MESOTHELIOMA UK

University of Sheffield

Mesothelioma and the Coroner: Understanding and Improving the Process for Families

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Executive summary

This report explores how bereaved families experience the coronial process following a death from mesothelioma - an incurable cancer caused by asbestos exposure. It has been produced by Mesothelioma UK in response to ongoing concerns from families about confusion, distress, and a lack of information around this legal and medical procedure.

The project has three main aims:

- To raise awareness of the coronial and procurator fiscal processes among professionals and the public.
- To understand the experiences of families affected by mesothelioma.
- To identify opportunities to better support families navigating this process.

The research includes a UK-wide survey and in-depth interviews with bereaved family members. In addition, over 50 individuals and several professional groups were consulted at various stages of the research.

Key themes emerged, including:

- A widespread lack of understanding about why a coroner is involved and what the process entails.
- The emotional impact of being informed about the need for coronial involvement (especially near the end of life), and other instances of poor communication.
- Variation in procedures across the UK, particularly around post-mortem examinations and police involvement.
- The impact of the process on families' mental health, and gaps in support and information.

This report highlights examples of good practice, particularly where communication was clear, timely, and sensitive; but also reveals areas where families felt confused, distressed, or unsupported.

Clearer information, earlier conversations, and greater consistency in practice could significantly reduce the burden on families. This report includes detailed recommendations for coroners, healthcare professionals, legal teams, and families, with the aim of improving experiences and outcomes for all those affected by a mesothelioma death.

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Introduction

By Sarah Thomas
Benefits Manager, Mesothelioma UK

One notable aspect of mesothelioma is the fact that a person diagnosed with, or suspected of having, mesothelioma will have their death referred to the local coroner (England, Wales, Northern Ireland) or procurator fiscal (Scotland).

In response to feedback from families, who have expressed confusion and concern about the coronial process, Mesothelioma UK undertook a comprehensive project to explore and understand the impact of this procedure on patients and their families.

The aims of the Mesothelioma UK coroner's project were;

- To raise professional and patient awareness of the coronial/procurator fiscal process.
- To investigate bereaved families' experiences.
- To examine the options available to bring about procedural change to benefit mesothelioma patients and their families.

The project revealed variability in practices across the UK, with experiences ranging from positive to negative. It also uncovered a widespread lack of understanding about the coronial process, particularly in relation to mesothelioma. This knowledge gap has caused, and continues to cause, distress and confusion for many families of mesothelioma patients.

Professionals involved in the support and care of mesothelioma patients have an important role to play in raising awareness of the coronial process. By doing so, they can help reduce confusion and alleviate unnecessary distress during an already difficult time.

This report aims to highlight the challenges and variations in the current coronial process and encourage reflection on how these issues can be addressed. We hope that the findings and recommendations within this report will inspire action to improve consistency and provide tailored solutions for families affected by mesothelioma.

If you would like to discuss any aspect of this report, or are seeking advice or support, we would be pleased to hear from you. Please feel free to contact us via the Mesothelioma UK Freephone Support Line on **0800 169 2409**.

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Mesothelioma

Mesothelioma is a type of cancer which has only one known cause: asbestos exposure. It mainly affects the linings of the lungs and the abdomen. Symptoms do not appear until decades after exposure. Mesothelioma is not currently curable and life expectancy for those with the disease can be very short. The symptoms of mesothelioma, such as breathlessness, cough, fatigue and pain, can be burdensome and difficult to control.

Mesothelioma and the coroner

If a death was caused by, or is suspected to have been caused by, an industrial disease then the coroner or procurator fiscal is legally obliged to investigate. In most cases mesothelioma is classed as an industrial disease because it was caused by exposure to asbestos in the workplace or via someone else's workplace (para-exposure).

The coroner's role is to find out who the deceased was, and where, when and how the death occurred. It doesn't mean there is a suspicion of any wrongdoing and the coroner cannot blame individuals or organisations for the death.

Coroners are typically doctors or lawyers appointed by the local authority, and each coroner has their own jurisdiction. There is no unified national coroner service in England and Wales, which means coroners operate with a high degree of autonomy. This leads to differences in procedures across regions, making it difficult to provide consistent advice to families about what to expect when a person with mesothelioma dies.

Typical coronial process in England, Wales, and Northern Ireland

- A death from mesothelioma is reported to the coroner, usually by a healthcare professional.
- The coroner opens an investigation and takes the deceased into their care.
- The coroner decides whether a post-mortem examination is necessary.
- Once any required examinations have been completed, the deceased is released into the care of a funeral director and the funeral can take place.
- There is no set timeframe for a coroner's investigation - some take weeks, but many take longer.
- Once the investigation is complete, the coroner will usually hold an inquest hearing.
- At the inquest, the coroner determines the cause of death. This marks the end of the coronial process.

“We had no idea this would happen”

Family experiences of coroner involvement after a mesothelioma death

The Smedley family


Marion and Robin Smedley

By Sarah Thomas
and Dr. Bethany Taylor

In 2017, Robin Smedley died of mesothelioma at home, surrounded by his close family. The family managed his end-of-life care with dignity and peace, but were both unaware of and unprepared for the involvement of the coroner and the police.

The family were first told that the coroner would need to be informed by the GP attending the death. “That was the first we’d heard of it…We were prepared for his death as a family…but we were very unprepared with all the other things like the coroner,” Joanne (Robin’s daughter) explained.

In the North East of England it is common practice for the police to attend mesothelioma deaths at home. Soon after the conversation with the GP, a police officer arrived and told the family that the coroner had been informed and that a post-mortem examination would be required. Joanne recalled: “He said the body becomes the property of the Crown…and he had to go to James Cook Hospital on the order of the coroner.” This was a shock to the family who were expecting their father to go directly into the care of the funeral director.

