

End of Study Report	
To be completed in typescript and submitted by the Principal Investigator (PI)	
Details of the PI	
Name	Dr Catherine Henshall
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Has the PI changed since the last progress report?	No
Details of the Study	
Full title of the study	Exploring clinical decision-making in mesothelioma treatment pathways across three NHS Trusts: a mixed methods study
Name of Research Ethics Committee (REC) (if applicable)	<i>Oxford Brookes University</i>
REC reference number	HRA reference: 19/HRA/7157 Because it was a study with staff we only received university ethics approval and HRA approval for NHS as the study did not require approval by an NHS REC.
Date of favourable ethics opinion	23.01.20
Sponsor (if applicable)	Oxford Brookes University
End of Study and / or Termination Dates	
Was the study completed or did it terminate without completion? Please describe	Study completed in May 2021. There was a delay due to the study being paused in 2020 for a number of months due to the Covid-19 pandemic.

Date the study completed / terminated early	May 2021
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Study Findings

Please provide details of your key study findings. Please try to limit to two A4 sheets of paper

Phase 1: Analysis of patient records

Patient records (n=232) were screened from three NHS Trusts: Trust A (n=139); Trust B (n=45); and Trust C (n=47). The mean age of patients at diagnosis was 75.8 years old (SD=9.3, range 33-95). The majority of patients were deceased at the time of data collection (75.4%). Most patients at all trusts (72.8%) had received best supportive care only (including pleural management). The majority of patients at Trust A (59.7%) received one or more active treatments (including chemotherapy, radiotherapy, surgery, treatment via a clinical trial, or immunotherapy). Fewer patients at Trusts B (45.7%) and C (27.7%) were receiving these treatments.

Phase 2: Documentary Analysis

The documentary analysis of key service and policy documents from our previous study looking at Patient Experiences of Mesothelioma Follow-Up Care (Henshall et al. 2021) was updated for the current study. Whilst the British Thoracic Society Guidelines (2018) provide national recommendations for mesothelioma treatment and care, there were no new non-COVID policies available. In line with previous study findings the documentary analysis pointed to different service structures and varied treatment and follow-up pathways across the region.

Phase 3: Interviews with Mesothelioma and Lung Cancer MDT members

Nineteen interviews with lung cancer and mesothelioma MDT members were carried out with healthcare professionals (HCPs) from a range of clinical backgrounds (oncology, respiratory, radiology, nursing, occupational therapy). Four themes were identified:

1. Collaboration and communication within and between trusts

HCPs highlighted the importance of communication between and within trusts in decision making. HCPs from smaller hospitals recognised the limits of their expertise in mesothelioma treatment and care given the relative rarity of the disease, and the benefits of hub and spoke models with larger hospitals. However, it is not clear that this collaboration between trusts is happening consistently, with some patients not being referred on. Models of care and team structures also impact upon how treatment decisions are made. A shared care approach that utilised the MDT as a key communication channel facilitated continuity and consistency. However, where shared care was not in place the pathway could be perceived as more fragmented.

The multi-disciplinary teams at each of the trusts are at the centre of a formalised referral and care pathway for mesothelioma patients from diagnosis through to first line and any additional treatment. However, the local lung cancer and regional mesothelioma MDTs are used differently at each of the trusts. There is a strong sense that a mesothelioma MDT is the most appropriate forum for discussing mesothelioma treatment and care. Benefits of the regional MDT highlighted by HCPs included:

- The opportunity for consensus and pooled expertise in decision making
- Greater time to discuss cases in an open, multidisciplinary forum
- Focus on trials and research
- The opportunity to continue to discuss cases as part of ongoing treatment plans
- The potential to form part of a hub and spoke model

However, despite these perceived benefits the regional MDT is being underutilised within the region. Reasons for this include the timing of the mesothelioma MDT as well as the perceived role and purpose of the regional MDT.

2. Evidence-base and knowledge

It is acknowledged by HCPs that there is little published guidance on mesothelioma treatment and care to inform clinical decision making, which is reflective of the limited treatment options available and relatively poor prognosis. Many HCPs acknowledge that there are key differences between mesothelioma and lung cancer that influence clinical decision-making processes. Recommendations from published guidance are not always consistently implemented, due to differing opinions on their utility and effectiveness. Moreover, the lack of a substantial evidence base also leads to differences in what treatments are offered, which can be frustrating for HCPs and patients. Research, and the ability to offer additional treatment to patients through clinical trials, is regarded by many HCPs as a fundamental component of mesothelioma treatment pathways for some patients. Although it is not clear that the criteria used to judge eligibility, access and the knowledge of HCPs about available trial options is consistent. Again, a hub and spoke model would help to overcome some of these challenges.

