

Written evidence from the UK Mesothelioma Alliance (ASB0014)

The [UK Mesothelioma Alliance \(UKMA\)](#) was established in 2017 to bring together [mesothelioma stakeholders](#) as one voice to raise awareness of mesothelioma through agreed projects. The UKMA is pleased that the Work and Pensions Committee have launched this inquiry and grateful to be able to offer evidence for consideration.

The UK Mesothelioma Alliance believes that:

- Equitable access to treatment and care wherever patients are in the UK is crucial to improve outcomes
- Raising awareness of mesothelioma and the dangers of asbestos is vital to both increase early diagnosis and reduce exposure to asbestos

Mesothelioma is a shameful, relentless UK public health disaster. It is clear the threat and devastating effects of asbestos did not disappear with the ban in 1999. The UK continues to have the highest incidence of Mesothelioma in the world with more than 2700 people diagnosed each year. It is a particularly unpleasant (perhaps the worst) cancer, treatments are limited, it is incurable with survival often being just months.

UKMA members include mesothelioma patient/carer advocates, campaigners and charities, and asbestos charities and support groups, campaigners and trade unions and we submit evidence relating to the following 3 questions.

1. What are the current risks posed by asbestos in the workplace? Which groups of workers are most at risk?
2. How robust is the available data about the risks and impact of asbestos in the workplace? What gaps in evidence need to be filled?
3. How effectively does HSE engage with external stakeholders and experts about its approach to the regulation of asbestos?

The UKMA draw your attention to the [Mesothelioma Patient Charter](#) – a collaborative document updated in 2020 by the UKMA and that highlights the priority rights, expectations and actions needed to improve the lives of mesothelioma patients and their families now and in the future and crucially the on-going work to prevent asbestos exposure to protect future generations.

Question

- 1. What are the current risks posed by asbestos in the workplace? Which groups of workers are most at risk?**

Mesothelioma Patient Charter Points 11 and 12.

Ensure the Health and Safety Executive asbestos regulations reflect the latest evidence and are enforced throughout the nation

Have mesothelioma and asbestos safety made a national priority

1. Traditionally thought of as disease only affecting those working in a job associated with asbestos (construction, power station, dock work etc) doctors, nurses, lawyers and benefit advisors, professionals who work with people diagnosed with Mesothelioma, have for some time been concerned about the apparent increase in low levels of asbestos exposure that have resulted in the disease.

2. 74% of university buildings, including student halls of residence buildings surveyed contained asbestos
81% of schools contact Asbestos
94% of hospitals in England contain Asbestos
500,000+ UK workplaces still contain Asbestos
3. Current occupation data is inadequate and does not reflect the working lives of those diagnosed with Mesothelioma. The average age of someone diagnosed with Mesothelioma is 74 and sadly following death occupational background is not recorded for over 75's.
4. Where asbestos is present no-one is spared the risk of exposure and therefore all are at risk of developing Mesothelioma.
5. Since 2001, at least 305 teaching and education professionals have died of exposure.
6. Between 2002-15, the ONS recorded 177 deaths of NHS staff due to mesothelioma and between 2004-17 there were 961 claims made against the NHS for negligence (regarding asbestos) that has resulted in mesothelioma.
7. There have been a total of 340 Armed Forces Compensation Scheme (AFCS) claims from people with mesothelioma between April 2016 and March 2020. Mesothelioma UK's patients survey in 2019 revealed that 15% of the 504 responders had worked in our armed forces (were veterans) and all forces were affected.

Here are a number of news article links that highlight the range in workplaces posing a risk

<https://www.asbestos.com/news/2019/02/14/mags-portman-hiv-mesothelioma/>

https://www.theguardian.com/media/2021/jul/11/musicians-widow-sues-bbc-over-his-exposure-to-asbestos-in-studio?utm_source=dvr.it&utm_medium=twitter

https://www.bbc.co.uk/news/uk-england-birmingham-51021204?fbclid=IwAR1U9dY_ZjGKlq2lgUU1YyUKp7yNG3G3XdMzY-n01YLtSSAf4C8TtdC5Kgs

https://www.thetimes.co.uk/article/asbestos-cases-rise-among-hospital-staff-and-teachers-xlnz80nwg?fbclid=IwAR3iw2zB-c4NQRVL3vgLsyjhnXeF6ivrjtxOeEnLvrMH7YOD_u_ARKbksyY

<https://www.manchestereveningnews.co.uk/news/health/asbestos-cancer-mesothelioma-death-warning-15075364>

<https://www.theguardian.com/society/2019/nov/25/uk-children-exposed-to-more-asbestos-than-other-countries-report?fbclid=IwAR16u4YbawkORHhy3xblgf5ggwbySli478fYu2hQUsg7dw0w29siOY3W12E>

<https://www.scotsman.com/news/environment/teachers-school-built-toxic-site-have-same-rare-cancer-546270>

https://www.bbc.co.uk/news/uk-england-49811603?fbclid=IwAR2Aled65mq0eu2la1ugdSL22C_HXUyhVP1f_mddMZd_6vyE_bfKnXlpDoE

<https://www.mirror.co.uk/news/uk-news/scandal-almost-300-british-teachers-22787332>

<https://www.manchestereveningnews.co.uk/news/greater-manchester-news/how-working-joiner-caused-devoted-15967026>

