



**James
Lind
Alliance**

Priority Setting Partnerships



**National Institute for
Health Research**

The James Lind Alliance (JLA)

Setting Priorities for Mesothelioma Research



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Thank you

This Priority Setting Partnership would not have been possible without the patients, current and bereaved carers, health and social care professionals, organisations and patient groups who disseminated and participated in the survey, prioritisation and workshop. Thank you for your time and participation.

The NIHR would like to thank the members of the Steering Group for all of their valuable input, Katherine Cowan, Senior JLA Adviser for independently facilitating the partnership, and Caroline Whiting for co-ordinating the project.

Photographs from the workshop are reproduced with the kind permission of all participants.



I was privileged to be a member of the Steering Group for the Mesothelioma Priority Setting Partnership (PSP) and found it extremely refreshing that patients, carers, health professionals and clinicians were all working together to identify the top research priorities.

My husband developed pleural mesothelioma and died in 2011. When we received his diagnosis and the devastating news that his life expectancy was 6-9 months we tried to be positive and felt sure there would be a care pathway to help prolong his life. What followed for our family were endless hours on the internet researching what other patients were doing in the UK and overseas. We found that in the UK there really wasn't that much going on at that time and various mesothelioma forums confirmed this too. After my husband died I wanted to use my experience of this dreadful disease to try and help shape future treatments and further research for mesothelioma patients.

Being part of the Steering Group for the Mesothelioma PSP enabled me to contribute to the development of the survey and its circulation so that it captured as many responses as possible to help us determine the most important questions. I was able to identify with many of the survey responses and the questions they felt needed to be answered.

Now we have the list of the Top 10 most important questions, I hope that they will be used to develop research into future treatments to help more mesothelioma patients and their families.



Heather Foot,
Steering Group Member



Ian Jarrold,
Head of Research at the
British Lung Foundation

This work represents a great step forward in understanding the mesothelioma research questions that really matter to patients, carers, their families and clinicians. Identifying mesothelioma treatment uncertainties is crucial to developing strategic priorities for research. This in turn will lead to improvements in the treatment and care of this devastating disease.

Introduction

Mesothelioma is a rare form of cancer with very poor survival rates. It is most commonly caused by breathing in asbestos dust.

In mid-2013, the National Institute for Health Research (NIHR) asked the James Lind Alliance (JLA) to run a Priority Setting Partnership (PSP) in mesothelioma, offering the funds to do so. This was the first time that the NIHR had fully funded a JLA PSP. 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.

“I would like to thank all the people who have contributed their ideas and suggestions, and the partner organisations who have supported this tried and tested process. With their help I believe we have built a genuine consensus - and a real impetus. I hope the research community will now respond by generating new research proposals that will provide robust evidence to help people with mesothelioma.”

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



Background

The NIHR was created in 2006 with the vision ‘to improve the health and wealth of the nation through research’. Known as ‘the research arm of the NHS’, it is an overarching entity which collectively represents all publicly-funded research in the NHS. The NIHR funds a range of research programmes to produce evidence that enables professionals, policy makers and patients to make informed decisions about healthcare and provides the means to turn new interventions into better care.

The JLA is a not-for-profit initiative, established in 2004. It brings patients, carers and clinicians together in PSPs. These partnerships identify and prioritise uncertainties, or ‘unanswered questions’, about the effects of treatments that they agree are the most important. The aim of this is to help ensure that those who fund health research are aware of what really matters to both patients and clinicians. The JLA is hosted by the National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC), based at the University of Southampton.

The JLA PSP process is described in detail in the JLA Guidebook at www.jla.nihr.ac.uk.

The Steering Group

Steering Group members were identified to oversee the PSP's process while representing the perspectives and interests of mesothelioma patients, carers and healthcare professionals. They approved the aims and objectives of the process, tested and ensured written materials were accessible to a range of audiences, and provided expert opinions on data analysis and evidence checking.

The Steering Group members were:

Helen Clayson, former hospice medical director and GP, Founder and Chair of Cumbria Asbestos-Related Disease Support (CARDS).

Liz Darlison, consultant nurse and clinical lead for Mesothelioma UK.

Dean Fennell, professor and consultant in thoracic medical oncology based in Leicester.

John Flanagan, representing patients and carers via his work for the Merseyside Asbestos Victims Support Group.

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

Kate Hill, trustee and director of the June Hancock Mesothelioma Research Fund.

Ian Jarrold, Head of Research, British Lung Foundation.

Chris Knighton, whose husband Mick was diagnosed with mesothelioma in August 2000 and died seven months later. Chris co-ordinates the Mick Knighton Mesothelioma Research Fund.

Loic Lang-Lazdunski, Professor of Thoracic Surgery at King's College London.

Andrew Lawson, who was diagnosed with mesothelioma in March 2007 and sadly died before the PSP was completed.

Nick Maskell, Consultant Respiratory Physician, Bristol.