The family took immediate steps to try to avoid a post-mortem, which they felt was unnecessary given the well-documented diagnosis. Robin’s wife Marion felt it was particularly important to advocate this for him, as he had expressed his wish not to return to hospital in life or death. They gathered key documents from the hospital and the GP, including a report confirming the diagnosis of mesothelioma. “We all worked as a team…to get the reports and take them to the coroner,” said Joanne.

They immediately took the documents to the coroner's office to provide evidence that the mesothelioma diagnosis was already established. The coroner accepted the evidence, the post-mortem examination was avoided, and the police officer stood down. The family were very relieved that a post-mortem would not have to take place, and the subsequent coronial investigation and inquest process went smoothly.

The family perceived that healthcare professionals had missed multiple opportunities to inform them about the coronial process at an earlier stage, which would have prevented their shock and distress. The family's experience prompted the development of this coroner's project, aimed at improving communication and procedures for families facing similar situations.

The Hargreaves family

As told to Dr. Bethany Taylor

"My dad died three weeks after diagnosis with mesothelioma. We were told by the nurse at his diagnosis that there would need to be a coroners inquest. We accepted this, and it made sense, as we already knew what caused mesothelioma. Dad died in hospital and the staff there contacted the coroner who then took charge. It did feel odd that Dad didn't go straight to the funeral directors, but instead his body went to the coroners for a post-mortem. For our family it was important to know if he definitely did die from mesothelioma, and anything else that could help us understand why this had happened.

The coroner's officers were very helpful, but it was difficult to receive unexpected phone calls from them, which threw me straight back into my grief for Dad's death. The inquest was online, and my son and I represented our family. I was apprehensive but the proceedings were undertaken sensitively, and the coroner had a wonderfully open and listening manner. We were both given ample opportunities to ask questions and to talk through our perspective on what happened. The coroner ended the inquest with very wise words, which I shared afterwards with the rest of the family. I felt a lightness and sense of peace when the inquest was completed, as I had some answers, and we had been given the opportunity to speak on behalf of Dad."

We thank the Smedley and Hargreaves families for sharing their experiences to help others navigate this challenging process.

Coroner questionnaire: Current practices in mesothelioma deaths

By Sarah Thomas

As part of our investigations, Mesothelioma UK conducted a questionnaire of coroner offices across England and Wales to better understand current practices in cases of mesothelioma. The questionnaire was sent to 78 coroner areas, with two rounds of follow-up contact, resulting in 24 responses - a 31% response rate. The questionnaire was conducted from May to August 2023.

We did not contact procurator fiscal offices in Scotland, as their service operates under a unified national system with broadly consistent practices, unlike the more variable approaches seen in England and Wales.

Police attendance at the time of death

When asked whether police attendance was routine in cases of industrial disease or mesothelioma deaths, none of the respondents answered yes. Instead, 13 confirmed that police attendance was not routine, while 11 indicated that it depends on the circumstances.

Questionnaire responses indicated that police attendance is generally not required where the death is expected and occurs under medical care, such as in hospital or a hospice. However, police may attend if the death is unexpected, sudden, or occurs in the community without a healthcare professional present, especially out of hours. In such cases, police may act as representatives of the coroner to verify the death and initiate notification processes.

Use of post-mortem examinations

When asked whether a post-mortem is typically conducted following a confirmed diagnosis of mesothelioma by biopsy during life, 15 respondents said no, and nine stated that it depends on the circumstances.

Responses categorised “it depends” indicated a general preference to avoid post-mortems where a biopsy-confirmed diagnosis exists but with the caveat that a case-by-case approach is taken, particularly where:

- Diagnosis was based on cytology* alone
- The cause of death is disputed
- The family requests further investigation
- There is uncertainty about whether mesothelioma directly caused the death

Fibre analysis practices

Fibre analysis is a specialist test that looks for asbestos fibres in lung tissue. Only a few experts can carry it out, so there is often a long wait, which can delay the coroner's investigation by several months. The questionnaire respondents were asked whether fibre analysis is a routine practice within their jurisdiction. Within the sample only two offices routinely request fibre analysis; 14 did not undertake this type of analysis and eight indicated it would depend on individual circumstances.

The specific circumstances they described were:

- When no diagnosis was made in life
- Where the cause of death is contested
- Where there is not a confirmed occupational exposure
- On the recommendation of the pathologist during post-mortem

The findings indicate that within the questionnaire sample, fibre analysis is reserved for cases where the diagnosis is unclear or legally challenged, rather than being a standard part of mesothelioma investigations.

This is the first questionnaire to explore coronial practices related to mesothelioma within a sample of 24 offices in England and Wales. It is not known whether the findings reflect practice within the other 54 offices which did not participate in the questionnaire. The questionnaire findings highlight a broadly pragmatic and sensitive approach among coroners, with a shared aim of avoiding invasive procedures where a robust diagnosis already exists. However, variation remains in how decisions are made in less straightforward cases, particularly where legal claims, uncertainty, or family concerns are involved.

The variation in coronial practices across England and Wales makes it challenging to give families clear, consistent advice about what to expect after a mesothelioma-related death. The questionnaire found differences in when police attend, whether a post-mortem is carried out, or if fibre analysis will be undertaken depending on local protocols, individual coroner's decisions, and the specific circumstances of the death. This uncertainty can add to the stress families face at an already difficult time.

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* Cytology is the examination of individual cells under a microscope. In mesothelioma, this may involve looking at fluid taken from around the lungs or abdomen. While it can suggest mesothelioma, it is generally considered less reliable than a tissue biopsy for confirming the diagnosis.

Civil claim proceedings: Understanding how the coronial process interacts with compensation claims

By Beth Liddle
Solicitor, Irwin Mitchell

The coronial process plays an essential role in mesothelioma civil compensation claims. The coroner's findings, particularly a conclusion confirming death due to industrial disease, serve as key evidence in establishing a clear link between the mesothelioma and asbestos exposure. Whilst a finding of death due to industrial disease is not decisive in the context of a civil claim, it certainly helps move the case forward on the issues of breach of duty and causation.

