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Supplementary file C: copy of the online national survey

Mesothelioma patient and carer experience Research Prioritisation Exercise (RPE)

If you agree to take part, submitting your online survey will be deemed as your consent to participate. Thank you for taking the time to complete this survey.

What is the purpose of this exercise?

The purpose of the mesothelioma RPE is to identify unanswered research questions about the mesothelioma patient and carer experience and to identify research areas of most importance.

The aims of this survey are to:

- learn from the experience of those living and working with mesothelioma
- provide people living and working with mesothelioma with the opportunity to inform the direction of future research
- develop recommendations for future mesothelioma patient and carer experience research.

We have spent the past few months reviewing the existing patient and carer experience research in the field of mesothelioma. We have created eight short videos to share the eight areas where research gaps exist. Each video is 1-2 minutes long. We would like to know whether these reflect real challenges and issues for people living with mesothelioma so we are asking you, the experts.

What would we like you to do?

Please watch each video and answer the following questions to tell us to what extent you think these topics require research. There is also space for you to add any other research ideas or topics that you feel are important and we have not identified. We are very interested to hear your thoughts.

The survey should take approximately 20-25 minutes to complete. You may find this survey more difficult to navigate using your mobile phone so, if possible, we recommend using a tablet or PC.

Who is taking part?

We are asking anyone directly affected by mesothelioma or working to support those affected by mesothelioma to tell us which areas of the patient and carer experience that they would like research to focus on.

This survey is being run by the Mesothelioma UK Research Centre – Sheffield. You can find out more about the Research Centre from <https://www.sheffield.ac.uk/murc>.

If you have any questions about the survey please email us at: mesotheliomaresearchcentre@sheffield.ac.uk

For further information about this study and how we will use the information you provide, click here

https://drive.google.com/file/d/1yVXh30WBR_1Ose43K0NL_yQadjcsV6I0/view?usp=sharing

* Required

To start we would like you to tell us a bit about yourself

1. How old are you? *

Mark only one oval.

- <30 years
- 31-40 years
- 41-50 years
- 51-60 years
- 61-70 years
- 71-80 years
- over 80
- years

Prefer not to say

2. It would help us to know where our respondents are based. If you are a patient or carer please provide us with the first four digits of your HOME postcode. If you are a professional or volunteer please provide us with the first four digits of your WORK postcode

3. If you are based outside of the UK, please tell us in which country you are based.

4. Are you: *

Mark only one oval.

- Male
- Female
- Prefer not to say
- Other:

5. Please select one option that best describes your ethnic group and background *

Mark only one oval.

- White
 - Mixed/ multiple ethnic group
 - Asian
 - African
 - Caribbean or Black
 - Prefer not to say
 - Other:
-

6. Are you a: *

Mark only one oval.

- Person with a diagnosis of mesothelioma
 - Family member / close friend of someone with a diagnosis of mesothelioma
 - Bereaved family members/ close friend of someone with a diagnosis of mesothelioma
 - Health care/ allied health professional
 - Asbestos Support Group professional
 - Legal professional
 - Other professional or volunteer
 - Other
-

7. If you are a patient or carer living with mesothelioma, are you, your family member or close friend living with

Mark only one oval.

- Pleural mesothelioma
- Peritoneal mesothelioma
- Testicular mesothelioma
- Pericardial mesothelioma
- Don't know

8. If you are a patient or carer living with mesothelioma, when were you, your family member or close friend diagnosed with mesothelioma?

Mark only one oval.

11. Please tell us about any other topics related to diagnosis that you think need further research

Please watch the video and respond to the questions below

The physical impact of mesothelioma

Research gap video - The physical impact of mesothelioma presented by Professor Angela Tod.

<http://youtube.com/watch?v=CUBA3jbbCuQ>

12. How important do you think research is in the following areas? 1 = Not at all important 10= Extremely important

Mark only one oval per row.

	1	2	3	4	5	6	7	8	9	10
Support for patients and carers to manage symptoms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The physical impact of treatments (including side effects)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

13. Please tell us about any other topics related to the physical impact of mesothelioma that you think need further research

Please watch the video and respond to the questions below

The psychological impact of mesothelioma

Research gap video - The psychological impact of mesothelioma presented by Virginia Sherborne.

