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MESOTHELIOMA UK

University of Sheffield

Mesothelioma & Education Workers Study (MEWS)

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Summary

Most UK schools contain asbestos. This has led some to ask whether those working or learning within them are at risk of exposure to asbestos and subsequently to developing mesothelioma.

Mesothelioma charities and those who care for people affected by mesothelioma have noted that former school workers seem increasingly to appear in their caseload. The objective of this review was to ask what is known about the topic in terms of the numbers of former school-based education workers (SEWs) developing mesothelioma and their experiences of disease presentation, diagnosis, treatment and care.

This report is divided into two main sections followed by a short conclusion. The first section concerns education workers' experiences. These were uncovered by a review, first, of academic literature and, second, of a wider range of UK sources. It found that education workers share some of the experiences of others with mesothelioma, particularly those from the traditional high-risk heavy industries. However, there were also important differences. These centred on causation and included shock and surprise that asbestos was present in schools, and a concern for others who might be exposed, particularly children. Coroners were sometimes reluctant to record mesothelioma as resulting from exposure to work; this reinforced the narrative that schools are not high risk. Because of that narrative, school workers may have difficulty in getting diagnosed in the first place and then, subsequently, with obtaining benefits, such as Industrial Injury Disability Benefit (IIDB).

The second section concerns, first, the numbers of SEWs who develop mesothelioma and, second, the risk to pupils. The official figures show a gradually increasing trend of deaths due to mesothelioma in the occupational group "Teaching and Educational Professionals". And in the most recent ten-year summary, in terms of the risk to women, teaching and educational professionals are now the highest risk group for mesothelioma. Of additional concern is that these figures do not include the large number of school ancillary workers, such as caretakers. Neither do they include those who die over the age of 74, as many with mesothelioma do, nor those who leave teaching to pursue other paths before retirement.

We therefore sourced the figures for the IIDB via a Freedom of Information request. This showed that the numbers of former SEWs who successfully applied for the benefit was far higher (averaging 70 per year) than the number of deaths in the official figures (averaging 23.1 per year). And this is even though IIDB is not paid automatically to former education workers with mesothelioma; indeed, it must be applied for. As such, while the IIDB figures show rates of mesothelioma amongst SEWs to be much higher than official figures suggest, nonetheless are still likely to be an underestimate.

Regarding pupils, there is little data to go on. However, there are some indications of concern, such as a large percentage rise (although small in numbers) in those developing mesothelioma below the age of 40. In addition, modelling suggests that if SEWs develop mesothelioma due to asbestos exposure, so then will some pupils in later life.

The study that this report is based upon has led to two published articles (1,2).

If you would like to comment on the report or discuss this or future research, please contact us at the Mesothelioma UK Research Centre (MURC).

Patient Stories

Gerry Courtney

Gerry spent 40 years teaching in East London displaying a dynamic approach to the pushing of boundaries, initiating numerous developments to improve the learning and lives of young people, there was never a problem that couldn't be solved or at least improved.

A community spirited woman, chairperson of the Maldon regatta for 20 years transforming it into a vibrant celebration that brought joy to visitors and locals alike, also chairing the Harbour commissioners improvement committee shaping the future of its cherished port ensuring the safety and buoyage and the continuing use of this popular port. Gerry was a true adventurer taking her boat sailing up to Iceland and the Baltic states and navigating in the 2007 Fastnet race.

Gerry was diagnosed with mesothelioma in 2015 with a prognosis of 15 months. She took part in every trial she was eligible for, not only for the hope of extra time but for the development of treatments for future patients. She shared her illness with only a handful of close friends and family, adamant it was not going to define who she was. During COVID she clocked up over 200 hours volunteering at a vaccination centre despite being vulnerable herself.

A true philanthropist who sadly passed away on November 1 2023 after a hard battle. Gerry's legacy and service will continue to inspire us all. What a woman!

Patient Stories

Dawn Hamilton

My lovely mum, Dawn, was a primary school teacher. She was born in Tamworth, Staffordshire. She did her teacher training in Manchester, and started her career there, before moving to live and work in Cumbria.

My brother, Tom, and I are from a family of teachers. We never thought it was a profession that would take the life of our mother.

What began with some breathlessness, pneumonia, and a chest drain, ended with the utterly devastating diagnosis of mesothelioma. She said she still felt like a healthy 64-year-old.

Mum had a very positive attitude to life, but because mesothelioma is a terminal cancer, at first she didn't think having treatment was worth it. After some persuasion she accepted the chemotherapy being offered. It made her very unwell, but good times were certainly had too.

Mum was concerned about all the pupils in her schools, who might get diagnosed with mesothelioma in the future.

She died two and a half years after her diagnosis. Primary school teachers should not be dying from an 'industrial disease.' This type of cancer can be prevented.

I miss her every day.

- Peggy Walker

The Mesothelioma and Education Workers Study (MEWS)

Introduction

Malignant Mesothelioma (MM) is a rare, life limiting and aggressive cancer with a high symptom burden (3). Incidence rates have been increasing since cases first started to be systematically recorded in the 1960s. Incidence is higher in certain occupational groups including asbestos mining and disposal and construction industries (4). These industries are male-dominated and as a result the disease itself disproportionately affects men (83%) (5).

The UK has the highest rates of mesothelioma in the world (6,7). A 2019 report predicted that cases in the UK would peak at approximately 2500 per annum but then begin to decline (8). However, the long latency period and continued use of asbestos worldwide suggests that mesothelioma will continue to be a disease burden throughout the 21st century (9). Nonetheless, says the report, the decline or elimination of new asbestos manufacture and use in the UK should see the turn in the tide cautiously predicted in the 2019 report. The report's caution was based on two uncertainties about the longer term.