Please note: the coroners findings will not impact a civil claim that was settled during the patient's lifetime.

Determining diagnosis

If a patient is able to have a biopsy during their lifetime which confirms the diagnosis of mesothelioma then a post-mortem examination is not essential. However, it is important for the purposes of the legal claim that the patient's medical records are retained in the event the diagnosis is challenged by the defendant.

If a biopsy is not possible during lifetime, treating hospitals will often make a radiological diagnosis of mesothelioma. Although this method is a sound route to a diagnosis, it cannot conclusively establish a diagnosis of mesothelioma in the same way that a biopsy can. In these cases a post-mortem examination is strongly recommended, as defendants frequently challenge radiological diagnoses.

A post-mortem can offer conclusive evidence of diagnosis and enables the cause of death to be definitively determined. This is particularly important where there are a number of potential causes of death, for example if a patient has another cancer in addition to the mesothelioma. If the coroner's findings support a diagnosis of mesothelioma, and confirm this as cause of death, this can help strengthen the civil claim and reduce the likelihood of the defendants challenging the diagnosis and seeking to obtain their own medical evidence.

Ultimately, it is a decision for the coroner as to whether a post-mortem examination is carried out, but families can express their wishes, and the legal representatives for the family can also put forward their views.

In some instances, the coroner may be happy to proceed without a post-mortem, even without pathological confirmation of the diagnosis. In these instances, the family can opt to have a private post-mortem examination carried out, and for the purposes of the ongoing civil claim this would be recommended.

If the family decide not to have a private post-mortem, this can have a detrimental impact on the civil claim. In the case of Currie v Rio Tinto Plc the defendant asked for a private post-mortem examination and the deceased's family refused. The court found this to be a deliberate refusal to gather or retain medical evidence and the claim was struck out as the absence of medical evidence was held to prejudice the defendant's case.

Evidence

Where a patient has started a claim in their lifetime, evidence from that claim will be used to help the coroner reach a conclusion. The coroner will look for information about the patient's work history, and whether or not they had any exposure to asbestos. A detailed witness statement, together with an employment history, can quickly and clearly show the coroner exactly where the patient worked, and how they came to be exposed to asbestos. The coroner can use this evidence to conclude that the patient's mesothelioma was caused by their occupational asbestos exposure.

The inquest also provides solicitors with an opportunity to gather evidence for the claim and to seek clarification on complex issues arising from post-mortem examination reports.

Impact on settlement

A clear and confirmed diagnosis obtained either during lifetime or following death can expedite the legal process, helping families reach settlement more quickly.

Once the coroner has the evidence to hand, inquests can usually be concluded by reviewing the written documents alone, rather than waiting what might be several months for an inquest hearing in person. This means that the final death certificate can be issued, and steps can be taken to progress the civil claim.

Alternatively, if a post-mortem examination is not carried out in cases where the diagnosis is uncertain, this could prolong the claim process as the defendant may dispute the diagnosis and seek to obtain their own medical evidence.

In some cases, there is a risk that mesothelioma may not be confirmed as the cause of death, despite a lifetime diagnosis being made. In such instances this could prejudice the civil claim for compensation.

Causation is a key element which needs to be proven in a civil claim for compensation. We essentially need to establish a clear link between the asbestos exposure and development of mesothelioma. The post-mortem report and inquest documents play a critical role as they help demonstrate the link.

If the coroner reaches a conclusion of death by natural causes this can provide an opportunity for a defendant to seek to challenge the claim. In these instances the civil claims can become much more complex and difficult to pursue as it is likely further medical evidence and/or tissue sample re-examination is required to carry out further investigation into the diagnosis.

Summary

The coronial procedure plays a central role in supporting civil claims for compensation for mesothelioma. The post-mortem examination and inquest documents provide crucial medical evidence relevant to the issue of diagnosis, the cause of death and medical causation (the link to asbestos) which can strengthen the legal claim.

Ultimately the need for a post-mortem examination will depend on the specific circumstances of each case. From a legal perspective, it will always be recommended where there is uncertainty around the diagnosis of mesothelioma or the cause of death.

It is vital that families who do not have legal representation seek advice immediately following the death of a loved one diagnosed with mesothelioma. Specialist solicitors can assess the case and ensure that all necessary evidence is preserved whilst the civil claim is investigated.

Mesothelioma and the Procurator Fiscal: The Scottish approach

By Carolyn MacRae
Mesothelioma UK Clinical Nurse Specialist
Team Leader Scotland

Mesothelioma and the procurator fiscal

In Scotland, the Scottish Fatalities Investigation Unit (SFIU) - part of the Crown Office and Procurator Fiscal Service (COPFS) - handles reports of deaths that are sudden, suspicious, unexplained, or fall into specific categories. They are the Scottish equivalent of the Coroners Office.

When a death is reported to the procurator fiscal, it is because they may need to investigate what happened. It does not always mean that the death is suspicious or that anyone is to blame.

Deaths due to notifiable industrial diseases, acquired during employment, must be reported to the procurator fiscal.

When someone with mesothelioma passes away, it's important that the doctor who knows the most about the circumstances of the death reports it to the SFIU as soon as possible. This should happen before a death certificate is issued. Reports are usually made during office hours, but if the death is suspicious or religious practices require immediate action, the on-call service can be reached through the police.

If a death certificate has already been issued and the procurator fiscal doesn't accept the stated cause of death, the certificate will need to be retrieved.

For families wanting more information, COPFS offers guidance on its website and provides an information booklet as well.

Scotland has three SFIU teams - North, East, and West - each with legal and administrative staff located in Glasgow, Dundee, Aberdeen, Inverness, and Edinburgh.

It is a unified service across Scotland and when reporting a death, the doctor should contact the SFIU team for the area where the death occurred.

