

New survey launches to help identify mesothelioma treatment uncertainties

An important survey has launched today that will help to inform future research into mesothelioma diagnosis, treatments and care. The survey is now available at www.psp.nihr.ac.uk/mesothelioma/survey, and will remain open for a few months to collect data from patients, carers and clinicians.

This is part of a project being carried out by a National Institute for Health Research (NIHR)-funded 'Priority Setting Partnership' (PSP) recently set up by the James Lind Alliance (JLA). The survey gives patients, carers and family members affected by the disease an opportunity to identify and prioritise unanswered questions about mesothelioma. The results of the survey will be published later this year and will be used to inform the 'top ten' priorities for clinical research, as determined by patients, carers and clinicians.

Mesothelioma is a rare and often fatal form of cancer with very poor survival rates. It is most commonly caused by breathing in asbestos dust, but symptoms sometimes don't show up until decades after exposure. This makes treatment difficult because the disease is often well-advanced before it is diagnosed. According to the latest government figures, in 2011 there were 2,291 deaths in Great Britain caused by mesothelioma.

Professor Dame Sally C. Davies, Chief Medical Officer and Chief Scientific Adviser at the Department of Health, said:

"It is vital that we gather and listen to the views of as many people as possible so everyone knows the topics that are a priority for clinical research. Mesothelioma research has been identified as an important area and everyone needs to hear what patients, carers, families and healthcare professionals believe are the most important unanswered questions around the diagnosis, treatment and care of mesothelioma."

Some of the ways that you can help make the project a success, are by:

- completing our survey now at www.psp.nihr.ac.uk/mesothelioma/survey
- passing on the information to encourage your family members, support networks, carers or colleagues to fill in the survey.
- circulating copies of our [mesothelioma postcard](#) to relevant groups.

Set up through the JLA and funded by the NIHR, this JLA PSP is supported by The British Lung Foundation, Mesothelioma UK, The Mick Knighton Mesothelioma Research Fund, Asbestos Victims Support Groups Forum UK, The June Hancock Mesothelioma Research Fund, and Cumbria Asbestos-Related Disease Support.

Graham Sherlock-Brown, Patient Representative, said:

"It is essential that research money is put into finding ways to relieve the suffering caused by this aggressive disease. Progress in treatment is long overdue and mesothelioma victims deserve far better – very few survive past five years and mesothelioma will continue to claim victims as long as asbestos is present in the UK. That's why I'm pleased to see the launch of this important survey, which gives patients and carers a much-needed voice."

To help put mesothelioma research in the spotlight and to get involved, visit www.psp.nihr.ac.uk/mesothelioma or email jl@soton.ac.uk with any questions. Videos about the PSP are available to watch at: www.psp.nihr.ac.uk/mesothelioma/videos.

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