- One is that the report assumes there are no other important higher-risk industries beyond those already identified. By contrast, some have spoken of a third wave of mesothelioma amongst those who work in buildings where asbestos is in situ, particularly where it is poorly maintained, such as schools and hospitals. For example, a report into the condition of school buildings undertaken by the National Audit Office for the Department for Education states raised many concerns about the condition of its schools. A 2023 report focused on the poor condition of asbestos in UK schools, hospitals, commercial premises and houses. It found high levels of medium to high damage in education and healthcare buildings. Where there was damage, this included amosite and crocidolite, the two most dangerous types of asbestos.

- The second uncertainty concerns the rate of decline, which might be slower than expected if the population at large is, or has been, exposed to greater levels of asbestos than predicted or assumed in the mathematical modelling.

One way in which these uncertainties have revealed themselves is in the mesothelioma death rates by gender. In men, the mesothelioma rate per million seem to have peaked in the period 2014-16; in women, the peak has not yet passed (see HSE 2024, page 5). This supports the idea that the rates in heavy industry may have peaked but those other occupations, previously thought to be low risk, may now come to the fore. Since 2020, the data has been disrupted by Covid which might have had the effect of masking deaths due to other causes – those with mesothelioma may have died from Covid, for example.

Schools are a particular concern. In 2013 the Committee on Carcinogenicity said that around 75% of schools have "some buildings that contain asbestos-containing products" [para. II] (10). (Subsequent Freedom of Information Requests put the figure a little higher, up to 86%) (11). In addition, the report says that,

"Because of differences in life expectancy, for a given dose of asbestos the lifetime risk of developing mesothelioma is predicted to be about 3.5 times greater for a child first exposed at age five compared to an adult first exposed at age 25 and about five times greater when compared to an adult first exposed at age 30." [Para. V]

In other words, children are more likely to live long enough after exposure to develop mesothelioma. It follows that the phenomenon of mesothelioma developed from asbestos exposure in schools is important. In addition, it is likely that the experiences of SEW mesothelioma patients will differ from those exposed through the more standard industrial routes.

The objective of the scoping review presented in this report was to identify and synthesize studies regarding the experiences of presentation, diagnosis, treatment and care for school-based education workers (SEWs) with mesothelioma. The research question was: What is known regarding the experiences of presentation, diagnosis, treatment and care for school-based education workers with mesothelioma in the so-called big five nations (UK and Ireland; Canada; New Zealand, Australia and USA)? In addition, we used the opportunity of the scoping review to uncover information concerning the extent of mesothelioma amongst SEWs in the UK. As the purpose of the review was to identify available evidence, this indicated the need for a scoping rather than systematic review (12).

This report is divided into two main sections. The first reports the data on the experiences of school-based education workers. The second reports the data on the extent of mesothelioma amongst present and former school-based education workers and former pupils in the UK.

1. The experiences of School-based Education Workers (SEWs)

1. Materials and methods

The eligibility criteria were:

a) Publications from the so-called big five predominantly Anglophone nations (UK and Ireland; Canada; New Zealand, Australia and USA).
b) Primary original research studies investigating SEWs' experiences of mesothelioma.
c) Online, newspaper and other reports of SEWs' experiences of mesothelioma [in the UK only] [time line from 2000].
d) English language: this was required as translation resources were not available for the project – however, given eligibility criterion a) above, we expected most resources to be in English.

The information sources used were:

- For primary research studies Medline, CINAHL, Scopus, PsychINFO, Education database and British Education Index; plus Google Scholar; in addition, ProQuest for doctoral theses.
- For newspaper reports of the experiences of SEWs with mesothelioma in the UK only, a database of UK news sources, Nexis.
- For other grey literature: a European open access repository of information unpublished in academic journals, OpenGrey, plus YouTube and Google for video diaries, blogs and similar.

The search was performed as follows. For primary research studies, Medline, CINAHL, and Scopus using the search terms "patient experienc* OR patient narrativ* OR patient stories OR patient story OR patient perspectiv* OR patient perception* OR "psych*" AND mesothelioma. PsycINFO, Education database and British Education Index were searched using the term "mesothelioma". ProQuest was searched using the term "mesothelioma". In addition, the search terms for Medline were used in Google Scholar and the first 1000 items were checked for additional articles.

The records were reviewed for reports from SEWs. Articles and theses of potential relevance were downloaded as full text and formally searched for relevant terms, such as teachers and janitors, and for the term 'school' in ten-word proximity with 'asbestos'.

For the Nexis search of online, newspaper and other reports of SEWs' experiences of mesothelioma, used the terms Mesothelioma AND Schools. The search was narrowed by i) date (from 2000), ii) Publication location Europe/United Kingdom, iii) Subject (Medicine and Health, Law & Legal system, Labour & Employment, Reports, Reviews & Sections, and Population & Demographics), iv) Industry (Educational Services and Health care).

2. Results

The PRISMA chart (Appendix 1) shows the figures for the search relating to SEWs' experiences of mesothelioma. From the search of academic literature, 1322 primary research studies were identified after removal of duplicates. Of these, 1291 were excluded as clearly irrelevant. Fifteen studies were identified from other review articles. The resulting 46 were reviewed. Of these, all 46 were excluded: although a few referred to schools or education workers, none had information on the experiences of SEWs with mesothelioma.

