

Health and Social Care Committee  
Recovery of Medical Costs for Asbestos Diseases (Wales) Bill  
RMCA19 – British Lung Foundation

30 January 2013

Professor Mark Drakeford AM  
Chair, Health and Social Care Committee  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

Dear Professor Drakeford,

**Re. Late submission to the consultation on the Recovery of Medical Costs for Asbestos Diseases (Wales) Bill**

I have enclosed a late submission from the British Lung Foundation (BLF) to the Health and Social Care Committee (“the Committee”) for its consideration of the Recovery of Medical Costs for Asbestos Diseases (Wales) Bill (“the Bill”). I am doing so with apologies and on the advice of the Committee officials that a late submission will be accepted.

The reasons for our late submission are as follows:

- The BLF is aware of a number of parallel discussions that are currently taking place regarding how the insurance industry might fund schemes relating to mesothelioma and other asbestos-related diseases. In view of the discussions that have taken place regarding the Bill, we hope that it will be of assistance to provide details of these (paragraphs 7-8 in our submission).
- Irrespective of the funding mechanism, there are a number of areas in which there is a pressing need for investment to benefit those with asbestos-related disease and their families, notably medical research. We very much hope that there will be coordination and planning to ensure that these needs are met, and have therefore included details of where the need lies (paragraphs 13-17).

I will, of course, be very happy to provide any further information that you require.

Yours sincerely,



Steve Crabb  
Director of Communications  
British Lung Foundation

## Submission to the Health and Social Care Committee: The Recovery of Medical Costs for Asbestos Diseases (Wales) Bill

### Background: BLF Wales and asbestos-related disease

1. Lung disease affects one in five people in Wales, and is the second most common long-term condition. British Lung Foundation Wales campaigns for service improvements for people with lung disease across all forms of healthcare. We also raise awareness of lung disease, promote positive change in the nations' lung health, provide direct support to people with lung conditions, and fund research into future treatments and cures.
2. The Recovery of Medical Costs for Asbestos Diseases (Wales) Bill ("the Bill") relates to four disease types: mesothelioma, asbestos-related lung cancer, asbestosis and non-malignant pleural disease. These vary in presentation, treatment and prognosis. Mesothelioma is always fatal, with median survival from diagnosis having been estimated at 8-9 months,<sup>i</sup> whereas asbestosis and non-malignant pleural disease are in some instances highly debilitating but may not be fatal.
3. With the annual number of mesothelioma deaths in the UK having nearly quadrupled in the last 30 years, the UK now has the highest mortality rates of mesothelioma of any country in the world.<sup>ii</sup> Recent figures taken by the Department for Work and Pensions (DWP) from a combination of studies suggest that UK-wide deaths from mesothelioma will peak in 2015-2017 at just under 2400 deaths per year and will decrease only very gradually in the latter part of the decade to around 2,240 deaths in 2023.<sup>iii</sup>
4. The UK-wide cost to the insurance industry of civil compensation claims for mesothelioma alone is in the region of £200-250 million per year. The figure for the other types of asbestos-related disease is likely to be considerably lower, as causality is often not ascertained.
5. According to figures from the DWP impact assessment for the proposed UK-wide untraced payment scheme, around 27% of mesothelioma cases do not lead to a successful civil claim as they are environmental, untraced, unclaimed or workers have been self-employed.<sup>iv</sup> Notwithstanding likely decreases due to improved insurer tracing and a lower burden of evidence for occupational cases, this figure differs markedly from the estimate included in the Explanatory Memorandum to the Bill of 80 out of 90 cases, which is based on CRU data. The proportion for asbestosis and asbestos-related lung cancer is likely to be substantially lower.