Mick Peake, Consultant and Senior Lecturer in Respiratory Medicine, Leicester.

Sanjay Popat, Consultant Thoracic Medical Oncologist, London.

Robert Rintoul, Lead Clinician for Lung Cancer and Mesothelioma, Cambridge.

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

Mark Slade, Respiratory Physician specialising in thoracic malignancy, Cambridge.

David Waller, Consultant Thoracic Surgeon, Leicester.

The group was chaired by Katherine Cowan from the JLA and was supported by Caroline Whiting and Sarah Fryett from NETSCC. Richard Stephens (an independent research scientist) carried out the survey analysis, evidence search and drafting of potential research questions.

More information about members of the Steering Group, and the PSP protocol, can be found at

www.psp.nihr.ac.uk/mesothelioma.

Launch

In December 2013, around 50 people - individuals and those representing organisations and groups – attended a meeting in London to hear about plans for the PSP. Representatives of the Steering Group, together with Katherine Cowan of the JLA and Dr David Cox, Deputy Director – Research Finance and Programmes, Department of Health, gave presentations providing context and explaining the importance of the initiative, and answered questions. Attendees signed up to be involved in the PSP, agreeing to help disseminate information about it to their patient and professional communities of interest.

Videos of the launch meeting can be seen on the PSP website at www.psp.nihr.ac.uk/mesothelioma.

Identifying the questions - the survey

An initial survey was drawn up and piloted by members of the Steering Group, following a template which had been used successfully by other JLA PSPs. Once finalised, the survey appeared on the PSP website and an email was sent to all known health professionals and patient and carer support groups, asking them to share the survey with their contacts. Between February and April 2014 the survey was promoted as widely as possible and made available at a number of national meetings and conferences as well as being promoted via Twitter. Paper copies were also available which could be returned by freepost.

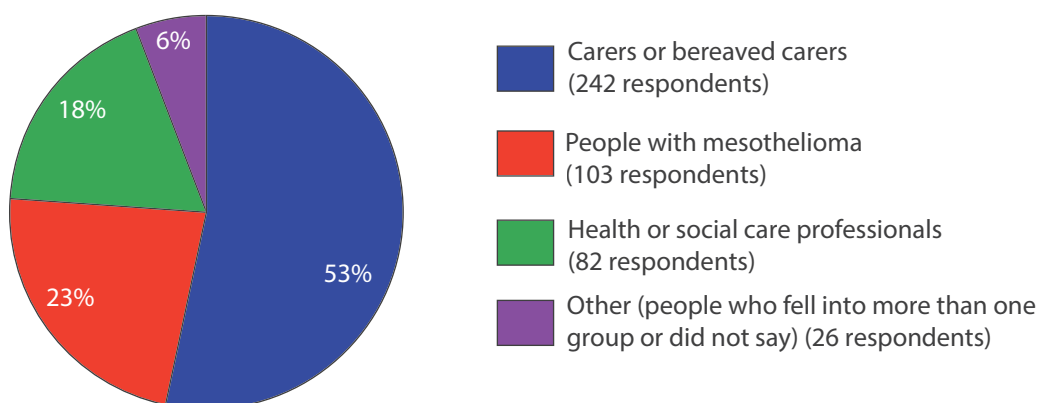
Patients, carers and health professionals were asked:

- Do you have questions or comments about your experience of the **diagnosis** of mesothelioma?
- Do you have questions or comments about your experience of mesothelioma **treatments**?
- Do you have any **other** questions or comments about your experience of the care of someone with mesothelioma?

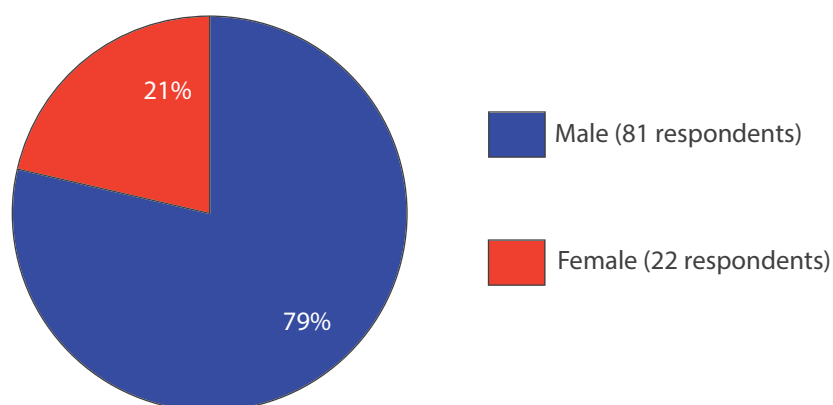
The demographic data, including age, gender and location of patients and carers who responded to the survey, were collected and monitored to ensure that as far as possible, a diversity of responses was received. Health professionals responding to the survey were asked to indicate their role, again to enable the targeting of under-represented groups. The Steering Group advised on any gaps and discussed strategies for addressing them.