<http://youtube.com/watch?v=Fe5zwbEDfDU>

14. How important do you think research is in the following areas? 1 = Not at all important 10= Extremely important

Mark only one oval per row.

	1	2	3	4	5	6	7	8	9	10
Exploring mental health and well being (positive and negative) across the mesothelioma journey	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The link between physical and psychological well being	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

15. Please tell us about any other topics related to the psychological impact of mesothelioma that you think need further research

The impact on family, informal (unpaid) carers and relationships

Please watch the video and respond to the questions below

The impact on family, informal carers and relationships presented by Dr. Stephanie Ejegi-Memeh.

<http://youtube.com/watch?v=c9qfTspo2k8>

16. How important do you think research is in the following areas? 1 = Not at all important 10= Extremely important

Mark only one oval per row.

	1	2	3	4	5	6	7	8	9	10
The impact of mesothelioma on family and intimate relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Supporting and communicating with families and caregivers from diagnosis to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Positive and negative impacts of informal caregiving	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17. Please tell us about any other topics related to the impact of mesothelioma on informal carers, family and relationships that you think need further research

Please watch the videos and respond to the questions below

Self-management of mesothelioma

Research gap video - Self-management of mesothelioma video 1 presented by Xueming Zhang.

<http://youtube.com/watch?v=33PBi6f5sf8>

Research gap video - Self-management of mesothelioma video 2 presented by Jennifer Ross.

<http://youtube.com/watch?v=NbksMT5fWqc>

18. How important do you think research is in the following areas? 1 = Not at all important 10= Extremely important

Mark only one oval per row.

	1	2	3	4	5	6	7	8	9	10
Management of physical symptoms e.g. cough, breathlessness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Management of psychological symptoms e.g. stress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Maintaining hope	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Role of support groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Preferences for the delivery of information about mesothelioma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

19. Please tell us about any other topics related to the self-management of mesothelioma that you think need further research

Healthcare professionals and systems

Please watch the video and respond to the questions below

Research gap video - Healthcare professionals and systems presented by Dr. Emilie Couchman

<http://youtube.com/watch?v=85TSAaSFLYU>

23. Please tell us about any other topics related to the patient and carer experience of mesothelioma treatment and trials that you think need further research

Asbestos exposure and compensation

Please watch the video and respond to the questions below

Research gap video - Asbestos exposure and compensation presented by Dr. Clare Gardiner.

<http://youtube.com/watch?v=1hzOZbBzCsE>

24. How important do you think research is in the following areas? 1 = Not at all important 10= Extremely important

Mark only one oval per row.

	1	2	3	4	5	6	7	8	9	10
Motivations for seeking or not seeking compensation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Barriers and facilitators to seeking compensation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Factors with predict who seeks compensation and who is most successful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. Please tell us about any other topics related to the patient and carer experience of asbestos exposure and compensation that you think need further research

Is there anything else you would like to add?

26. Please use this space to write about any other research topics or ideas that have not been * recognised in this survey. Please tell us about any aspects of the mesothelioma patient and carer experience that matter to you.

What happens now?

All survey responses will now be collated and combined. A smaller group of experts will then help to refine and rank research ideas in order of importance. These experts will include patients and carers living with mesothelioma and professionals and volunteers working to support, treat and care for them. Once we have compiled a list of research priorities, this will be shared widely in order to influence the future mesothelioma research agenda.

Thank you so much for your contribution.

Please leave your email at the end of this survey if you would like to be kept up to date with the next steps for the Research Prioritisation Exercise and other research activities undertaken by the Mesothelioma UK Research Centre.

If completing this survey has prompted any concerns or questions about your treatment and care or the treatment and care of your friend or family member, please contact the Mesothelioma UK helpline for advice and support 0800 169 2409.

If you would prefer for us to put you in contact with Mesothelioma UK, please contact us using the following email address mesoresearch-group@sheffield.ac.uk.

Thank you and best wishes from the Mesothelioma UK Research Centre Team.

27. Thank you for taking the time to complete our Patient and Carer experience research prioritisation survey. Please provide your email address below if you would like to join the Mesothelioma UK Research Centre mailing list to receive updates on our research.

Google Forms