The Nexis search resulted in 1323 hits, which were examined for relevance by searching for the following terms: teacher, janitor, caretaker, dinner, kitchen, secretary, headmaster, headmistress, cleaner, staff. One hundred and twelve articles had at least one of these terms and were downloaded to a spreadsheet. These articles were generally short reports from coroners' courts or as part of a legal team's call for witnesses. In addition, we found a report published in December 2009 and updated in March 2014. This was a compilation by Michael Lees[1] of news articles including asbestos incidents in schools as well as reports relating to illness in staff and pupils (13). The method for finding these articles is not described. However, in the search period it describes, up to 2014, it had found a small number of relevant articles that were missing from our search; these were added.

This wider literature had found physical, emotional and social impacts in patients with mesothelioma.

From our search and the Lees report we found reports on 84 current or former education workers who had been diagnosed with mesothelioma. Most had died by the time of the report. Nineteen were non-teaching staff such as caretakers, cleaners, dinner ladies and one secretary; the remainder were teachers and head-teachers. Among the 84 cases, six had online video resources with relevant material. These were transcribed and added to the data. All data were then entered into a qualitative analysis software package, QUIRKOS. The data were analysed thematically initially using a framework of themes developed from the literature on the experience of mesothelioma patients in general, rather than specific occupational groups, as found in reviews by Moore et al (14) and Bonafede et al (15). In addition, we used a review with case studies by Buchholz (16).

This wider literature had found physical, emotional and social impacts in patients with mesothelioma. Physically, the condition has a substantial impact with a high symptom burden, particularly of pain and breathlessness. Emotionally, the impact is perhaps even greater, with high levels of fear, anxiety, depression and feelings of isolation. Anger is also noted, related to exposure being in schools, which should be environmentally safe: this emotion was also strong in family members. In this regard, it is worth noting also that the emotional impact on carers and families is also large. Socially, patients noted

1. Michael Lees MBE is the widower of Gina Lees, a nursery school teacher who died of mesothelioma due to asbestos exposure at work in 2000. He has campaigned on this issue and was a founder of the Asbestos in Schools Group.

the impact in terms of changes of role, such as loss of work, changes in relationships, such as increased dependency on partners, and in terms of increased social isolation.

In the articles we reviewed, physical and emotional impacts were also apparent in education workers and their family members. There was little on the social impact, a point we return to in the discussion. The physical aspect of the mesothelioma was reported in three stages. The first related to the lead up to diagnosis, with people reporting increasing levels of pain, breathlessness and tiredness as well as oddities such as a rattle in the chest. The second related to ongoing symptoms, such as pain and the problems of the different treatments. The third concerned the end-of-life and was often reported by relatives and carers rather than the patients themselves. Unsurprisingly, the physical impacts of mesothelioma in education workers are the same as those reported by the wider group of mesothelioma patients in the reviews noted above.

Our search found little on the social impacts of mesothelioma, such as changes in roles and relationships, in the reports. There was more said concerning emotional impacts. As with physical impacts, many were similar to the wider group of patients reported in the literature, such as anxiety, fear and shock on first learning of the diagnosis and its implications. Alongside this, there is also at least one report of what has been termed the nihilism of clinicians in relation to this diagnosis (17–19).

"A consultant turned up and she told me quite blankly that I had less than a year to live so I was in considerable shock. It seemed rather sudden and they diagnosed mesothelioma." **John Slade, a teacher with mesothelioma**

More marked than in the wider group of patients, however, was disbelief on learning the likely origin in asbestos at their place of work. Some patients were surprised to find themselves being quizzed about their exposure to asbestos.

"They started asking me whether I've been exposed to asbestos and I was thinking no I don't think so. I did you know and the chest surgeon didn't say you know he didn't, couldn't believe a teacher would have it because I wasn't in any of the industries known for this disease."
Rosie Peters, a teacher with mesothelioma

More often there was surprise and anger that asbestos which could cause mesothelioma was present in schools at all. In addition, SEWs often had no awareness or training in relation to asbestos.

"It's quite shocking to think that I paid that heavily for a job I really enjoyed."
Elizabeth Bradford, a teacher with mesothelioma

"Teaching is not a profession you associate with asbestos exposure." **Margaret Worthington, a teacher with mesothelioma**

Whether or not patients had been surprised by their exposure to asbestos, a common reaction was anger. In some cases, this was anger at misinformation and mismanagement.

"At least four of the schools my wife taught in had no asbestos management plan and were unaware of the whereabouts of asbestos. One school had no idea that any asbestos existed at all, let alone that every ceiling, wall and radiator contained it." **Michael Lees, husband of Gina Lees – a teacher who died of mesothelioma**

"In the case of my husband the solicitors tried to track down the source of asbestos in the London school where he worked but there was only a very scanty record, and by that I mean scrappy notes on a sheet of A4 paper."
Wife of Alan Anthony, a teacher who died of mesothelioma

"A former school cleaner and caretaker died as a result of exposure to asbestos throughout her career, a court heard yesterday… she was never told the dangers the potentially deadly substance posed, nor was she given any protective equipment such as a face mask when working with it."
Article about Brenda Butcher, a school cleaner and caretaker who died of mesothelioma

Causation was by far the main theme in the articles we reviewed; it had two elements, initial exposure and concern for others. Relating to initial exposure, some of the articles included requests from the patient's legal team for witnesses who had worked in the same school or schools as their clients in an attempt, presumably, to build a case for negligent asbestos exposure. Other reports were simply of patients or carers reporting their memory of working in the school and their beliefs concerning where they were exposed to asbestos. These are summarised in Table 1.