The survey received 453 responses. Of these, 240 were on paper, and 213 were submitted online.

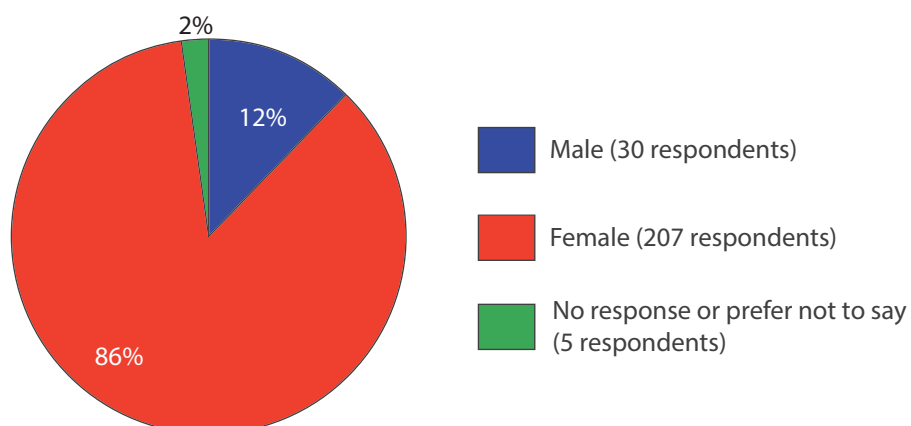
Respondents to the survey



Gender of patients who responded

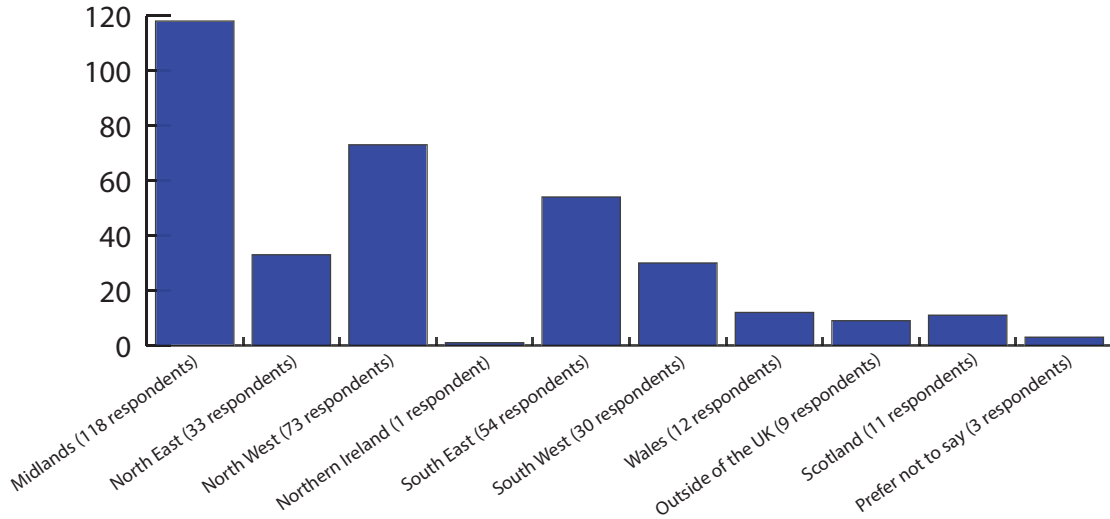


Gender of carers who responded

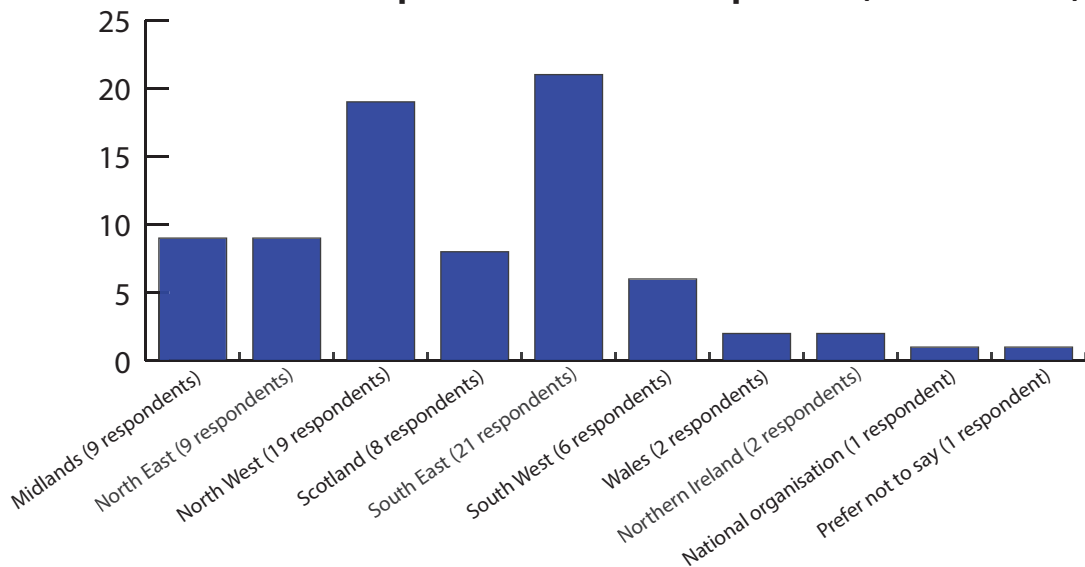


A copy of the survey and other materials used during the PSP process are on the PSP website at www.psp.nihr.ac.uk/mesothelioma.

