MESOTHELIOMA UK

Mesothelioma UK Audit and Research Strategy 2020-2023

Supporting People With This Asbestos Cancer

www.mesothelioma.uk.com

Foreword

The story of Mesothelioma UK began in 2004 with the launch of the National Macmillan Mesothelioma Resource Centre. Fast forward to 2009 and the Mesothelioma UK Charitable Trust was formed to secure our long-term future and financial independence. The charity is respected nationally and internationally within the mesothelioma community.

Through integrated working practices, the charity supports UK healthcare professionals and providers to ensure equitable access to world-class care and treatment. We also aim to raise the profile of mesothelioma and help to prevent future cases of this asbestos-related disease.

In 2016, Mesothelioma UK launched a new strategy that explains what we will do to 'Make Mesothelioma Matter'. We want to reach out to more people affected by mesothelioma, improving their experience and outcomes of treatment and care. Recognising that this vision will only be realised through relevant and scientific research, we have developed a new and exciting research strategy. This research strategy reaffirms our commitment to excellence.

The Mesothelioma UK 2020-2023 Audit and Research Strategy outlines the charity's plan to offer a range of grant opportunities that will fund research and explore patients' experiences of care, through to research on patient treatments and outcomes of care. As part of this, the charity will fund an academic institute to host a new centre for research, called the 'Mesothelioma UK Research Centre'.

New funding streams will support new and existing audit research collaborations with academics, healthcare professionals and the charitable sector. Our vision is to use one-third of our income to fund this work. Our Scientific Committee will review all funding opportunities and determine where best to spend our money.

Mesothelioma UK is reliant on the generosity of people and organisations who support our work and vision. We have achieved so much with your support and strive to achieve so much more. We promise to spend every penny wisely to support our research and audit objectives over the coming years. Where possible, we will also work with other charitable organisations or funding bodies to combine our efforts and extend our opportunities.

As we look to the future, we are excited about what we can achieve and hope that you share that excitement with us.

Liz Darlison
Head of Services
Mesothelioma UK

Background

The UK has the highest incidence of mesothelioma in the world. Treatment options, outcomes, working toward a cure and improving individuals' experience of care is dependent on quality research and audit. Research and audit are core activities for Mesothelioma UK.

Mesothelioma UK is registered with the Charity Commission. We clearly state in our submissions to the Commission and in our current Five Year Strategy (2016-2021) that we will sponsor and undertake research.

'The UK has the highest incidence of mesothelioma in the world'

A Strategic Review

Mesothelioma UK is committed to spending the vast majority of its income on charitable activities. This includes working with the NHS to provide a growing team of clinical nurse specialists, and funding innovative research and audit projects to improve the care of patients diagnosed with mesothelioma.

Over the past three years, Mesothelioma UK has spent between 12-28 per cent of its annual income on audit and research. In monetary terms, this amounts to £960,248. Our aim moving forward is to increase this expenditure to one-third.

We want to focus on supporting quality research and audit to improve treatment options, patient experiences, care and outcomes for those affected by mesothelioma.

We will continue to fund existing research and audits including the:

- National Mesothelioma Audit
- Mesothelioma Patient Experience Audits

In addition, we will also search for new and exciting opportunities.

Mesothelioma UK funded projects 2015-2020

Date Awarded	Title	Main Researcher	Grant Awarding Partner
07/11/2019	Role of Mesothelioma UK's CNSs in Palliative Care	Dr Clare Gardiner	-
22/07/2019	Exploring clinical decision-making in mesothelioma treatment pathways across three NHS Trusts: a mixed methods study	Dr Catherine Henshall	NCLFN
27/06/2019	MAGS: Healthcare worker Mesothelioma Asbestos Guidance Study: Healthcare workers and mesothelioma, experiences of presentation, diagnosis, treatment and care	Dr Peter Allmark	-
02/2019	Gendered Experience of Mesothelioma Study (GEMS)	Professor Angela Tod / Dr Steve Robertson	
03/01/2019	Genomics of Peritoneal Malignancy including rare forms of mesothelioma	Professor Sarah Ennis	Basingstoke (co-funder)
01/2019	Mesothelioma Outcomes Research and Experience (MORE)	Mesothelioma UK	
01/2019	Mesothelioma Organisation Audit	RCP	
05/09/2018	Living well with mesothelioma: Improving the patient experience. A qualitative study	Dr Karen Lord	NCLFN
25/07/2018	Mesothelioma patients' experiences of follow up care across three NHS Trusts	Dr Catherine Henshall	NCFLN
2018	Immunotherapy for malignant mesothelioma using IL-6-neutralising CAR T-cells	Dr John Maher	BLF
12/2017	Military Experiences of Mesothelioma Study (MiMES)	Professor Angela Tod	LIBOR (super funder)
06/2017	Non invasive diagnosis of mesothelioma using structured light plethmography	Amy Kerr	NCLFN
06/2017	Receiving A DIagnosis Of Mesothelioma - Improving the patient experience (RADIO Meso)	Dr Beth Taylor and Professor Angela Tod	NCLFN
2017	MEDUSA – Mesothelioma Evolution: Deciphering drUgable Somatic Alterations as potential targets for synthetic lethal therapy	Dr Edward Hollox	BLF
2016	Addressing Hypoxia as a New Target for Treatment of Asbestos-induced Cancer	Professor Marija Krstic-Demonacos	BLF
Every Year since 2016	National Mesothelioma Audit	Royal College of Physicians	
2015	A new approach for personalising therapy for mesothelioma	Professor Dean Fennell	BLF