Cause	Teaching staff	Other staff
Pinning items to walls and boards	6	
Ceiling or floor tiles	2	2
Work on lagging of pipes and cables		2
Art and science room specialised equipment	3	
Building work in the school	3	
Storage areas	1	
Wear and tear, vandalism	4	
Boiler room	3	3

Table 1: Possible sources of exposure

Noteworthy here is the cause related to wear and tear, and vandalism.

"Frighteningly, the disturbance was what could be described as natural 'wear and tear' – pupils disturbing it with bags, rulers etc." **Legal representative of Joan Henry, a teacher who died of mesothelioma.**

"A boy had made a hole in the wall at one time and pupils would kick at the walls. There were holes in the corridor walls." **Elizabeth Belt, a teacher who died of mesothelioma**

This has implications for the management of asbestos in these environments; we return to this point in the discussion.

In many cases, however, no known causes were cited other than, for example, a dusty environment in a school known to have asbestos present. As noted above, for some coroners this was sufficient to conclude that the school or schools was the origin of the asbestos exposure (in the absence of any other likely exposure).

The second element in the theme of causation was concern for others, particularly pupils. Given that i) we found 84 cases of education workers developing mesothelioma in reports and ii) it has been suggested that up to nine pupils will develop mesothelioma for every such case then we might have expected many reports of such cases. In fact, we saw very few, a point we return to in the discussion. Despite this, many former education workers and their carers were sometimes concerned about colleagues' and, in particular, pupils' possible exposure.

"I keep wondering about those children. I'd like to know if there have been any repercussions to those children but how do you know."
Elizabeth Bradford, teacher with mesothelioma

"What was also incredibly upsetting to Pearl was the idea that children may have been put at risk on those premises. It doesn't bear thinking about." **Freddie Davis, husband of Pearl Davis a teacher who died of mesothelioma**

"Mum was incredibly angry when she got her diagnosis as she was working in a school with asbestos. She worked in schools across Buckinghamshire, in primary schools with five-year-olds in reception. She hadn't been able to protect them." **Lucie Stephens, daughter of Sue Stephens a teacher who died of mesothelioma**

Causation also arose in some of the articles in a different context. We noted in the introduction that official figures regarding deaths of SEWs due to asbestos exposure in schools are likely to be underestimates. Many of the articles we reviewed were reports from coroners' courts[2]. It was striking that some of these suggested inconsistency in approach. In the data sheet available with this article is a table containing the reports where the coroner's judgement is given. In 7/28 cases, the coroner records an open verdict and/or natural causes. Thus, we have, for example, one saying that

"Although there was some contact with asbestos, this was unlikely to be the cause of death." **Article about the death of Elsa Goodwin, a retired teacher who died of mesothelioma**

Another report states that

[The] coroner recorded an open verdict that SM had died from malignant pleural mesothelioma but that he could not determine if it was a natural disease. **Article about Shirley Matthews, a former school dinner lady who died of mesothelioma**

These suggested that there is some inconsistency in coroners' judgements. Where mesothelioma occurs in those who worked in industries known to be high-risk, coroners will record this as caused by asbestos exposure at work. In 7/28 cases of education workers, however, an open verdict or verdict of natural causes was recorded.

"the coroner ruled the death was industrial disease, but said it was not clear where PD had been exposed to asbestos." **Article about Pearl Davis, a teacher who died of mesothelioma.**

"But Coroner RW recorded an open verdict because he said he could not be sure asbestos at the school was the culprit." **An article about John Kelly, a teacher who died of mesothelioma**

2. Mesothelioma is an industrial disease and all deaths caused by mesothelioma are termed unnatural. Therefore, all mesothelioma deaths in the UK must be referred to the coroner's service for investigation (Procurator Fiscal in Scotland)

This reluctance was not shared by all coroners. In the remaining 21 cases, a verdict of industrial disease was given. In 11 of those cases, the coroner attributes the asbestos exposure to work in schools. For example, the following article reported the death of a deputy head who had worked only in schools and where no direct evidence of asbestos exposure had been found.

"Summing up, Gloucestershire Assistant Deputy Coroner Katy Skerrett said she was satisfied Mr MacDonald's exposure to asbestos had caused the mesothelioma and recorded a verdict of death from industrial disease." **Article about David MacDonald, a headteacher who died of mesothelioma.**

Similar judgements were made in other cases, that is, even where negligence was yet to be shown.

"The coroner said, it is clear that he was exposed to asbestos during his time working as a teacher." **Article about Joe Gallagher, a teacher who died of mesothelioma**

"[The coroner] could only conclude that she had died after breathing in asbestos while she was working in the school as there was no evidence to show she had been exposed to it elsewhere." **Article about Jean Whitwam, a teacher who died of mesothelioma**

In 8/21 cases, it is unclear from the short newspaper report whether the coroner associated this exposure with employment in school. In 2/21 cases, the coroner specifically excludes the school as a potential cause of asbestos exposure; this seemed to be largely because the coroner did not think it his or her role to apportion blame in the case under review. The significance of this point is returned to in the summary of this report.

3. Summary

The research question was: What is known regarding the experiences of presentation, diagnosis, treatment and care for school-based education workers with mesothelioma in the so-called big five nations (UK and Ireland; Canada; New Zealand, Australia and USA)? The search of academic sources suggests that there have been no studies examining this topic. We found several secondary sources in UK newspaper reports and some online video materials. We examined these for insight into the research question.

We have not, for example, quoted widely from reports of physical symptoms or emotional reactions such as depression, even though these were apparent. They are, however, common to those diagnosed with mesothelioma in all occupational groups (see, for example, those described in two literature reviews undertaken by the Mesothelioma UK Research Centre) (18,19).

The issues of difference, however, centred on causation. These included shock and surprise that asbestos was present in schools in ways that could cause mesothelioma, and a concern for others similarly exposed, particularly children.