### Funding from liable employers and their insurers

6. The Bill contains provisions allowing Welsh Ministers to recover health system costs associated with the treatment of asbestos-related diseases. There is currently no other legislative recourse for Welsh Ministers to recoup health care costs from employers and their insurers in cases of asbestos-related disease.
7. Separate UK-wide discussions are, however, taking place regarding ways (legislative and non-legislative) in which the insurance industry can fund schemes which benefit those with mesothelioma and other asbestos-related diseases. These take as their starting point, as does the Bill, the overwhelming responsibility of negligent employer practices for the present asbestos-related disease burden. There are two main areas:
  - Compensation for untraced claims. A new fund will be launched in July 2014 to compensate those with occupational mesothelioma who are not able to trace a

former employer or insurer in order to make a civil claim. The fund will be worth £30-35 million per year, and will be funded by a levy on all employers' liability insurers, for which the DWP will introduce legislation to the UK parliament this year. The fund is for those with mesothelioma only, and hence excludes other asbestos-related diseases.

- Medical research. Four insurance companies provided £3 million between 2010 and 2012 for medical research into asbestos-related disease. The BLF was chosen as the charity partner by the Department of Health, Ministry of Justice and the ABI to channel the funding into research. The BLF has strategically managed this funding over the last three years, commissioning several ground-breaking research projects (see paragraph 16 below). A small proportion of the funding was used to promote awareness of asbestos among DIY enthusiasts and tradespeople through the BLF's "Take 5 stay alive" campaign.
8. The £3 million research fund was a one-off arrangement, and the BLF will allocate the final grant round in the coming months. The ABI and some individual insurers wish to continue funding medical research with a view to developing effective treatments. The avenue for future research funding does not yet seem clear and at the time of writing the BLF is not aware of any insurer funding arrangement agreed for medical research going forward.
  9. The Committee, the National Assembly and the Welsh Ministers must give detailed consideration, in conjunction with Westminster counterparts, to how the current and potential funding mechanisms interrelate, and whether legislation or voluntary agreement is the optimum arrangement for each. Legislation carries the benefit of compulsion but brings disadvantages including: delayed implementation; administrative expense; legal challenge; and narrowing of parameters on legal or administrative grounds (e.g. this Bill excludes those who have not made a successful civil claim and other systemic costs such as local authority-funded social care or non-recouped state benefits).
  10. The salient objective must always be to improve conditions for those with asbestos-related disease, their family and carers to the greatest possible degree.

#### **Investment need for asbestos-related disease**

11. Section 16 of the Bill establishes the intention (although not an obligation) for the sum recovered in medical costs to be used 'for the purposes of treatment of, or other services relating to, asbestos-related diseases'.
12. There are numerous ways in which additional funding could benefit people with asbestos-related diseases and their families. In this sense, there is a pressing need for the funds that would be recovered through the Bill.
13. Care and support. Areas in which there is an investment need include:
  - a wider range of tailored information, including post-diagnosis information packs and support and self-management information;
  - patient pathway development and sharing of best practice for asbestosis treatment;
  - mesothelioma specialist nurse posts to provide expert patient support and information (Mesothelioma UK currently raises funds in response to unmet need for mesothelioma clinical nurse specialists in areas of high demand);

- funded hospice services; and
  - funding for asbestos disease-specific patient support groups (this could follow the model of the network of support groups for people with dementia that has recently been established with Welsh Government funding).
14. Medical research. There is currently no cure for mesothelioma or asbestosis and there are few effective treatments. Although a variety of treatment options exist for lung cancer, including for lung cancer caused by asbestos, only around 5.5% of lung cancers are currently cured, and the improvement in cure rate has been slower than for other common cancers.<sup>v</sup> Research into effective treatments must therefore be the primary objective of any funding source established to benefit those with asbestos-related disease. In addition to improving the lives of patients, research may play a crucial role in minimising future costs to the NHS.
  15. Medical research is an area of significant unmet need. National Cancer Research Institute (NCRI) statistics are published for all types of lung-related cancer (including mesothelioma) combined. These data make for startling reading: although lung cancer research receives NCRI funding totalling approximately a quarter of that allocated to breast cancer, a third of that allocated to leukaemia, and half of that allocated to bowel cancer, it currently kills more people per year than all three combined.<sup>vi</sup> Moreover, NCRI estimated that last year only around 4 per cent of lung cancer spend by NCRI partners was in fact specific to mesothelioma. We are not aware of any research spend data for asbestosis or non-malignant pleural disease, but the figures are likely to be small in research terms.
  16. In particular, opportunities exist to build on research developments from the wider cancer field to develop effective treatments for mesothelioma. Since 2010, the BLF has allocated almost £2 million from the insurer grant to research into asbestos-related diseases. In a short period this funding has led to improved quality and renewed interest in mesothelioma research, enabling landmark projects including:
    - the first centralised bank of mesothelioma tissue and clinical data in Europe;
    - research on the genetic make-up of mesothelioma cells and the means of targeting them through treatment - the approach thought most likely to yield a cure; and
    - PhD studentships to build future mesothelioma research capacity.
  17. Meaningful long-term funding is required to build on this progress and develop effective treatments. However, mesothelioma research receives very little funding from unrestricted research funders; and no large-scale mesothelioma research is currently being undertaken outside of the BLF programme.
  18. The purposes set out for the recovered funds in section 16 of the Bill do not appear to include medical research. Although this would not in itself preclude investment in research, the BLF strongly recommends that the wording be amended so that medical research is included on the face of the Bill. Doing so would provide the Welsh Ministers with a strong mandate to invest a proportion of the recovered funds in research to reduce the long-term human and economic burden of asbestos-related disease.