Securing funds for Audit and Research

Mesothelioma UK aims to spend a third of the charity's income on audit and research in the following ways:

- Our fundraising team will continue to raise funds to support our research and audit vision
- We will also work with other charities to create exciting opportunities to fund research and increase the impact of our work
- Apply for grants and trusts relevant to our work
- Establish a named Mesothelioma UK audit and research grant opportunity with a variety of levels and options e.g. The Bob Smith Mesothelioma UK Research Fund, The Manchester Mesothelioma UK Research Grant
- Work closely with the commercial sector, particularly legal panel members and partner organisations, to raise the profile of the Mesothelioma UK Research Fund
- Liaise with existing mesothelioma grant holders and researchers to identify sources of funding suitable to their area of study - for example, women and meso, Armed Forces, healthcare workers

Partnerships

Our work will be strengthened by teaming up with other groups of research funders including charities, universities and the NHS. By working together, we can support larger scale or innovative research projects, which will be to the benefit of patient care.

One of our first exciting projects is to establish a Mesothelioma UK Research Centre with an academic institution.

The tender will be for three years. The provider will:

- Receive an annual core fund to support the research team
- Work closely with Mesothelioma UK to identify key research priorities
- Have access to an annual sum for research costs
- Seek to appoint at least one PhD student during the term of the tender

We will work collaboratively with researchers and clinicians who share a similar vision and have complementary skills to focus on mesothelioma research. It is important that we support existing and new talent, and support leading researchers of the future.

> ‘By working together, we can support larger scale or innovative research projects, which will be to the benefit of patient care.’

Meet some of our Grant Holders

Dr. Bethany Taylor

Beth works at the University of Sheffield and has completed a research study called RADIO Meso (Receiving A DIagnosis Of Mesothelioma). Following a series of interviews, Ten Top Tips were identified for communicating a mesothelioma diagnosis. The tips have been used to inform practice guidelines on breaking bad news and have been adopted by the Mesothelioma UK team of nurses and beyond. This research will improve patient experiences and make them feel like the most important person in the room, at the centre of the communication process.

Dr. Karen Lord

Karen is working on a research project called Living Well with Meso. This is an ongoing research study designed to explore how we can improve patient experiences when diagnosed with pleural mesothelioma.

This is a collaborative study with the University of Sheffield, in association with Lung Cancer Nursing UK. The research team wanted to explore:

- How people cope and adapt to their situation
- How their priorities change
- What do they do to help them manage challenging situations

Dr. Sarah Ennis

Mesothelioma is commonly associated with the lining of the lungs but it is also found in the lining of the abdomen. This type of cancer is very rare.

Mesothelioma UK has funded a research project with scientists from the University of Southampton and with the Peritoneal Malignancy Institute in Basingstoke. The team is looking at tissue samples of peritoneal cancers to understand their genetics.

Sarah and her team want to use this genetic information to look for any changes that are specific to different types of mesothelioma. They want to know how their behaviour influences a patient’s prognosis and how we might be able to treat them better.

Communicating our research and audit activity

To augment the fundraising team's efforts, and to raise additional audit and research specific monies, the Communications Team will establish a robust reporting system to give a high profile to all audit and research funded by Mesothelioma UK.

Grant holders will provide regular updates and an end-of-audit study report for sharing on the charity website, social media platforms and in the charity magazine. They will acknowledge the charity by using Mesothelioma UK logos on all publications and presentations.

The research section of the Mesothelioma UK website will be updated with each audit or study progress in real-time.

Named funders will be encouraged to tell their fundraising stories and these will be published on the Mesothelioma UK website and included in the quarterly magazine.

All funded audit and research studies will be subject to a launch, completion and publication of findings in press releases and academic journals.

Governance

The charity's Research and Audit Scientific Committee (RASC) is responsible for overseeing all of Mesothelioma UK audit and research activity.

All audits and research funded by Mesothelioma UK will be subject to robust governance measures and peer review, where appropriate. We will apply for full membership of the Association of Medical Research Charities.

The amount available for audit and research will be confirmed by the trustees at year-end and after completion of the charity's annual accounts.

The proportion allocated to each of the funding streams, allowing for agreed cross-year commitments, will be proposed by the RASC and approved by the trustees.

Expenditure will be accounted for in the year it was awarded, not the year it was transferred to the grant holder.

Supporting Mesothelioma UK Research

You can help to support Mesothelioma UK's research activity into treatments and care for mesothelioma patients by helping us with fundraising and donations or leaving a legacy gift in your will. For more information, please visit www.mesothelioma.uk.com/getting-involved

Summary

Funding research and audit is a core activity for Mesothelioma UK. The charity aims to spend a third of its income on audit and research. This first research strategy sets out a robust structure for allocating funds, and allows for collaborative working and relationships to be formed.

The charity is well established in the mesothelioma community both nationally and internationally, and works closely with a variety of professional organisations.

We are well placed to support high-quality research, which we will share and disseminate widely to enhance patient care and experiences.

For more information on Mesothelioma UK audit and research, visit www.mesothelioma.uk.com

The charity aims to spend a third of its income on audit and research

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