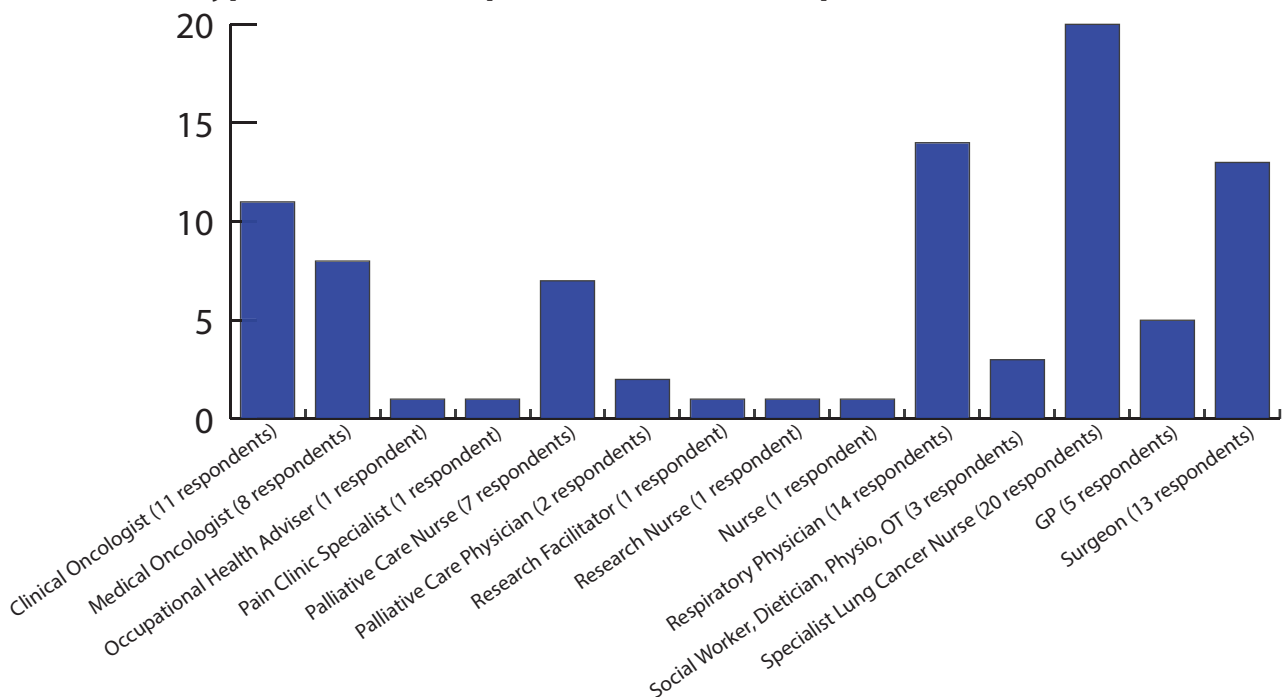
Location of patients and carers who responded (where stated)



Location of healthcare professionals who responded (where stated)



Type of healthcare professionals who responded (where stated)



Analysing the results

From the 453 survey responses, 820 individual questions were extracted.

These were allocated into themes and reviewed. Questions which did not fall into the scope of the PSP were recorded (this is discussed further on). Of the in-scope data, duplicate and similar questions within each theme were combined, resulting in a total of 52 unique questions, which were checked against national guidelines, systematic reviews and existing research evidence to confirm that they had not already been definitively answered by research.

The Steering Group oversaw the process and offered expertise and advice on the evidence checking.

Interim priority setting

The list of 52 questions needed further reduction, to create a shortlist of questions which was a manageable size for discussion at the final workshop. An interim prioritisation survey was designed with input from the Steering Group. It was circulated by email and post to the original survey respondents who had asked to stay involved, as well as to others who had expressed an interest and supported the project since its launch.

The interim prioritisation survey asked patients, carers and health professionals to rank each of the 52 questions on a scale of one to five indicating how much of a priority for research they felt it was. They could indicate if they were unsure and therefore couldn't comment on the importance of the question. Questions were grouped into nine categories which appeared in random order on the online version:

1. Screening and diagnosis
2. Chemotherapy
3. Radiotherapy
4. Surgery
5. Other treatments
6. Treatment issues
7. Side effects and symptoms
8. Post primary treatment issues
9. Peritoneal mesothelioma

The interim survey took place between August and September 2014. A total of 202 responses were received, of which 38 came from people with mesothelioma, 98 from carers, 50 from health professionals and 16 from organisations representing patients and carers.