We were surprised by the number of cases we found in newspapers; 84 is a high proportion of those education workers known to have developed mesothelioma. Newspapers would be less likely, perhaps, to report cases of former carpenters and builders who developed mesothelioma. It is the presence of danger from asbestos in schools that provokes interest and concern. It may also explain the lack of information on the social effects of the diagnosis as this may also be of less interest to newspapers.

Newspaper interest is also driven by concern for pupils. It is striking that there is no official data or modelling of how exposure to asbestos as a pupil is affecting rates of mesothelioma in later life.

There is no official data or modelling of how exposure to asbestos as a pupil is affecting rates of mesothelioma in later life.

In addition, our findings reflect a concern about management. The current law in the UK says that while the new use of all forms of asbestos is banned, existing asbestos is allowed to remain in situ provided it is in good condition and undisturbed (22). It is for this reason that many schools, the vast majority in the UK, continue to contain asbestos. However, such in-situ management needs to be set against the presence of vandalism and excessive wear and tear in schools noted in the findings of this review. An algorithm published by the UK Health and Safety Executive draws attention to,

High levels of disturbance, in area children running in and out of classroom, knocking wall panels, wall displays (23) [p.57]

Unfortunately, it is far from clear that this concern has been fully acknowledged in practice in, for example, asbestos management plans in schools that might be, as noted above, merely "scrappy notes on a sheet of A4 paper".

We move on now, in section 2, to the data on the level of mesothelioma amongst former school workers in the UK.

2. The extent of mesothelioma amongst school-based education workers and pupils in the UK

1. The official figures

In the introduction we noted that some have spoken of a third wave of mesothelioma amongst those who work in buildings where asbestos is in situ, particularly where it is poorly maintained, such as schools and hospitals. Between 2001-16 the UK Office for National Statistics recorded 305 deaths in England of teaching and educational professionals (24). Commenting on earlier but similar data, Peto et al state,

> There was little or no evidence of increased risk in non-industrial workplaces such as schools or hospitals after excluding those who also worked in higher risk jobs. (4) [p.44]

Since then, however, Peto, who is one of the UK's leading epidemiologists, has noted data of concern relating to female teaching and educational professionals. This is now the highest risk group by occupation in women for mesothelioma[3]. This is statistically significant and, in contrast to the earlier statement from Peto, constitutes evidence of "increased risk in non-industrial workplaces such as schools."

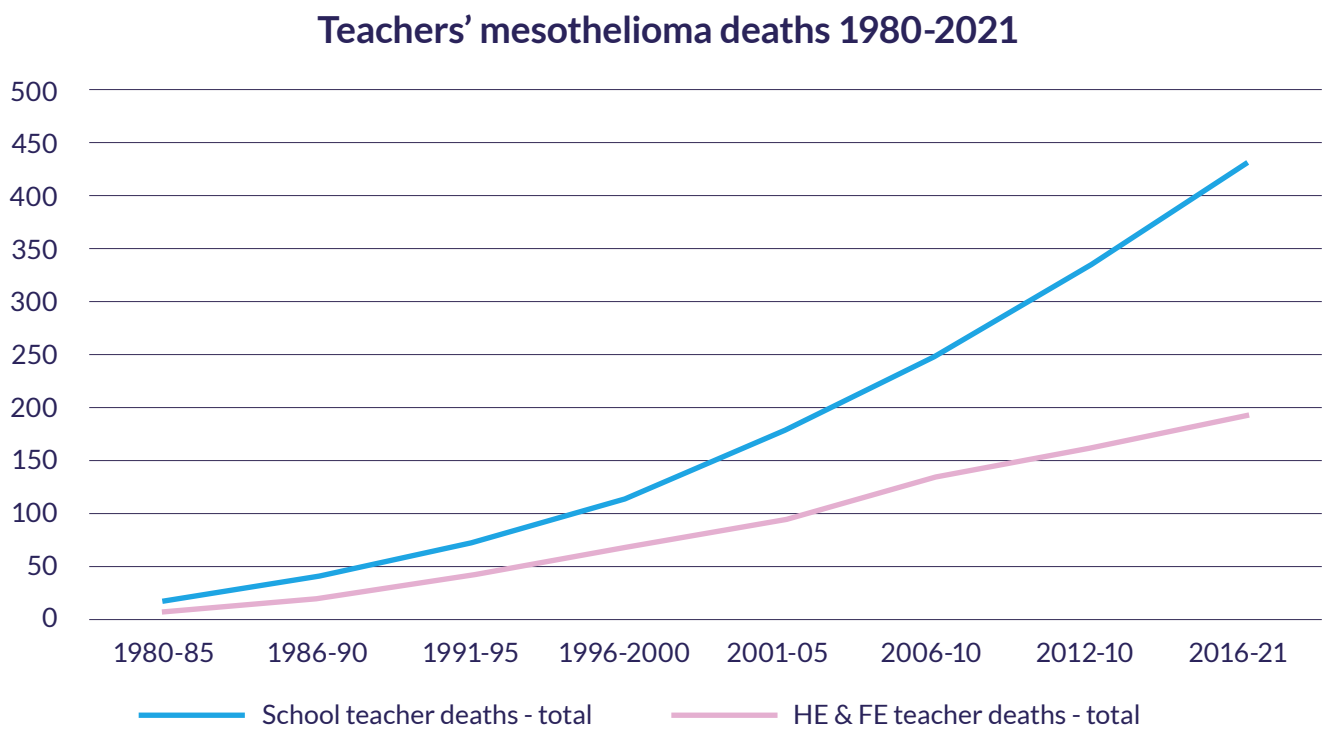
Table 1, below, shows this trend, with the top ranking of women teachers highlighted. Note that occupational categories changed in the two periods but are broadly comparable.

