

Mesothelioma patient and carer experience research priority statement

Conducted by the Mesothelioma UK Research Centre, Sheffield in 2021

Five research priorities relating to mesothelioma patient and carer experience were identified as the **most urgent**. These are as follows (in no particular order):

- Symptom management (support for patients and carers to manage symptoms, management of physical symptoms e.g. cough, breathlessness, and management of psychological symptoms e.g. stress)
- Receiving a mesothelioma diagnosis (patient experience immediately after diagnosis, barriers and facilitators to early diagnosis, occupational history taking at diagnosis)
- Palliative and end of life care (supporting quality of life across the patient pathway, from diagnosis to the end of life and bereavement)
- Experience of treatments (the physical impact of treatments (including side effects), factors influencing treatment decisions)
- Barriers and facilitators to joined-up service provision (access to services; how different health, care, and other services are brought together to meet the needs; choices and aspirations of the individual; geographical variation across the UK)

A further six research priorities relating to mesothelioma patient and carer experience were also identified as important. These are as follows (in no particular order):

- Care delivery (the role of different professionals in supporting patients and their families, maintaining hope, preferences for the delivery of information about mesothelioma, the role of support groups)
- Living with peritoneal mesothelioma (all aspects of the peritoneal mesothelioma experience need further research). Research recognising the experiences of peritoneal mesothelioma patients and carers may be integrated into the other research priorities.
- Mental health and wellbeing (the link between physical and psychological wellbeing, exploring mental health and wellbeing (positive and negative) across the mesothelioma journey)
- Experience of clinical trials (factors influencing clinical trial participation, costs and benefits of taking part in a clinical trial)
- Experience of caregivers (supporting and communicating with families and caregivers from diagnosis to bereavement, positive and negative impacts of informal caregiving, the impact of mesothelioma on family and intimate relationships)
- Compensation (barriers and facilitators to seeking compensation)

Methods

Background

Mesothelioma is an under-researched cancer. It was identified as a priority research area by the National Institute for Health Research (NIHR) in 2013. The NIHR subsequently funded a Priority Setting Partnership conducted by the James Lind Alliance. This focused on treatment and interventional research. Research that focused on patient and carer experience was not in the scope of this work.

In 2021, the Mesothelioma UK Research Centre – Sheffield conducted a Research Prioritisation Exercise to identify research priorities explicitly in the area of patient and carer experience. Without research that focuses explicitly on patient and carer experience, there is a risk that new interventions, treatments and innovations in service delivery will not meet the needs of those receiving them.

Aim

The aim of the Research Prioritisation Exercise was to identify unanswered questions about the mesothelioma patient and carer experience and then to prioritise these areas, through consultation with patients, carers and professionals.

Methods

Following a systematic process that included a review of evidence, a national survey and a consultation, we identified the current research priorities relating to mesothelioma patient and carer experience. An overview of this process will be reported separately.