The ranked order of importance for the questions was calculated for each of those four sub-groups of respondents, giving each group equal weighting, then added together to give a shared ranked order. The process was scrutinised by the Steering Group, who agreed that the top 30 questions should be taken to the final workshop.

The final prioritisation workshop

On 10 November 2014, 30 people attended a workshop in London to discuss and agree the order of priority of the 30 unanswered questions. Care was taken to achieve a balance of perspectives at the workshop. Half of the participants were people with mesothelioma and their families and representatives and half were health professionals from a variety of clinical areas, including specialist nursing, surgery, medical oncology, clinical oncology, palliative care and respiratory medicine. Some of the health professionals had research interests, but all were currently working with people with mesothelioma, so were eligible to participate.

In advance of the workshop, participants were asked to review and familiarise themselves with the 30 questions. They each completed a form to confirm they had no conflicts of interest, and biographies of each participant were circulated to everyone attending the workshop.

The workshop was chaired and facilitated by Katherine Cowan, Senior JLA Adviser, with support from two other JLA Advisers, Richard Morley and David Crowe. It followed the standard JLA final workshop format, using small group sessions to discuss and rank the questions, before agreeing an overall priority order with the whole group. Each participant was encouraged to share their views and give consideration to other people's opinions.



"I thought Monday's workshop was brilliant! The opportunity to discuss the whole subject of mesothelioma in one meeting, with such a pre-eminent cross section of UK experts and on an equal footing was exhilarating. I must admit I had some misgivings about the outcome at the beginning but in the end thought it was exactly right."

Graham Sherlock-Brown, *Steering Group Member and Patient*





"An extraordinarily interesting project. I've never been to an event with such a large contribution from patients and carers. Their presence made the day special and unique in my experience."

Jeremy Steele, Consultant Medical Oncologist



"Just reflecting on working in one guise or another with patients with a mesothelioma diagnosis since the early 90's it would have been almost inconceivable back then to dare imagine a room full of patients/carers/clinicians sharing the stage and having an equal say about such important issues. It was a massive privilege to be included in the process and be able to offer some comment and opinion. The facilitation of the more vocal clinicians and carers was exceptional and ensured that everyone could safely have their voice heard. It truly was an amazing experience and I am looking forward to the future of relevant trials in this previously desolate landscape."

Naomi Horne, Macmillan Lung Cancer Nurse/Mesothelioma UK Nurse



Results

After a day of lively and impassioned discussion, the final Top 10 was agreed, with another three questions noted as being important to highlight. The questions prioritised were:

1. Does boosting the immune system (using new agents such as PD-1 or PD-L1) improve response and survival rates for mesothelioma patients?
2. Can individualised chemotherapy be given to mesothelioma patients based on predictive factors (e.g. the subtype of mesothelioma (epithelioid, sarcomatoid, or mixed), or thymidylate synthase inhibitor status (the protein that drugs like pemetrexed act against), etc)?
3. What is the best way to monitor patients with diffuse pleural thickening and a negative biopsy who are considered to have a high risk of developing mesothelioma (e.g. repeat biopsies, imaging, etc)?
4. In mesothelioma patients, what is the best second line treatment (i.e. what chemotherapy drugs should be used if a cancer has recurred following first line chemotherapy, usually with cisplatin and pemetrexed)?
5. Which is the most effective current treatment for ascites (excessive accumulation of fluid in the abdominal cavity) (e.g. denver shunt, pleurex catheter, etc) in patients with peritoneal mesothelioma?
6. What are the relative benefits of immediate standard chemotherapy compared to a watch and wait policy for mesothelioma patients?
7. For mesothelioma patients, what is the best follow-up strategy post-treatment, to identify and treat emerging side effects and other problems?
8. In mesothelioma, is there a role for intrapleural immunostimulants (a drug designed to stimulate an anti-cancer immune response, such as corynebacterium parvum extract) in addition to any other treatment?
9. Does an annual chest x-ray and/or CT scan and medical examination in high-risk occupations (e.g. carpenters, plumbers, electricians, shipyard workers) lead to earlier diagnosis of mesothelioma?
10. What, if any, are the benefits of pleurectomy (pleurectomy/decortication) compared to no surgery, and which mesothelioma patients might benefit?

In addition to the Top 10, the workshop participants requested that the following three questions also receive a special mention for their importance:

11. Can PET-CT scans (which produce 3D images of the inside of the body) help to diagnose mesothelioma (as well as aiding the assessment of response to treatment)?