If the deceased wasn't formally diagnosed with mesothelioma during their lifetime, the family should be informed about the possibility of compensation and asked about their views on a post-mortem examination, if it is required for a formal diagnosis.

In many cases, a post-mortem can be avoided if the industrial disease was clearly diagnosed and documented before death. However, if the cause of death isn't clear, the procurator fiscal may request a post-mortem to confirm it and ensure that any necessary evidence is preserved.

What actions might the procurator fiscal take?

Once a death is reported, the procurator fiscal may:

1. **Accept the cause of death listed** on the certificate and take no further action.
2. **Request a police report** if more information is needed. This doesn't mean the death is being treated as criminal - police officers act as agents for the procurator fiscal to gather additional details. SFIU tries to avoid police involvement when possible to minimise distress for the family.
3. **Order a post-mortem examination** if the cause of death is unclear or if no doctor can certify it.
4. **Release the body** once legal responsibility is no longer required - usually after the death certificate is issued.

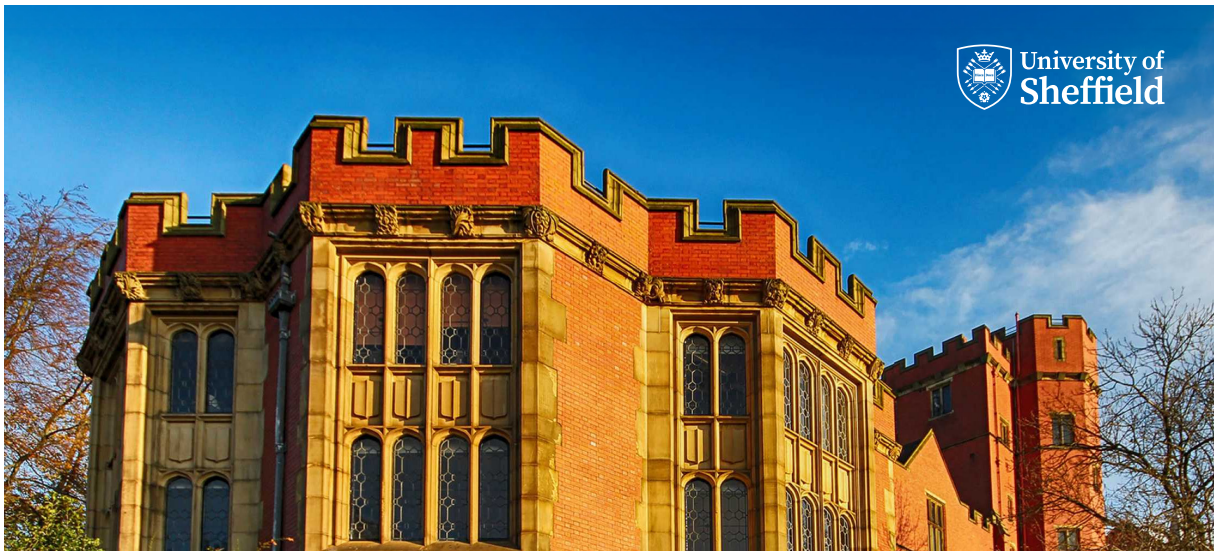
The Scottish Mesothelioma UK Clinical Nurse Specialist team plays a key role in helping patients and families understand the requirement to report a death when mesothelioma is confirmed or suspected. They may also be contacted after death to provide information to COPFS/SFIU.

The Scottish Mesothelioma Network, supported by Macmillan, Mesothelioma UK, and NHS Scotland, brings together clinicians across the country to share best practice, deliver high-quality care, and ensure equal access to clinical trials. The network is committed to improving care across the entire patient journey.

One of the network's key metrics measures the number of patients who have died with a confirmed diagnosis of mesothelioma who subsequently undergo post-mortem. The target for this is less than 10%. While this target has been met for the last several years, the network continues working with COPFS to further improve care and support for those affected.

Family experiences of the coronial investigation: A study by the Mesothelioma UK Research Centre

By Dr. Bethany Taylor, Dr. Sarah Hargreaves, Prof. Angela Tod and Prof. Clare Gardiner, University of Sheffield



Introduction

This research study is the first to investigate bereaved family members' experiences of the coronial investigation* when a person has died from mesothelioma. We designed our study to answer the following research question: "How do family members experience coroner involvement following a mesothelioma death"? The methods we chose to best answer this question are outlined in the following section.

The Mesothelioma UK Research Centre is based at the University of Sheffield. Established in 2020, and funded by Mesothelioma UK, the centre conducts a portfolio of robust and rigorous research with a reputation for excellence. We work closely with Mesothelioma UK, health, advocacy, legal professionals, patients and their families to improve the experiences of people affected by mesothelioma.

* For ease of reading, the terms 'coroner' will be used in placement of procurator fiscal and 'inquest' in placement of Fatal Accident Enquiry for the remainder of this section.

Methods

Ethical approval for the study was given by the University of Sheffield, and people with lived experience were involved throughout.

This study had three stages:

1. Consultation

We held a series of online meetings with people who had lost a family member to mesothelioma and with professionals who work in this area. These discussions helped shape the study using both personal experience and expert knowledge.

Participants included:

- Nine people from three mesothelioma bereavement support groups
- The Mesothelioma UK Research Centre's Patient and Public Involvement panel (25 members)
- The Mesothelioma Coroner Focus Group (15 members)
- Nine mesothelioma Clinical Nurse Specialists

2. National survey

We designed a survey based on earlier discussions and existing research. It included 33 questions about what it was like for bereaved families to go through the coronial process and inquest after losing someone to mesothelioma. All participants were over the age of 18 years, lived in the United Kingdom, could read and write in English and had lived experience of the coronial process after their family member had died of mesothelioma.