<https://www.manchestereveningnews.co.uk/news/greater-manchester-news/how-working-joiner-caused-devoted-15967026>

<https://www.manchestereveningnews.co.uk/news/health/asbestos-cancer-mesothelioma-death-warning-15075364>

<https://www.yorkshirepost.co.uk/news/people/retired-yorkshire-hairdresser-diagnosed-asbestos-related-cancer-after-being-exposed-toxic-dust-inside-hairdryers-1749131>

<https://www.doncasterfreepress.co.uk/health/data-reveals-impact-of-deadly-asbestos-related-cancer-in-doncaster-as-inquiry-is-launched-3307337>

<https://www.northamptonchron.co.uk/health/data-reveals-impact-of-deadly-asbestos-related-cancer-in-northampton-as-inquiry-is-launched-3307687>

<https://www.theoldhamtimes.co.uk/news/19442739.data-reveals-impact-deadly-asbestos-related-cancer-oldham-inquiry-launched/>

<https://www.wandsworthguardian.co.uk/yoursay/news/19442740.data-reveals-impact-asbestos-related-cancer-wandsworth/>

https://www.thisislocallondon.co.uk/news/local_news/19442740.data-reveals-impact-asbestos-related-cancer-wandsworth/

<https://www.dailyecho.co.uk/news/19443066.data-reveals-impact-asbestos-related-cancer-southampton/>

<https://www.shieldsgazette.com/health/south-tynesides-asbestos-death-toll-3307539>

<https://www.northumberlandgazette.co.uk/health/northumberlands-asbestos-death-toll-3307533>

<https://www.hartlepoolmail.co.uk/health/hartlepoons-asbestos-death-toll-3307529>

2. How robust is the available data about the risks and impact of asbestos in the workplace? What gaps in evidence need to be filled?

1. The data on risks and impact of asbestos in the workplace **is not** robust and **does not** represent the true occupational exposure history of people living with Mesothelioma.

Mesothelioma Patient Charter Point 13.

Prevent future exposure to asbestos by providing a safe working environment with up to date inspection/monitoring and all necessary equipment to protect

employees.

2. The UKMA suggest that we do not need to focus on the gaps in data, we need to concentrate on removing the risk. We know there is no safe level of exposure to asbestos, and we know many workplaces are still riddled with asbestos. The risk of exposure for many is currently unavoidable.
3. Source of exposure does not influence treatment or care, once diagnosed patients have a limited life expectancy and the focus is usually on navigating the NHS to achieve the best treatment and care. Exploring one's work history is rarely a priority for the patient. Benefits advisors and for those engaged in a civil compensation claim, a legal team, will often seek to piece this information together. Sadly, this information is not captured by the ONS or National Cancer Registries.
4. Current occupation data is inadequate and does not reflect the working lives of those diagnosed with Mesothelioma. The average age of someone diagnosed with mesothelioma is 74 and sadly following death occupational background is not recorded for over 75's.
5. Despite the presence of asbestos in our hospitals and schools there is no asbestos mandatory training for people employed in these settings. They are not advised of its presence, educated how to monitor it or avoid exposure.
6. In one example an NHS employed Clinical Nurse Specialist who is required to complete 28 modules of mandatory training including a comprehensive Health and Safety module, none of the 28 modules mention Asbestos, or the dangers of disturbing it or risk of airborne asbestos fibres contained within the workplace.
7. The ONS records only the final occupation of the deceased; Armed Forces, teachers, nurses, or anyone who goes on to have a second career will not be recorded as such.
8. An examination of ONS data alongside data on numbers of teachers and nurses employed in a period from 1960-1980, highlighted that 125 teachers and 66 nurses up to age 74 died from mesothelioma over the period 2002-2010.
9. Teachers and nurses experienced about four and two times higher mesothelioma deaths respectively than would be expected from typical asbestos fibre concentrations in buildings containing asbestos containing materials in good condition.
10. The claim that levels of mesothelioma in the UK will start to fall, now that the known high-risk occupations are largely protected is not evidenced by research and is in stark contrast to the numbers of patients seen in clinic.
11. There are cases where NHS staff with mesothelioma have not been able to pursue a claim because they had insufficient evidence of negligence, so these cases are not necessarily captured.

3. How effectively does HSE engage with external stakeholders and experts about its approach to the regulation of asbestos?

Mesothelioma Patient Charter Point 14

Work with unions and individuals to ensure enforcement of current regulations to safeguard all employees.

1. The UK Mesothelioma Alliance (UKMA) was established in 2017 to bring together [mesothelioma stakeholders](#) as one voice to raise awareness of mesothelioma through agreed projects. UKMA members refer to HSE awareness materials, and the website is a priority when needing statistics on incidence and we are all very grateful for the resource.
2. The UKMA and its individual members have not had any communication from HSE so cannot comment on how effectively HSE engage with stakeholders or experts. As our members include mesothelioma patient/carer advocates, campaigners and charities, and asbestos charities and support groups, campaigners and trade unions the UKMA would welcome engagement with HSE.
3. Those people unfortunate enough to already be living with Mesothelioma and those that have tragically died have made it clear we must do all we can to prevent more people getting this terrible cancer, our focus must be preventing exposure to asbestos, and we have to do better.

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