3. Role of the clinician:

Individual clinical judgement, particularly in more complex cases, is a key factor influencing treatment decisions. The importance of individual judgment is particularly prominent in mesothelioma given the limited treatment options and evidence base. Interviews with HCPs revealed both therapeutic nihilism, emerging from the poor prognosis and high symptom burden of mesothelioma, as well as therapeutic optimism, associated with incremental improvements in outcomes and patient quality of life. Having HCPs with a specialist interest and expertise in mesothelioma is crucial to combatting therapeutic nihilism, allowing for more nuanced clinical decision making, treatment and care.

4. Role of the patient:

Patient performance status is a primary factor associated with treatment options as well as eligibility for trials. However, patient preference, around the therapeutic relationship and treatment, is also central to decision-making. In this regard, the level of patient understanding of available options, and the communication of information is key.

Cross-cutting themes:

Throughout the interviews, the role of the mesothelioma specialist nurse was emphasised as crucial to improved, patient-centred mesothelioma treatment and care. HCPs also highlighted the impact of COVID-19 on the care pathway (incl. diagnosis and follow-up), clinical trials, and on the availability treatment (incl. the approval of immunotherapy).

Please provide a general summary of the project. This will be featured on our website, so it needs to be easy to understand. Please avoid jargon, difficult terminology, and acronyms. Please try to limit to one paragraph. Please include detail of any deviations from the original proposal

The study's aim was to develop a collaborative, evidence-based, patient-centred approach to mesothelioma clinical decision-making across three NHS Trusts: Oxford University Hospitals, Royal Berkshire, and Buckinghamshire NHS Foundation Trusts.

Objectives to be compared across three trusts were:

- Guidelines, policies and processes exist to inform clinical decision-making in relation to mesothelioma treatment pathways, how closely they align and why
- Factors influencing multi-disciplinary team decision-making in mesothelioma treatment
- Clinicians' awareness of/engagement with mesothelioma research and how this informs practice
- Current and potential strategies for improving clinician engagement with mesothelioma research

The study involved: 1) accessing the records of mesothelioma patients treated at the three trusts over five years (n=232) to collect data on diagnoses, treatments, survival rates and clinical care teams. 2: collecting local and national documents relating to mesothelioma patients' treatment pathways 3: Interviews with lung-cancer multidisciplinary team members at each trust to explore how much research was embedded in clinical decision-making and how the multidisciplinary team and other clinical factors influence decision-making in mesothelioma care. Findings compared similarities and differences between the trusts' and have led to the production of collaborative, evidence-based recommendations to promote shared knowledge and clinical decision-making.

Why is this research important? What impact do you think it will have in the short and long term?

The research has the potential to influence policy and practice around mesothelioma clinical decision-making through the generation of evidence that identifies what some of the key barriers and challenges to clinical decision making in this patient group are. The study has led to the production of a number of recommendations that will be disseminated through peer reviewed publications and to Mesothelioma UK stakeholders. These recommendations, alongside recommendations from our previous study exploring patient experiences of Mesothelioma Care pathways, form a robust evidence base that can be used to focus mesothelioma care on the patient pathway. It also makes a strong case for the need for more mesothelioma nurse specialists, for more joined up care and for more evolved multi-disciplinary team practices which take into account the fluidity of the mesothelioma patient journey. We aim to present our findings at a number of national and international conferences over the next 12 months.

How has this research grant helped you?

The grant has helped me to undertake more research into the experiences of mesothelioma patients and to develop my expertise in this area. Additional benefits include:

- Development of a mesothelioma research team within my department at Oxford Brookes University.
- Publication and conference outputs (completed and pending)
- Opportunities to apply for further external grant funding to build on the findings from this project
- Networking and collaboration opportunities. These include supervising NIHR doctoral fellowship awards with a mesothelioma research focus, being a steering group member of the Mesothelioma UK Research Centre (Sheffield) and being appointed as Chair of the Research Interested group of Lung Cancer Nursing UK.

The above would not have been possible without the interest and networking opportunities generated as a result of the Meso UK grant award(s).

Budget	
Have there been any major deviations from the budget proposed at the start of the project?	No
Please attach final finance report	Attached in separate document

Other Issues	
Are there any other issues that you wish to report to the Committee, about this study? If yes, please provide a response	No
Have you disseminated any results from this study to date? If yes, please provide details and references (<i>publications, conference papers, newsletters etc</i>)	Yes <i>Study methods and preliminary findings presented at IMIG 2021:</i> Davey, Z 2021. 'Decision Making in Mesothelioma', <i>IMig2021 Virtual</i> , May 7-9 Findings paper in preparation for submission to BMJ Open in Autumn 2021

	I have provided study updates to Meso UK's magazine upon request
Do you have a Researchfish reference number? Please insert if you do or write N/A if not.	N/A

Declaration	
Signature of Principal Investigator	
Print Name	Catherine Henshall
Date of Submission	26.07.21