3. Interviews

We also spoke in more depth with some bereaved family members to learn about their experience with the coroner. These conversations covered what happened, what went well, what could be improved, and how the experience compared to what they had expected. Interviews were done by video or audio call, depending on what each person preferred. They lasted about an hour and were recorded and transcribed. Personal details were removed to protect people's privacy. We looked at the survey and interview responses to find common themes in people's experiences.

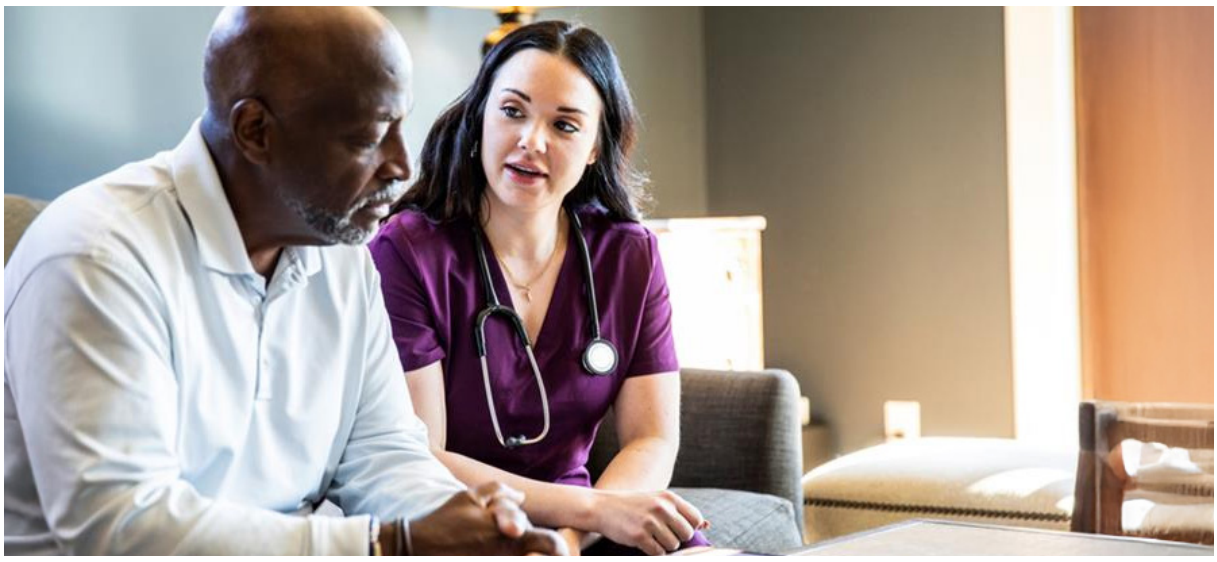
Over 50 individuals were involved in the consultation exercise. The survey received 39 responses from bereaved family members with experience of the coronial process. Thirteen survey respondents later took part in a semi-structured interview. This table describes the characteristics of the 13 interview participants.

Participant number	Location (country)	Age band	Relationship to deceased	Time between diagnosis and death (to nearest month)	Type of mesothelioma
P1	England	40s	Daughter	1	Pleural
P2	England	60s	Wife	18	Pleural
P3	England	50s	Daughter	22	Pleural
P4	England	70s	Wife	2	Pleural
P5	England	60s	Wife	27	Pleural
P6	England	60s	Daughter	5	Pleural
P7	England	40s	Daughter	30	Pleural
P8	Scotland	30s	Daughter	3	Pleural
P9	England	40s	Daughter	8	Pleural
P10	England	60s	Husband	20	Peritoneal
P11	England	60s	Wife	16	Pleural
P12	England	60s	Wife	18	Peritoneal
P13	England	40s	Daughter-in-law	1	Pleural

Key findings

Eight themes about family members' experiences of the coronial process were identified. These are each described below. Pseudonyms are used throughout.

1. There is a lack of understanding among bereaved families about why a coronial investigation is required and what this involves
2. Informing families of the need for a coronial investigation near the end of life or after death can exacerbate stress and emotional trauma
3. Variation in coroner procedure across the UK impacts on family member experiences
4. The inquest can be both informative and emotionally challenging
5. Sensitive and clear communication enhances family members' experience of the coroner process
6. Timelines and clear expectations matter to families
7. The coronial investigation can have a profound impact on family members' mental health and wellbeing
8. There are gaps in information and support after a mesothelioma death



Finding 1:
There is a lack of understanding among bereaved families about why a coronial investigation is required and what this involves

Almost all participants conveyed a sense of uncertainty and confusion regarding the nature and necessity of a coroner's investigation. Many were unclear about the purpose and process of a coronial investigation following a mesothelioma-related death, with some questioning its relevance, especially when a histological diagnosis had already been established during the individual's lifetime. Others had misconceptions about both the investigation's purpose and its procedures.

"I didn't really know what that [coroner involvement] entailed, if I'm perfectly honest. And it probably would have been good to get more information about why and what that was." (P8)

"I think people think, well, why does there have to be an inquest? Will I be questioned? Because that's one thing my mum said, why is there an inquest, is it because he died at home? Do they think I did something wrong?" (P9)

Finding 2:
Informing families of the need for a coronial investigation near the end of life or after death can exacerbate stress and emotional trauma

Sixty-nine percent of survey participants (n=27) reported learning about the need for coroner involvement near the end of life or after the death of the person with mesothelioma. Findings suggest that receiving this information at this late stage can cause additional distress and emotional trauma. This period is already difficult, as people are often overwhelmed by the physical and emotional demands of end-of-life care or grieving.

"I think had we known before, then we would have been able to prepare and actually just put that out of our minds. Because it was brought to our attention literally within hours before he died, it wasn't good, and we struggled massively with that." (P9)

While family members acknowledged that there is no ideal moment for these difficult conversations, they largely agreed that knowing before the end of life was preferable.