12. How can the levels of mesothelin (a protein present in mesothelioma cells that can be measured in the blood) best be incorporated in the diagnosis, response and progression of mesothelioma?
13. What is the best current treatment for breathlessness in mesothelioma patients (e.g. exercise, handheld fans, etc)?

The additional 17 questions discussed at the workshop, in priority order, are at Appendix A. The remaining 22 questions which were not shortlisted for the workshop are at Appendix B.

Out-of-scope questions

The remit of JLA PSPs is to identify and prioritise unanswered questions about the effects of treatments and interventions (including for diagnosis and care), which is how the scope and aim of the Mesothelioma PSP was defined.

From the survey, however, a number of questions arose which were outside of this scope, but which were nevertheless of clear importance to people with mesothelioma, their families and to healthcare professionals. These questions were recorded during the data analysis and are listed at Appendix C. There is commitment from the organisations represented on the Mesothelioma PSP Steering Group to review and consider how to make use of these questions. Other organisations and groups working with people with mesothelioma are encouraged to take note of the out-of-scope questions and consider their relevance for mesothelioma campaigning, lobbying and awareness-raising activities.

Next steps

The Top 10 unanswered questions identified by this PSP were formally announced on 8 December 2014. The JLA will work with Steering Group members and the NIHR to promote the questions to researchers and research funders. The NIHR will review the uncertainties for suitability for its research commissioning programmes. In late 2014 it issued a highlight notice stating that it “welcomes proposals for clinical and applied health research into mesothelioma”. More information about this can be found at www.themedcalls.nihr.ac.uk/mesothelioma.

All the questions identified will be published in the UK Database of Uncertainties about the Effects of Treatment (UK DUETs) at www.library.nhs.uk/duets.

What can you do to help?

Use the priorities

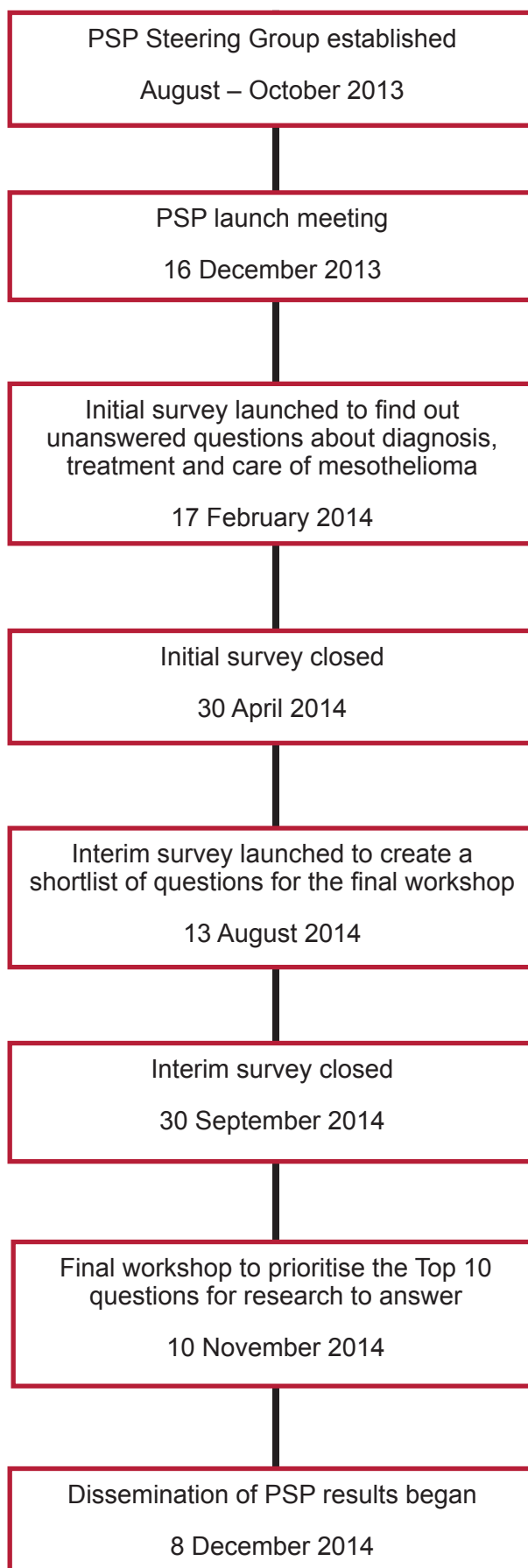
People with mesothelioma, their families and health professionals have taken time to tell the PSP what questions they want to see answered by research. They are part of a small community fighting a rare but highly aggressive disease. The medical research community owes it to them to make every effort to address these unanswered questions.

Tell us how you are using the priorities

The more information there is about how the mesothelioma priorities are influencing what research is happening, the better the NIHR can understand the impact of its investment in this PSP. This will also help future PSPs to become more effective.

Tell other people about the priorities

The more people who know about the mesothelioma research priorities, the more likely organisations and individual researchers are to tackle the questions that patients, carers and health professionals have told us they want answered. Please help to spread the word about what needs to happen.



