

Using JLA methods in setting mesothelioma research priorities

What are James Lind Alliance Priority Setting Partnerships?

The James Lind Alliance (JLA) is a non-profit making initiative, established in 2004 by Sir Iain Chalmers (Cochrane Collaboration), Dr John Scadding (MRC and retired neurologist) and Sir Nick Partridge (INVOLVE). Its Priority Setting Partnerships (PSPs) provide a method for patients, carers and health professionals to work together on equal terms to identify and agree on the questions that are a priority for researchers to answer.

Since April 2013, JLA PSPs have been co-ordinated by the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) with support from a team of approved JLA advisers. Interest in running PSPs continues to grow and partnerships have now been completed in over 25 areas including Acne, Schizophrenia, Type 1 Diabetes and Multiple Sclerosis. You can find full details of past and current PSPs on the JLA website www.jla.nihr.ac.uk

Why Mesothelioma?

In mid-2013, the National Institute for Health Research (NIHR) asked the JLA to run a PSP in mesothelioma, offering the funds to do so. Mesothelioma is a rare form of cancer with very poor survival rates. It is most commonly caused by breathing in asbestos dust.

"Mesothelioma research has been identified as an important area. I'm delighted that the NIHR can support the James Lind Alliance in forming a Priority Setting Partnership to bring together patients, carers and clinicians in this area. The Priority Setting Partnership process is a tried and tested way for them all to contribute equally to decisions about what the important questions are for mesothelioma research to address."

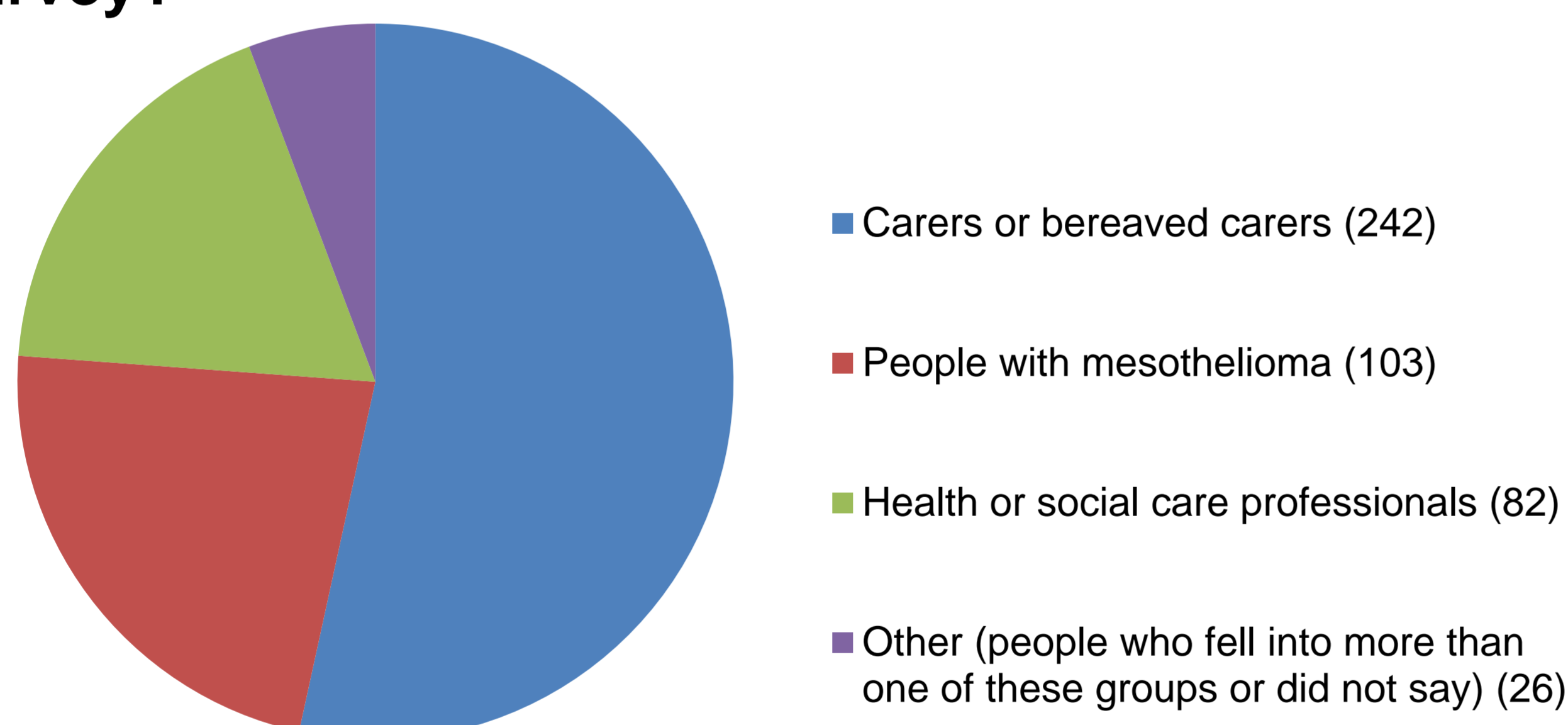
Professor Dame Sally C. Davies, FRS FMedSci, Chief Medical Officer and Chief Scientific Adviser at the Department of Health

What happened?

The aim of the PSP was to ask patients, carers and health professionals to identify and then prioritise the unanswered questions that concern them most about mesothelioma diagnosis, treatment and care. Around 50 people attended the PSP launch meeting in December 2013.

A survey was distributed online and on paper between February and April 2014, asking people to tell us their questions and experiences about the diagnosis, treatment or care of mesothelioma.

Who were the 453 people who responded to the survey?



What did we find?

820 questions were submitted via the survey	52 questions were verified as being unanswered
5 more questions were identified from systematic reviews of existing research	46 out of scope questions were received (to be published separately)
Only 1 question identified was definitely already answered	

How were patients and carers involved?

As steering group members:



Chris Knighton, whose husband Mick was diagnosed with mesothelioma in August 2000 and died seven months later.



Heather Foot, whose husband Alan was diagnosed with mesothelioma in November 2006. Alan survived for five years after his diagnosis.



Graham Sherlock-Brown, who was diagnosed with mesothelioma 12 years ago.

Representatives from **The British Lung Foundation, Mesothelioma UK, Asbestos Victims Support Groups Forum UK, The June Hancock Mesothelioma Research Fund, The Mick Knighton Mesothelioma Research Fund and Cumbria Asbestos-Related Disease Support** were on the steering group. Each group has strong connections to patient and carer communities.

As survey respondents:

345 people who completed and returned the original survey identified themselves as either patients, carers or family members.

As workshop participants:

The final workshop included 30 participants. Half of these were patients and carers and their representatives and half were health professionals.

What does this mean for the mesothelioma research areas that are prioritised at the end of the process?

- The top 10 prioritised questions will be announced on the PSP website very soon. See <http://www.psp.nihr.ac.uk/mesothelioma> for details.
- The joint working between patients, carers and health professionals, together with the wide consultation, underlines the importance of the agreed research questions to those actually living with, caring for and treating mesothelioma.
- The exclusion from the prioritisation workshop of pure researchers with no clinical practice ensured that these questions were influenced only by patients and those who treat and care for them.
- All of the unanswered questions that were discussed at the final workshop will be considered carefully by the NIHR and promoted to other research funders, with particular emphasis on the top 10 priorities jointly agreed at the workshop.
- All of the unanswered questions will be published on the free-to-access, publicly available database UK DUETs, for all researchers and funders to use.