Major Group	Occupation	Mesothelioma	Rank
2011-21			
Male	Teaching and educational professionals	129	15
Female	Teaching and educational professionals	120	1
		249	
2001-10			
Male	Teaching and research professionals	157	11
Female	Teaching and research professionals	75	12
		232	
Bottom line	Teaching	481/21 years	22.9 pa

Table 2: Risk to teaching and educational professionals, based on ONS data

3. Guardian report 15 Jan 2023:
https://www.theguardian.com/global/2023/jan/15/uk-unions-call-in-cancer-expert-over-fears-of-asbestos-risk-to-female-teachers

The Joint Union Asbestos Committee has usefully put the official figures into a graph[4]. This shows the increasing level of mesothelioma deaths in teaching and educational professionals.



	1980-85	1986-90	1991-95	1996-2000	2001-05	2006-10	2011-15	2016-21
School teacher deaths - total	15	40	71	114	177	250	335	431
Higher & further education teacher deaths - total	6	18	40	66	93	133	161	192

4. https://the-juac.co.uk/resources/

From official figures, therefore, there is some cause for concern about mesothelioma levels in school workers (we will talk about pupils later). But there are several reasons to doubt the accuracy of the official figures.

- The first is that mesothelioma death rates increase with age, with most dying in the over-75 categories. The Office for National Statistics (ONS) does not record the occupation of the deceased in the over-75 category. Given the slow rate of growth of the disease, particularly where exposure is relatively low-level, this is likely to mean that those exposed in environments such as schools and hospitals will not be recorded as such. A recent report made an estimate of the numbers of teachers dying of mesothelioma aged 75 or over. It used a method that reduced the distorting effects of teaching being an industry with a female-majority workforce. The result was that the death of teachers in all ages between 1980-2017 is estimated at 692 rather than the 380 recorded in ONS data. If deaths over the age of 75 were included in occupational data it is possible that occupations such as teachers would emerge as disproportionately at risk from asbestos exposure.

- A further problem is that the ONS record only the final occupation of the deceased; those who went on to other careers or who became housewives or house-husbands and informal carers (and so on) will not be recorded as former teachers.

- In addition, it is not always clear in the data that someone has worked in a healthcare or education environment; this is particularly the case if they are recorded as engaged in ancillary work, such as caretaking, cleaning or kitchen work. Some education support worker deaths are recorded in the ONS data, 71 deaths between 2003-17. This figure would rise to 142 if the ratio adjustment suggested above were performed. In addition, a recent report suggests that support staff often work in areas where they are most likely to be exposed, such as boiler rooms and kitchens. The report estimates deaths of such staff in the 2003-17 period at over 300 (25).

2. Freedom of Information Request

On 28 April 2023 we put in a Freedom of Information (FOI) request to the Department for Work and Pensions (DWP).

Could you provide me with the following cross-referencing information:

1) Number of people who have received payment from the Industrial Injuries Disablement Benefit under category D3 (diffuse mesothelioma) AND
2) Have reported their place of employment or employers to be a school (e.g. teachers, teaching assistants and caretakers)

I would like this on an annual breakdown basis if that is possible.

The Industrial Injuries Disablement Benefit (IIDB) can be applied for by anyone who develops mesothelioma and believes it is an industrial injury, that is, due to exposure at work rather than, say, from exposure due to a partner who works in a high-risk industry and brings home asbestos on their clothing. The DWP decides whether to grant the award using a set of decision-maker guidelines. This includes "a list of occupations where exposure to asbestos may have occurred and where mesothelioma could reasonably be attributed to work." [Para67834]. This list includes the traditional high-risk occupations and are male dominated and largely manual.

The list does not include those working in buildings containing asbestos; and for our purposes, note that it does not include those working in schools. As such, any education worker applying for IIDB must make a case for doing so, for example, that there was an asbestos exposure incident where they were working. It can be challenging to make a case where the patient has not worked in a traditional high-risk industry and cannot recall a specific exposure. Thus, the DWP can turn down an application, although their data suggest that this rarely occurs with mesothelioma. The effect is, perhaps, more likely to be felt "upstream", in former education workers not applying in the first place because they feel unable to meet the IIDB criteria. It is noteworthy that there is always a gap between annual mesothelioma deaths and IIDB cases (see the 2024 HSE report at page 3); this shows that not all who develop mesothelioma get the IIDB.

Despite this obstacle, some of those working in schools who have developed mesothelioma have applied for and received IIDB. The figures given in the DWP FOI response are summarised in the table below.

A	B	C
Source	ONS data	DWP FOI2023/33335
Category	SOC 23 Teaching and educational professionals	Number of claimants who received an IIS[5] payment after undergoing a payable assessment for D3 and who worked in primary or general secondary education, 17/18 to 21/22
Grouping		'Primary Education' (SIC code 8520) or 'General Secondary Education' (SIC Code 8531)
Total	231 over 10 years	350 over 5 years
Annual rates per annum	23.1pa	70pa

5. The DWP responded to our request for information with the term IIS (Industrial Injury Scheme) rather than IIDB (Industrial Injuries Disablement Benefit). Our understanding is that, while IIDB is only one of several IIS benefits, for the purposes of counting occupation and mesothelioma , IIDB and IIS numbers are the same. However, we have asked the DWP for clarification and will amend this footnote when we have it.