Appendix A – questions 14 – 30 discussed at the workshop (in priority order)

Appendix B – the remaining 22 unanswered questions identified but not shortlisted for the final workshop (in no order of priority)

Appendix C – out-of-scope questions (in no order of priority)

Appendix D – resources involved

Appendix A – questions 14 – 30 discussed at the workshop (in priority order)

14. Is giving a course of chemotherapy to mesothelioma patients before or after surgery beneficial?
15. What is the best current method of managing mesothelioma patients with chronic recurrent pleural effusions (e.g. tunnelled indwelling drain vs pleurodesis and repeated pleural tap)?
16. Should treatment for mesothelioma, if the patient has no symptoms, be given immediately or delayed?
17. Is giving a course of radiotherapy to mesothelioma patients (especially new techniques such as Intensity Modulated Radiotherapy) before or after surgery beneficial?
18. Is giving a course of radiotherapy to mesothelioma patients (especially new techniques such as Intensity Modulated Radiotherapy) before or after chemotherapy beneficial?
19. Would early referral to palliative care be beneficial for mesothelioma patients?
20. What is the value of weekly telephone support for mesothelioma patients during chemotherapy in reducing hospital admissions, side effects and anxiety?
21. What is the current best method (e.g. contrast enhanced MRI vs PET) to accurately assess disease progression in mesothelioma patients?
22. Can rehabilitation be used to improve long term chronic side effects in mesothelioma patients (especially following surgery) - e.g. the use of a comprehensive cancer rehabilitation team of health care professionals?
23. Is there an overall benefit for standard chemotherapy in terms of QALYS (Quality Adjusted Life Years, a measurement that combines survival and quality of life) compared to supportive care alone, for mesothelioma patients?
24. Should radiotherapy be given to mesothelioma patients at the incision site (as a result of surgery or thoracoscopy) to stop cancer cells spreading?
25. What, if any, are the benefits of palliative surgery (partial pleurectomy/surgical debulking) for mesothelioma patients?
26. Should interventions (e.g. cordotomy or radiotherapy) be used to control severe pain after surgical interventions for mesothelioma such as biopsy, VATS, pleurodesis, etc?
27. What is the best current treatment for fatigue in mesothelioma patients (e.g. drug interventions)?
28. What is the best way to monitor patients with pleural plaques (e.g. CT scan) for development of mesothelioma?
29. In mesothelioma patients, what is the best current treatment for sweating (e.g. Cox2 inhibitors)?
30. What is the best treatment to alleviate mucus in mesothelioma patients (e.g. steam inhalation, carbocisteine, physiotherapy, etc)?

Appendix B – the remaining 22 unanswered questions identified but not shortlisted for the final workshop (in no order of priority)

- Are cox inhibitors (a form of non-steroidal anti-inflammatory drug) effective in mesothelioma, when added to any other treatment?
- Are biphosphonates (which are usually used to prevent or slow down bone damage, but may inhibit the growth of mesothelioma cells) effective in mesothelioma when added to any other treatment?
- Can a brief psychological intervention help with body image and sexual concerns?
- Does the addition of ADI-PEG20 (a novel protein that breaks down an amino acid (arginine) that cancer cells need to survive and grow) to standard chemotherapy in mesothelioma patients improve overall survival?
- Does metformin (an oral anti-diabetic drug which may act directly on cancer cells) delay progression or recurrence in mesothelioma?
- In localised areas of disease, is the application of extreme cold to destroy cancer cells (cryotherapy or cryoablation) more effective than radiotherapy?
- Is there a role for less aggressive first line chemotherapy (such as monotherapy e.g. oral vinorelbine) in patients with poor fitness levels?
- Is it beneficial to screen psychological conditions, and give anti-depressants to patients with depression?
- Is giving six cycles of chemotherapy more effective than four?
- Is there a role for maintenance chemotherapy (with pemetrexed, or oral vinorelbine)?
- Is chemo-embolization (delivering the drugs intravenously to the vicinity of the tumour) a more effective way of giving chemotherapy than the standard intravenous method?
- Is chemoperfusion (rinsing the abdominal cavity with chemotherapy) more effective than standard chemotherapy in patients with peritoneal mesothelioma?
- Is brentuximab vendotin (a drug which acts against CD30 antigen, a protein given off by cancer cells) effective in patients with mesothelioma?
- Is hyperthermia (increasing body temperature to damage cancer cells) of value in patients with peritoneal mesothelioma?
- Is acupuncture effective in relieving and/or controlling pain?
- Is laser-induced thermal therapy effective in patients with mesothelioma?
- Is photodynamic therapy (activating photosensitive drugs using light energy) effective in mesothelioma?
- Is hyperthermia (increasing body temperature to damage cancer cells) plus standard chemotherapy effective in mesothelioma?
- Is there a benefit in reducing the chemotherapy doses (by say 10% or 20%) in less fit patients?
- What is the value of cyto-reductive surgery (removing some of the tumour) for patients with peritoneal disease?
- What is the effect of vitamin supplementation on outcomes (infections, side effects, etc)?
- What are the relative benefits of other established chemotherapy regimens compared to the standard drugs (cisplatin, or carboplatin, and pemetrexed)?

