challenge, as numerous barriers to an effective autopsy consent process exist, even prior to the addition of less-invasive options such as MIA and NIA [1, 27]. These barriers could be compounded by the increasing complexity of the available autopsy options, patchy availability of MIA and NIA, and the relatively high-turnover environment of clinical staff. Consideration will need to be given as to how autopsy options might be offered.

Conclusion

This study contributes to the literature about acceptability of less invasive autopsy in a high-income country and supports the finding that less invasive autopsy is a viable and preferable option for many parents. Large-scale studies in other high-income settings would add to the generalisability of the results. Further clinical work is required to assess concordance between MIA, NIA and standard autopsy in order that appropriate counselling is possible across a range of clinical scenarios, for example, stillbirth versus infant death. Economic and implementation evaluations are required to assess cost implications as well as how less invasive autopsy could be offered routinely as a clinical service within the NHS. Finally, evaluation of actual uptake is needed to confirm findings from this research.

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Contribution to Authorship: CL designed the survey instrument, implemented the study, oversaw data collection, analysed the data, and drafted and revised the paper. MR conducted qualitative interviews, conducted data analysis and revised the draft paper. MH conducted data analysis and revised the draft paper. OA interpreted the data and revised the draft paper. JCH interpreted the data and revised the draft paper. LSC designed the study, interpreted the data and revised the draft paper. CB, JF and JW contributed to the design of the survey and revised the draft paper. NJS designed the study, interpreted the data and revised the draft paper.

Details of Ethics Approval: This study was approved by the London-Bloomsbury Research Ethics Committee on 4/4/2016 (16/LO/0248). Interview participants provided written consent to take part in in the study. Returning a completed survey was considered implied consent to take part.

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Table 1: Survey responders' demographics

	Total sample N=859 % (n)	**Prospective recruitment N=68 % (n)**	**Retrospective recruitment N=791 % (n)**
Age	Range 18-73; Mn 35.9; Mdn 35.0; SD 8.1	Range 20-50; Mn 32.6; Mdn 33.0; SD 5.5	Range 18-73; Mn 36.2; Mdn 35.0, DS 8.3
Sex			
Female	94.9% (615)	94.1% (64)	97.5% (751)
Male	2.7% (23)	5.9% (4)	2.5% (19)
Country of Birth			
UK	94.5% (774)	76.1% (51)	96.1% (723)
Other	5.5% (45)	23.9% (16)	29 (3.7)
Education			
No formal qualification	1.7% (14)	1.5% (1)	1.7% (13)
GCSE or equivalent	21.5% (177)	23.9% (16)	21.2% (161)
A level or equivalent	24.4% (201)	20.9% (14)	24.7% (187)
Degree or equivalent	32.8% (271)	26.9% (18)	33.4% (253)
Postgraduate qualification	19.5% (161)	25.4% (17)	19.0% (144)
Ethnicity[a]			
White or White British	95.0% (783)	64.2% (43)	97.8% (740) **
Black or Black British	2.5% (21)	23.9% (16)	0.7% (5)
Asian or Asian British	1.3% (11)	10.4% (7)	0.5% (4)
Mixed	0.6% (5)	1.5% (1)	0.5% (4)
Other	0.5% (4)	0% (0)	0.5% (4)
Do you have a religious faith?			
Yes	48.2% (393)	68.9% (42)	46.5% (351) *
No	51.8% (423)	31.1% (19)	53.5% (404)
If YES, which faith?[b]			
Christian	44.8% (358)	72.7% (32)	93.2% (326) **
Muslim	0.8% (6)	4.5% (2)	0.5% (4)
Jewish	0.8% (6)	4.5% (2)	0.5% (4)
Sikh	0.5% (4)	6.8% (3)	0.1% (1)
Hindu	0.4% (3)	4.5% (2)	0.1% (1)
Jehovah's Witness	0.4% (3)	2.3% (1)	0.3% (2)
Buddhist	0.1% (1)	0% (0)	0.1% (1)
Other	1.5% (12)	0% (0)	1.6% (12)

Note: Percentages may not total 100% due to rounding. In some cases total number of participants per category does not add up to total N due to missing data.
Statistically significant differences between prospective and retrospectively recruited participants:
[a] *Significance calculated as White or White British v Other*

