Mesothelioma Patient and Carer Experience Research: A Research Prioritisation Exercise (RPE)

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Background

• Malignant mesothelioma is a rare, life-limiting and aggressive cancer with a high symptom burden that is caused by exposure to asbestos.

• The UK has the highest global incidence and thus it is important that mesothelioma is recognized as a national priority.

• It is vital that research efforts and funding are directed towards topics that patients and carers consider to be important.

The RPE aimed to identify research gaps and to prioritise them through consultation with patients, carers, and professionals.

The RPE comprised three components:

A systematic review of evidence to identify research gaps
A national online survey of patients, carers and professionals
A consultation & ranking exercise with stakeholders

Research priorities for mesothelioma patient and carer experience research

The top five priorities (in no particular order):

• **Symptom management** (e.g. support for patients and carers to manage symptoms)
• **Receiving a mesothelioma diagnosis** (e.g. patient experience immediately after diagnosis)
• **Palliative and end of life care** (Support from diagnosis to the end of life and bereavement)
• **Experience of treatments** (e.g. the physical impact of treatments)
• **Barriers and facilitators to joined-up service provision** (e.g. access to services)

A further 6 research priorities were also identified (see www.sheffield.ac.uk/murc)

Conclusion

• This unique exercise enabled patients, carers and professionals with expertise in this area to shape the future research agenda and build an evidence base to feed through to policy and practice

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