

MESOTHELIOMA PATIENT AND CARER EXPERIENCE: A RESEARCH PRIORITISATION EXERCISE

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Aim: to identify unanswered questions about the mesothelioma patient and carer experience in the UK and prioritise research areas of most importance through consultation with patients, carers and professionals.

This Research Prioritisation Exercise is the first of its kind to focus on mesothelioma patient and carer experience research.

Evidence synthesis

- Peer reviewed literature (Ejegi-Memeh *et al*, 2022)
- Grey literature (inc. reports, theses, statements, guidelines)

Online survey

- Respondents scored identified research gaps according to importance
- 150 responses received: patients (n=56), carers(n=36) and professionals (n=58).

Consensus exercises

- Online meetings
- Ranking exercises
- Undertaken by project steering group (16 experts; patients, carers, professionals)

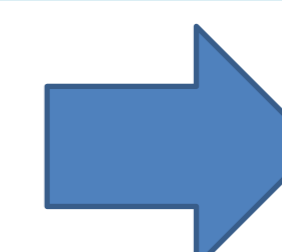
The Research Prioritisation Exercise identified 11 research priorities. Five were identified as the most urgent:

Priority	Detail
Symptom management	Support for patients and carers to manage symptoms, management of physical symptoms e.g. cough, breathlessness, 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 were identified as important:

Priority	Detail
Care delivery	The role of different professionals in supporting patients and their families, preferences for the delivery of information about mesothelioma, role of support groups
Living with peritoneal mesothelioma	All aspects of the peritoneal mesothelioma experience need further research
Mental health and well being	The link between physical and psychological well being, exploring mental health and well being (positive and negative)
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, the impact of mesothelioma on family and intimate relationships
Compensation	Barriers and facilitators to seeking compensation

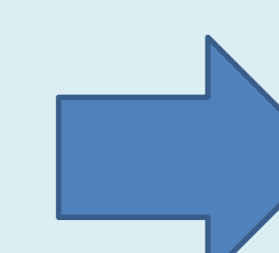
Find our published Research Prioritisation Exercise journal article (Taylor *et al*, 2023) here



Looking forward

- The research priorities provide direction for researchers and research funders to ensure that future patient and carer experience research aligns with the priorities of mesothelioma patients and their families.
- Current research studies at the Mesothelioma UK Research Centre informed by this Research Prioritisation Exercise include:
 - Pathways and experiences of care in Peritoneal Mesothelioma
 - Supporting our Supporters (SoS): Improving the experiences of family and caregivers of people with mesothelioma
 - MINNOW: Investigating the mental health implications of a mesothelioma diagnosis and developing resources to optimise wellbeing
 - Bereaved carer experiences of the coroner/ procurator fiscal investigation following a mesothelioma death

You can find more information about our current studies on our website. Get in touch with the team if you have any questions or would like to know more.



Ejegi-Memeh S, Sherborne V, Harrison M, Taylor B, Senek M, Tod A, Gardiner C. (2022) Patients' and informal carers' experience of living with mesothelioma: A systematic rapid review and synthesis of the literature. *Eur J Oncol Nurs*, 58:102122. doi: 10.1016/j.ejon.2022.102122.
Taylor B, Tod A, Gardiner C, Ejegi-Memeh S, Harrison M, Sherborne V, Couchman E, Senek M, Bachas Brook H, Ross J, Zhang X. Mesothelioma patient and carer experience research: A research prioritisation exercise. *Eur J Oncol Nurs*, 63:102281. doi: 10.1016/j.ejon.2023.102281.