Table 2: Survey responders' experience of loss

	Total sample N=859 % (n)	**Prospective recruitment N=68 % (n)**	**Retrospective recruitment N=791 % (n)**
Experience of loss (tick all that apply)			
Miscarriage (loss up to 12 weeks gestation)	34.3% (295)	30.9% (21)	34.6% (274)
Late miscarriage/fetal loss (12-24 weeks gestation)	18.7% (161)	38.2% (26)	17.1% (135)
Stillbirth	47.4% (407)	26.5% (18)	49.2% (389)
Termination for fetal anomaly	18.3% (157)	26.5% (18)	17.6% (139)
Neonatal/infant death (0-12 months)	22.0% (189)	17.6% (12)	22.4% (177)
Child death (1-16 years)	2.3% (20)	7.4% (5)	1.9% (15)
None	0% (0)	0% (0)	0% (0)
If YES, were you approached about autopsy in any of those cases?			
Yes	83.2% (711)	89.2% (58)	82.7% (653)
No	7.4% (63)	7.7% (5)	7.3% (58)
Not sure	2.1% (18)	1.5% (1)	2.2% (17)
Coroner's office issued a compulsory autopsy	7.4% (63)	1.5% (1)	7.8% (62)
If YES, which type of autopsy were you offered? (tick all that apply)			
Standard autopsy examination	67.1% (477)	84.4% (49)	65.5% (428)
Limited autopsy – only certain organs you consent to are examined	21.8% (155)	36.2% (21)	20.5% (134)
Minimally invasive autopsy with tissue sampling and MRI	6.3% (45)	19.0% (11)	5.2% (34)
Non-invasive autopsy with MRI	3.5% (25)	15.5% (9)	2.5% (16)
Non-invasive autopsy with X-ray	4.5% (32)	17.2% (10)	3.4% (22)
Not sure	31.6% (225)	10.3% (6)	33.5% (219)
Which type of autopsy did you accept?			
Standard autopsy examination	48.6% (346)	58.6% (34)	47.8% (312)
Limited autopsy – only certain organs you consent to are examined	6.5% (46)	1.7% (1)	6.9% (45)
Minimally invasive autopsy with tissue sampling and MRI	1.5% (11)	0.0% (0)	1.7% (11)
Non-invasive autopsy with MRI	0.6% (4)	1.7% (1)	0.5% (3)
Non-invasive autopsy with X-ray	1.8% (13)	3.4% (2)	1.7% (11)
Not sure	9.1% (65)	1.7% (1)	9.8% (64)
None – I declined an autopsy	33.5% (238)	34.5% (20)	33.4% (218)

Note: Percentages may not total 100% due to rounding. In some cases total number of participants per category does not add up to total N either due to missing data, because some participants were not required to complete the question, or in the case of experience of loss, because of multiple losses.

Table 3: Likely uptake and acceptability of standard autopsy, MIA and NIA

Likely uptake of…	**Yes** **% (n)**	**No** **% (n)**	**Not sure** **% (n)**
Standard autopsy	53.8% (462)	26.0% (223)	20.3% (174)
MIA	74.3% (638)	8.3% (71)	17.5% (150)
NIA	77.3% (664)	5.2% (45)	17.5% (150)
Acceptability of…	**Acceptable** **% (n)**	**Unacceptable** **% (n)**	**No strong opinion** **% (n)**
Standard autopsy	77.3% (664)	9.4% (81)	13.3% (114)
MIA	86.3% (741)	3.0% (26)	10.7% (92)
NIA	87.3% (750)	3.1% (27)	9.5% (82)

Note: Percentages may not total 100% due to rounding.

Table 4: Factors associated with decision making

	Not at all important				Extremely important
To understand why it happened	1.7%	1.6%	4.2%	6.8%	85.7%
To understand if it might happen again	2.4%	1.2%	3.8%	6.7%	85.3%
To prevent this from happening to others	1.8%	3.1%	10.5%	21.4%	63.1%
To reassure me it was not my fault	10.2%	6.6%	17.6%	14.8%	50.7%
Feeling that my baby/child had 'suffered enough'	8.5%	6.6%	22.0%	13.4%	49.3%
Not wanting my baby/child to be cut	7.3%	9.6%	19.8%	14.1%	49.1%
To improve medical knowledge	6.4%	6.6%	16.9%	21.2%	48.7%
Concern about the baby/child's appearance afterwards	8.6%	9.0%	19.4%	20.0%	42.9%
Concern about what would happen to the tissue/organs afterwards	8.4%	12.0%	19.3%	17.6%	42.6%
To help with the grieving process	13.1%	7.5%	20.1%	18.3%	40.9%
The description of autopsy given by the health professional	17.7%	10.2%	21.8%	16.1%	34.1%
Concern that my baby/child might be moved to another hospital	19.8%	12.1%	20.2%	13.9%	33.9%
Concern about the length of time it may take to get the results	24.2%	12.0%	20.6%	19.7%	23.3%
Feeling that I already knew what caused the loss of my baby/child	28.4%	12.5%	29.2%	10.3%	19.5%
Feeling that it would add to my grief	30.7%	13.6%	25.3%	16.7%	13.5%
The complexity and length of the consent form	43.3%	12.9%	20.8%	9.9%	12.9%
Concern it would delay funeral arrangements	46.3%	13.3%	18.6%	10.3%	11.4%
My religion's views about autopsy	84.7%	4.8%	5.3%	1.9%	3.2%

Note: Percentages may not total 100% due to rounding.