Column B has the official data, which averages out at 23.1 deaths annually. Column C has the numbers from the FOI request. This averages out at 70 annually. Note that the grouping is different, being an SIC code rather than an SOC code. The SIC code is more inclusive; it includes those who work in primary and secondary education, not just teaching and educational professionals. As such, it will include some ancillary workers, but not all. For example, cooks have a separate SIC code.

The difference in the levels is striking. It is likely to be due to several factors. The possible inclusion of:

- Those over the age of 74
- Those whose last occupation was not in schools
- Those who worked in schools but were not recorded as teaching and educational professionals in the ONS data, such as caretakers

The difference in the levels is striking.

It must be borne in mind, however, that the IIDB figures are likely to underestimate the number with mesothelioma because of the way it is awarded, as described above. As such, we can safely conclude that the number of former school workers who develop mesothelioma is a great deal higher than those indicated by the official data.

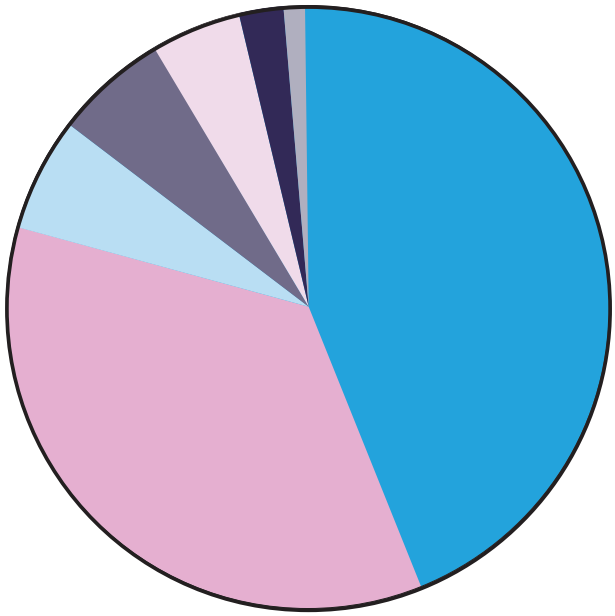
This conclusion is important. Current Government policy is based solely on the official data. This includes, for example, the decision not to implement a recommendation to remove asbestos from public buildings, including schools. That decision should be revisited in the light of more realistic figures, such as those from the FOI request.

An additional reason to revisit that request in relation to schools is the possible risk of pupils developing mesothelioma because of asbestos exposure. We turn to that in the next section.

3. Data from legal firms

Mesothelioma UK has a Legal Panel of specialist solicitors who are experts in providing specialist legal advice to people diagnosed with mesothelioma and their families. Three of these legal firms shared the number of school cases they had taken on over the period 2015-2023.

Breakdown of 90 legal cases 2015-2023



- Teachers, including headteachers
- Maintenance staff, janitors, caretakers
- Administrative staff
- Cleaners
- Special Needs Assistant
- School cook
- Pupil

Between 2015-2023, the three legal firms took on 90 cases. 1 case was relating to a pupil. The other 89 were people who worked in a school environment. Only 36/89 were teaching staff. The remaining 53 people (60%) worked as non-teaching staff. These people would not be counted in the ONS data.

Teachers, including headteachers	36
Maintenance staff, janitors, caretakers	29
Administrative staff	5
Cleaners	5
Special Needs Assistant	4
School cook	2
Pupil	1

We know from our consultation with legal professionals that it is extremely hard to win a legal case against a Local or Education Authority regarding asbestos exposure in a school. Many people will not pursue a claim against a Local or Education Authority. Therefore, the numbers shown above are an underestimate of the number of people who develop mesothelioma following exposure to asbestos in a school.

In summary, this data from legal firms supports the suggestion that many former school workers who i) developed mesothelioma and ii) believed this to be due to asbestos exposure at their workplace are not included in the ONS data.

4. The risk to pupils

Pupils can be exposed to asbestos in schools. It is not known how many die in later life as a result; no official records are kept and there is no estimate endorsed by official bodies such as the UK NHS. In 2013, Professor Peto informed the House of Commons Education Select Committee that he believed around 100-150 female deaths per year were due to asbestos exposure in school buildings in the 1960s and 70s (26). (Peto also presumed a similar number of male pupils would be exposed, such that we should expect 200-300 deaths of former pupils each year due to this exposure).

More recently, Peto noted a change in the number of deaths from mesothelioma in those below the age of 40. The numbers here are small. But in a seminar that is not yet published, Peto noted a large percentage rise in the number: from 2.7pa from 2008-17 to 6.3pa from 2018-21[6]. This figure will need monitoring to see whether it is a trend. Deaths from mesothelioma in under 40s is a proxy for wider childhood exposure and an increase would suggest, therefore, that exposure of pupils is starting to show in official figures (27).

Finally, a US report from its Environmental Protection Agency used data from industry and schools to develop an extrapolation model for deaths due to asbestos exposure in school. It concludes that "about 90% of the premature deaths are expected to occur among persons exposed as school children. The remaining 10% includes teachers, custodians and other adult occupants of the buildings." If this is correct, for every school education worker who dies of mesothelioma, nine former pupils will die. As the level of teacher deaths from 1980-2017 was between 380 (under 75) and 692 (corrected to cover all ages), this gives a figure of up to 6228 former pupils dying of mesothelioma.

The Joint Union Asbestos Committee (JUAC) put the modelling from the US report alongside a simple model based on Peto. This suggested that from 1980-2017 there were between 3890 and 9000 deaths of former pupils due to exposure in schools (28). Note that this modelling estimate is based on the official ONS data. If these figures were replaced with those from the FOI request, which are about three times higher, the estimates are likely also to be higher, although how much would depend on modelling assumptions.