"I think as early as possible really, so you know that is something that is going to happen during the journey and not at the end when you've got so many other things going on in your mind." (P12)

The findings also suggest that a person's ability to absorb information may be significantly impacted by the emotional distress they are experiencing or the overwhelming amount of details they receive.

Finding 3:
Variation in coroner procedure across the UK impacts on family member experiences

Survey and interview data revealed significant variation in how investigations are conducted across the UK, and the impact this has on the experiences of family members. Examples of variation include:

Police attendance: Three of the 39 survey respondents reported that a police officer attended after the person died of mesothelioma. Despite efforts by the police to manage the situation sensitively, the findings suggest that for families already navigating the unique difficulties of a mesothelioma death, police attendance adds an extra layer of complexity at this challenging time.

"You know it's got to happen [police attending], but because of the timing, it's not ideal. You just accept it." (P7)

Post-mortem: Twelve of the 39 survey respondents (31%) reported that a post-mortem was required for their family member. Of these, eight were satisfied with the decision, and 11 felt they received sufficient information to understand why the post-mortem was needed and what it involved. However, five of these 12 people (42%) experienced delays to the funeral as a result of the post-mortem.

Some participants valued the information provided by a post-mortem, particularly in cases where there had been no confirmed diagnosis during the person's lifetime or where the PM findings were crucial for a civil compensation claim. However, the majority found the process deeply distressing.

Three interview participants described feeling overwhelming relief upon learning that a post-mortem would not be necessary. For some, the very possibility of a post-mortem caused unnecessary anxiety during an already devastating time.

"It was such a worrying time, and I feel that if the person has been diagnosed officially with mesothelioma, a post-mortem should not be required. It would make a heartbreaking time a little easier knowing this wouldn't be happening." (Survey response)

Our study suggests that the need for, or even the potential for, a post-mortem can exacerbate families' distress and that providing early clarity on whether a post-mortem will be required can help ease this burden.

Finding 4:
The inquest can be both informative and emotionally challenging

Participants reported different types of inquest: online (n=2), in-person (n=17), and documentary (n=7), while some were unsure (n=5). Of the 39 survey respondents, 38% (n=15) attended. Reasons included honouring their family member, gathering information, representing family, or following advice to attend. Reasons for not attending (44%, n=17) included emotional distress, discouragement from family, travel difficulties, being told attendance was unnecessary, the inquest being documentary or not being invited.

Some family members described the inquest as informative but also upsetting and intimidating due to its formality and unfamiliarity. One participant described attending the inquest as *"walking into the unknown." (P12)*

While some participants described the process as *"smooth"* and conducted with *"sensitivity and kindness"*, most desired more information beforehand.

"I think maybe a little bit more information out there for people of what it involved would be a good thing, if only to make them realise that in a lot of cases it's not a big deal…it's just really a case of giving people the information so they don't have to make it up." (P10)

When asked about advice for people embarking on the coronial process, nearly all participants advised bringing a family member or friend to the inquest for emotional support and to help absorb information. Those who had a staff member or volunteer meet them at the door and answer questions found this helpful.

Finding 5:
Sensitive and clear communication enhances family members' experience of the coroner process

The majority of family members (29/38 responses) (71%) were 'very satisfied' or 'satisfied to some extent' with their communication with the coroners officer. The data therefore contains many examples of good practice. Participants highlighted the importance of sensitive, respectful communication and the impact it had on their experience of the inquest. Informing families in advance about upcoming phone calls and warning them if the information might be upsetting helped.

"The coroner was extremely nice and very sensitive to the fact that my family and I were still traumatised by my husband's death." (P14)

"I felt that they treated us with real kindness and courtesy." (P6)

Referring to the person who had died by name was another way one participant felt that the coroner demonstrated respect for the family and their loss, *"she used his name, [Dad's name]." (P9)*

Unfortunately, some participants reported negative experiences when communicating with the coroner or coroner's officers. Instances of poor practice included being sent incorrect links for virtual inquests and missing key documents. One participant was distressed that a crucial statement from their late husband was left out. *"His voice wasn't heard, and that was the important voice."* (P2). Another issue was incorrect information on official documents, such as listing the wrong location of death on the death certificate. One person was not pre-warned that the press might attend the inquest. These oversights contributed to stress experienced by grieving families.

An overall lack of communication was reported and this included unanswered calls, delayed responses, and unclear updates, leaving families feeling frustrated and disregarded:

"So, for us, the coroner's experience was not good. I think we had to do a lot of the chasing." (P7)

"The lack of communication, it was really upsetting. It really made me feel as if it didn't matter. He was just a number in a book...it just left me feeling really anxious as well, because I kept thinking should I ring up? Or maybe, best not, they will contact me. I felt really disregarded." (P11)

Families appreciated the coroner taking the time to manage their expectations and give prior warning to potentially distressing aspects of the process. One example is the information file that is referred to throughout the inquest and includes information about the person's life, their asbestos exposure and medical notes. Several family members who had not received the information file prior to attending the inquest found hearing the information upsetting.

"I first heard this information at the inquest which was quite difficult to process. It would have been much better if i had been able to read it prior to the actual inquest." (Survey response)

"She [coroner] did say that it [the information file] might bring up quite a lot of memories for us. She was very good at how she explained what the report looked like." (P1)

Finding 6:
Timeliness and clear expectations matter to families

For 46% of participants (n=17), the coronial investigation was completed within a month, with timelines ranging from under one month to seven months (mean: 2.38 months). Over half (n=19) agreed that the process was completed in a suitable time frame, while others felt neutral (n=11) or dissatisfied (n=8) with the time frame.

Delays and a lack of updates caused distress. Families valued clear timelines and proactive communication, especially when expectations changed. Many tracked the process closely and adjusted plans accordingly. Some expressed frustration when promised updates were delayed.