#### **Ability of Bill to carry out its stated objectives**

19. The BLF is not best placed to advise on legislative competency, powers for subordinate legislation or cross-jurisdictional issues in respect of differing locations of asbestos exposure and medical treatment.

20. Cost recovery mechanism. If the Bill does proceed to statute, it is vital that the maximum possible proportion of the recovered costs is spent to benefit those with asbestos-related disease. Calculating a simple but effective cost recovery system will be a particular challenge given the considerable complexity involved in the treatment of asbestos-related diseases, and the variable diagnosis and treatment pathways for less common conditions such as asbestosis. The BLF supports the tariff-based approach outlined in the Explanatory Memorandum as the best way of minimising administrative costs.
21. Purpose and scope of the recovered funds. The Bill is non-prescriptive regarding how the recovered fees can be spent, to the extent that it is not clear whether the primary purpose would be to reimburse the health service for services already provided or to provide additional services for the benefit of those with asbestos-related disease. While we appreciate that there may be value in retaining a high degree of flexibility, greater clarity in two areas in particular would assist the Bill in fulfilling its objectives if it is passed:
- The BLF recommends the explicit mention of medical research on the face of the Bill, so that Welsh Ministers feel mandated to pursue funding options in this area (see paragraph 18 above).
  - Although it may not be appropriate to place firm conditions on the use of the money, it would be possible to stipulate, as an addition to section 16 of the Bill, a formal annual reporting mechanism for how recovered funds have been spent. This would further the objectives of the Bill by encouraging a more transparent allocation process and making clear to the public and the Assembly the benefits served by the Bill.

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<sup>i</sup> *Mesothelioma Framework*. Department of Health, 2007

<sup>ii</sup> Cancer Research UK: <http://info.cancerresearchuk.org/cancerstats/mortality/cancerdeaths> (last accessed June 2012); Peto, Rake, Gilham & Hatch. *Occupational, domestic and environmental mesothelioma risks in Britain: a case-control study*. 2009. HSE report RR696 Research report. <http://www.hse.gov.uk/research/rrpdf/rr696.pdf> (last accessed June 2012)

<sup>iii</sup> *Mesothelioma Payment Scheme and Mandatory Membership of Employer Liability Tracing Office (ELTO)*. Department for Work and Pensions impact assessment, 2012 (<http://www.dwp.gov.uk/docs/elci-compensation-meso-ia.pdf>)

<sup>iv</sup> *Mesothelioma Payment Scheme and Mandatory Membership of Employer Liability Tracing Office (ELTO)*. Department for Work and Pensions impact assessment, 2012 (<http://www.dwp.gov.uk/docs/elci-compensation-meso-ia.pdf>)

<sup>v</sup> *Lung Cancer: the diagnosis and treatment of lung cancer*. NICE clinical guideline 121, 2011

<sup>vi</sup> National Cancer Research Institute: <http://www.ncri.org.uk/default.asp?s=1&p=3&ss=6> (accessed June 2012); Cancer Research UK: <http://info.cancerresearchuk.org/cancerstats/mortality/cancerdeaths> (accessed June 2012)