It is difficult to draw specific conclusions given the shortage of empirical data. It seems likely, however, that pupils continue to be exposed to asbestos in schools and that this will result in future cases of mesothelioma. And the models suggest these numbers could be worryingly high. It is of note that as pupil deaths and exposure is not included in official data, it is not factored into Government decisions, such as whether it should initiate a policy of removal of asbestos from schools.

6. The relevant graphs MESO-02 and MESO-03 are at the site https://www.hse.gov.uk/statistics/tables/index.htm#lung

3. Conclusion

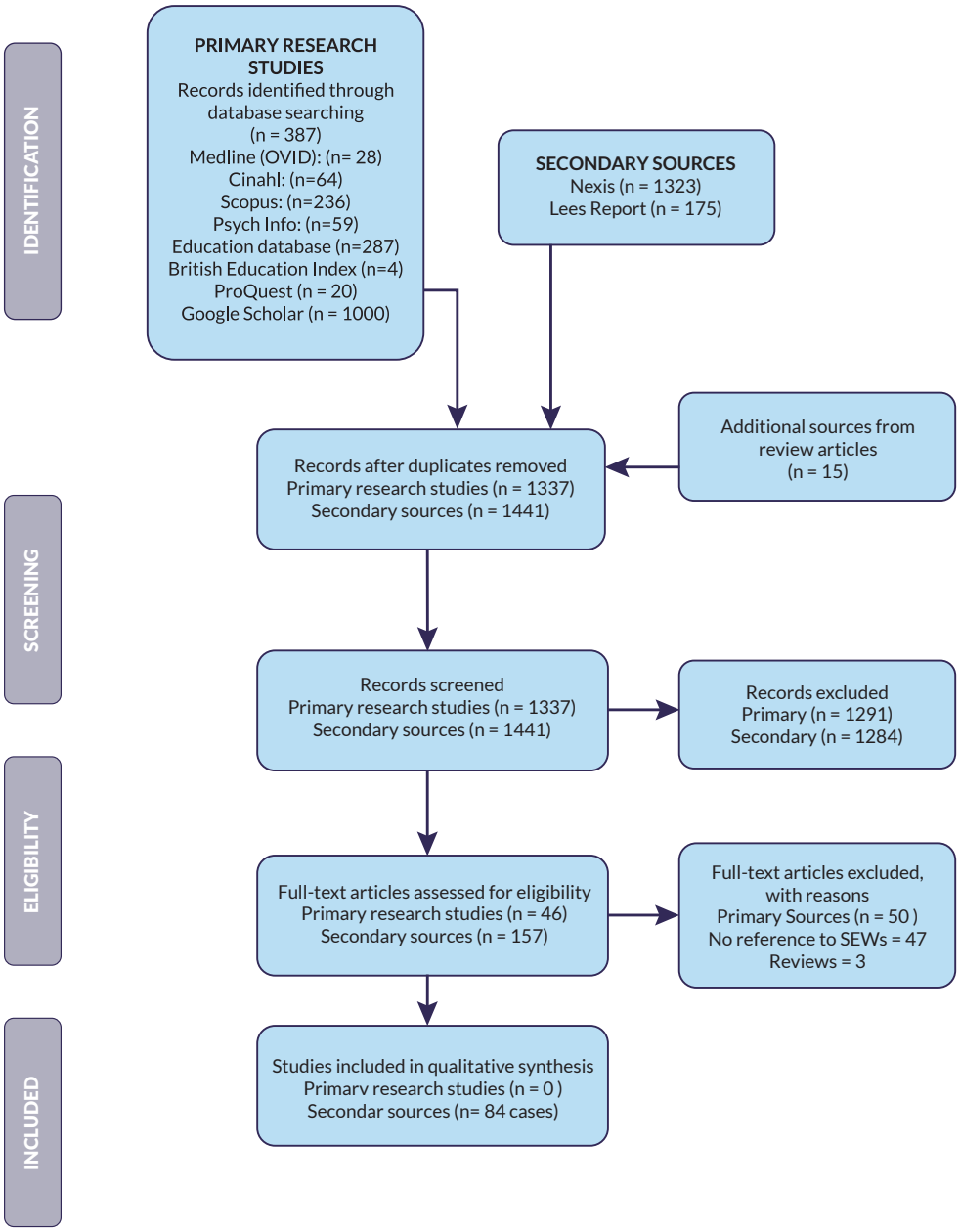
There is little or no academic research into the experiences of school-based education workers who develop mesothelioma. We found other evidence, however, that these experiences may be different to those of workers in standard high-risk industries. Education workers may also be a useful source of information when considering how to tackle the risk of asbestos in schools. A case could be made, therefore, for undertaking prospective research in this area.

In terms of the official figures on mesothelioma and occupation, we found these almost certainly to greatly underestimate the number of former school workers who develop mesothelioma. The IIDB figures are almost three times higher and these, in themselves, are very likely to be underestimates. Official policy is based solely on the official, and woefully inadequate, figures. There is also a spiral of misinformation; the IIDB decisions are based on official figures and therefore place male-dominated heavy industry as almost the only areas where asbestos is likely to cause mesothelioma. Coroner's decisions sometimes reinforce this false picture.

Finally, we noted that there is probably risk to pupils exposed to asbestos at school. This has not been included as a factor to consider in Government decisions, such as whether asbestos removal should be initiated.

We hope that our investigations, and those of others, such as the Joint Union Asbestos Committee, will help provide a broader and more accurate base for policy-level decision-making.

Appendix 1: Prisma Chart



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