"If someone says they're going to phone you on Monday probably and they phone you on Friday, you've spent the whole week waiting for a phone call. So accuracy I think would be good." (P10)

Families emphasised the importance of clear and sensitive guidance before the inquest, including logistical details (transport, parking, what to wear) and what to expect afterward (e.g., obtaining the death certificate).

Finding 7:
The coronial investigation can have a profound impact on family members' mental health and wellbeing

Our findings indicate that the emotional burden of mesothelioma is further intensified by the coronial investigation. While some family members viewed the process as *"just a formality for us" (P7)*, the majority found that it heightened their emotional distress. The knowledge that mesothelioma is a preventable disease added to their grief and deepened the trauma of losing their family member.

Findings suggested that the coronial investigation prolonged the grieving process. This extended period of uncertainty and emotional strain made it difficult for family members to fully process their loss. Once the investigation was concluded, some people described a sense of closure that enabled them to grieve their loss.

Finding 8:
There are gaps in information and support

Participants accessed support from asbestos support groups and the national charity Mesothelioma UK. Some acknowledged the assistance provided by funeral directors or solicitors. Despite this, many highlighted a broader lack of support throughout the process.

"When dad died the support faded away." (P3)

Gaps in support included a lack of clear guidance on what a coronial investigation involves, why it is required, and what the process involves. Some participants described having to seek out this information themselves.

"I sort of Googled what an inquest actually is…but you should be told what an inquest is, what the process is and what information is going to be used at your particular inquest." (P13)

Conclusion

This is the first study to explore how families experience the coronial process following a death from mesothelioma, an industrial disease. Our findings indicate that this process can add to the emotional strain families already face while grieving. Variations in local practices and the absence of a standardised approach make it more challenging to share information with families about coronial procedures. In some cases, specific local processes can further add to the burden on families.

Although we found many examples of good practice, there are still gaps in the information and support available. Clear, timely communication and consistent procedures are key to reducing distress and helping families feel supported during this difficult time. These findings have important implications for both healthcare and coroner services. They offer a strong evidence base for the recommendations that follow in this report. We also aim to create practical tools based on this evidence to help guide charities, researchers, and other organisations in improving support for bereaved families.

If you have any questions about this study or would like further information please contact Bethany (btaylor3@sheffield.ac.uk) or Sarah (sarah.hargreaves@sheffield.ac.uk).

You can also visit the Mesothelioma UK Research Centre website at www.sheffield.ac.uk/murc

Recommendations

By Sarah Thomas, Dr. Bethany Taylor, Dr. Sarah Hargreaves and Prof. Nick Maskell

We recognise that practice and procedures can vary widely across the UK. These recommendations are intended to encourage reflection on the challenges within existing systems, explore opportunities for change or improvement, and inspire you to create tailored solutions.

1. Recommendations for the Coroner's Service

- To consider a national unifying policy removing the need for police attendance in the event of an expected death at home from mesothelioma.
- To consider whether there is a need for a post-mortem examination if there is in-life proof of diagnosis.
- During a post-mortem, lung blocks should be taken if fibre analysis is requested by either side in a legal case. Mesothelioma UK's medical and legal specialists consider fibre analysis unnecessary in most mesothelioma cases where there is clear evidence of asbestos exposure, or where pleural plaques are visible on scans or during the post-mortem.
- To coordinate with local registrars to ensure that the next of kin are provided with a Tell Us Once code when the interim death certificate is issued.
- To refer or signpost patient/family members to mesothelioma support networks for additional information and support on the coronial process.
- To proactively engage with and provide information on local procedure to stakeholders who support people with asbestos-related illnesses.
- To be conscious that families who are dealing with grief and stress can struggle to understand and retain information, especially if it is only given verbally. Consider using written information such as email or letter to back up verbal communication.
- Ensure communication remains open, understanding, and focused on the family's needs, providing regular updates - especially when addressing sensitive subjects such as post-mortems and the location of the body.

2. Recommendations for healthcare professionals involved in the care of mesothelioma patients and their families

- Familiarise yourself with the local coronial procedure for mesothelioma related post-mortems, deaths at home and police attendance. Contact your local coroner's service for information and advice.
- Ensure that the patient's primary care providers are aware that the coroner will need to be informed of the death. Consider how best to achieve this in your area.
- Discuss the coroner's involvement with the patient and next of kin at an appropriate time for them, with an awareness that finding out at end of life (or after death) can cause additional distress.
- To refer or signpost patient/family members to mesothelioma support networks for additional information and support on the coronial process.
- To look for opportunities to raise awareness on this issue, such as educational days, forums, lung cancer nurse network days etc.