Appendix C – out-of-scope questions (in no order of priority)

Standardisation

- Is there geographical variation across the UK with regard to diagnosis, treatment and care of patients with mesothelioma, and how might this be corrected?
- Would the development of a specific mesothelioma pathway (covering prognosis, treatment, etc) be beneficial for patients and their families?
- Would increasing the knowledge base of medical staff improve the treatment and care of mesothelioma patients?
- How can continuity of care (and communication between health professionals) be improved?
- Should mesothelioma Multi-Disciplinary Teams be set up?
- Would outcomes be improved if patients were seen at large centres with experienced staff rather than small local centres with less experienced staff?
- Would the development of more specialist hubs, clinicians and nurses improve the outlook for patients with mesothelioma?
- Should all diagnoses be centrally reviewed?
- Can a checklist of symptoms (cold/cough/breathlessness/weight loss/lack of appetite/pleurisy/[back] pain/pleural plaques etc) and patient characteristics be developed as a trigger for investigation/referral?
- How can a diagnosis at Post Mortem be avoided?

Diagnosis

- Would greater awareness of mesothelioma amongst GPs improve the diagnosis and referral rates?
- How can the time it takes to diagnose mesothelioma be reduced (to reduce anxiety/assist planning for the future/increase treatment options and outcomes, etc)?
- Can the time taken to diagnose peritoneal mesothelioma be reduced?
- Can a reliable diagnostic blood test be developed?
- Can a reliable diagnostic tool be developed that does not involve a biopsy or invasive surgery?

Treatment

- How can delays in treatment be avoided, to avoid unnecessary distress?
- Should all peritoneal patients be referred to a colorectal, rather than a lung, specialist?
- Can the number of biopsies undertaken be reduced (if only being done to decide treatment, or for legal reasons)?
- Can genetic profiling be used to develop targeted therapies?
- Can molecular targets be identified, so that improved therapies can be developed?
- Can we identify the prognostic factors that determine which patients will benefit from thoracoscopy and which will benefit from surgical VATS?
- How can post-operative infections be reduced?
- Can we identify the prognostic factors that determine which patients will benefit from immediate chemotherapy and those for whom it is better to 'watch and wait'?
- Can treatment deplete the immune system and increase the likelihood of the disease spreading?

Care

- Should palliative care for mesothelioma be different from lung cancer?
- Can community nurses be more available at night and weekend?
- As patients live longer does this lead to an increased risk of developing metastases?
- What should trigger starting further treatment?
- What is the risk of 2nd cancers and should patients be monitored for this?

Support

- How could nationwide support groups, to help patients' carers and family, be set up?
- What information would be most helpful for patients, carers and their families, and how best could this be delivered?
- Is there too much focus on compensation, rather than information on care, support, pain relief, etc?
- What is the impact on carers, and how can this best be managed?
- What are the benefits of being active and mobile as possible, and with a sensible healthy diet?
- What are the benefits of a healthy lifestyle (diet, relaxation, being more active, etc)?

Understanding mesothelioma

- Can predictive analyses define subgroups (e.g. epithelioid tumours) that are likely to benefit more (or less) from chemotherapy?
- Can we identify the prognostic factors affecting mesothelioma patients (including staging), in order to better target treatment etc?
- Can factor analyses (using factors such as lifestyle, co-morbidities etc) be used to predict long term survivors?
- What factors in addition to asbestos exposure lead to the development of mesothelioma?
- Can we investigate long term survivors?
- Is it possible to predict if and when the disease will spread and/or the patterns of spread?
- What is the relationship between smoking and mesothelioma?
- What are the causes of pleural effusions?
- Can mesothelioma cause ARDS (Acute Respiratory Disease Syndrome)?
- Is mesothelioma always caused by asbestos?
- What is the risk of childhood asbestos exposure, as a result of the levels of asbestos in schools?

Appendix D - resources involved

The direct costs of this PSP were in the region of £40,000, funded by the NIHR, which includes the cost of a JLA Adviser to independently oversee the project, and an Information Specialist to analyse the survey responses, form the research questions and check existing research evidence. Administrative co-ordination was provided by JLA staff based within NETSCC.

Patients and carers on the Steering Group were paid an honorarium for their participation in Steering Group meetings. Expenses incurred by all Steering Group members when travelling to Steering Group meetings were reimbursed, as were expenses incurred by everyone who attend the final priority setting workshop.

Contact Information

If you need further information or support with any aspect of mesothelioma, please contact Mesothelioma UK by visiting <http://www.mesothelioma.uk.com> or telephoning 0800 169 2409.

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