3. Recommendations for legal professionals with mesothelioma clients

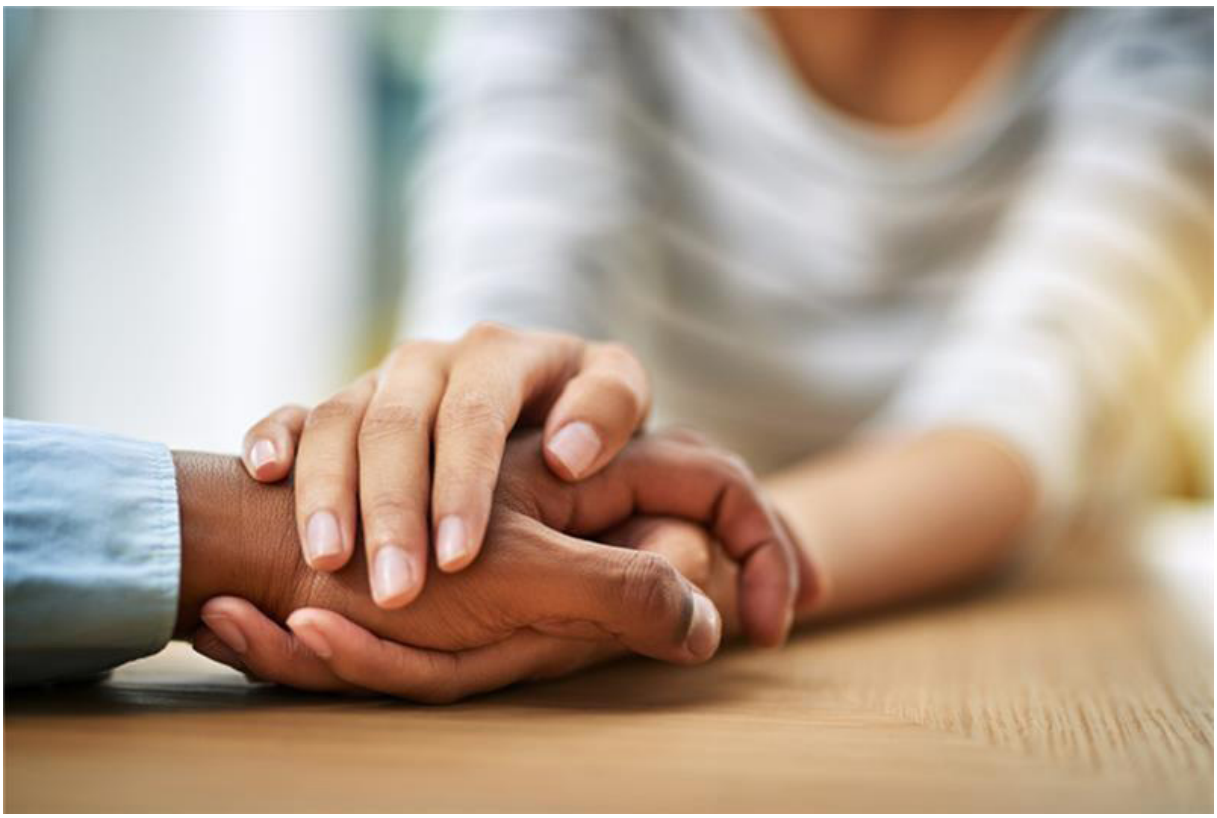
- Discuss the coroner's involvement with your client and next of kin at an appropriate time. This is especially important if:

    - a civil compensation case is still in progress at the time of death.
    - the diagnosis has not been confirmed and a post-mortem examination will be required to proceed with a civil case.

- Ensure your client/next of kin is aware the coroner will require information about both ongoing and concluded civil compensation cases and that they know how to provide this.
- To refer or signpost your client/next of kin to mesothelioma support networks for additional information and support on the coronial process.

4. Advice for mesothelioma patients and their families

- Be aware that, due to the rarity of mesothelioma, there can be a lack of knowledge within primary care services (e.g., GP's, district nurses) that the coroner will need to be informed.
- If you would like to know the local coronial procedure for deaths at home, contact your local coroner's office or contact Mesothelioma UK and we can make enquiries on your behalf.
- If a civil case is ongoing or concluded inform the coroner of the solicitor's involvement and provide their contact information.
- People are often unfamiliar with the coronial process and will usually have questions. Your coroner's officer is there to support you and provide any information you require.
- While experiences of the coronial process can vary, there is support available if you are finding it confusing, emotional or difficult. Please contact Mesothelioma UK for information about support in your area.



Biographies

Sarah Thomas

Sarah is the Benefits Manager for Mesothelioma UK, leading a team that delivers complex benefits advice and advocacy for people affected by this asbestos-related cancer. She is committed to improving access to financial support and works closely with medical and legal professionals. Sarah also has a particular interest in supporting families with practical matters following a bereavement.

Dr. Bethany Taylor

Bethany is a Research Fellow at the Mesothelioma UK Research Centre (MURC), at the University of Sheffield. She has eight years' experience in mesothelioma research, and her work focuses on addressing inequalities, improving communication between patients, families and professionals, and raising awareness of the ongoing risks of asbestos.

Dr. Sarah Hargreaves

Sarah is a Research Fellow at the Mesothelioma UK Research Centre (MURC) at the University of Sheffield. She has been a post-doctoral researcher in health since 2014 and joined MURC in 2021. Prior to this she had a 20 year career in the NHS as an information professional, latterly as a Senior Public Health Analyst. In 2025 she was awarded a Yorkshire Cancer Research Fellowship to explore supporting decision making on place of death and care in mesothelioma.

Beth Liddle

Beth Liddle is a solicitor in Irwin Mitchell's Asbestos and Occupational Disease Team, based in Newcastle upon Tyne. She specialises in asbestos-related disease claims, including lung cancer, asbestosis, and pleural thickening, and assists on complex litigated mesothelioma cases. Beth is passionate about helping clients and their families through challenging times and values working within a supportive, collaborative team.

Carolyn MacRae

Carolyn MacRae is the Mesothelioma UK CNS based at the Queen Elizabeth University Hospital, Glasgow and Mesothelioma UK CNS Team Lead for Scotland. She provides specialist advice and holistic support for those affected by a diagnosis of mesothelioma throughout the care pathway and works with the Scottish CNS team to help deliver Scottish Mesothelioma Network and Mesothelioma UK goals with the aim of improving patient care and outcomes.

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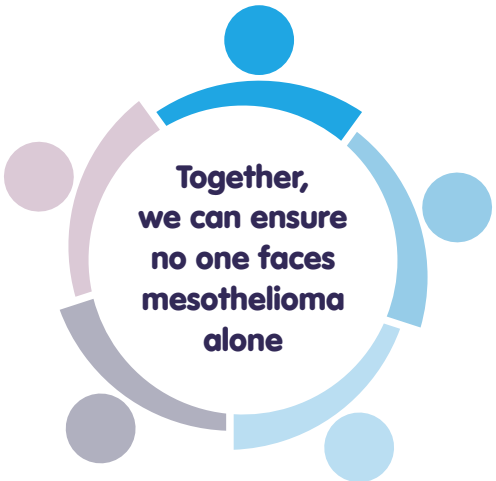

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