

## End of Study Report to Mesothelioma UK

To be completed in typescript and submitted by the Principle Investigator

### 1. Details of the Principle Investigator

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Has the PI changed since the last progress report:	No

### 2. Details of the study

Full title of the study:	Mesothelioma patients experiences of follow up care across three NHS Trusts
Name of Research Ethics Committee (REC)(if applicable):	NHS Solihull Research Ethics Committee
REC reference number:	19/WM/0022
Date of favourable ethics opinion:	2019
Sponsor (if applicable):	Oxford Brookes University

### 3. End of Study and/or termination dates

Was the study completed or did it terminate without completion? Please describe.	Completed
Date the study completed/terminated early:	February 2020

### 4. Study summary

Please provide a general summary of the project in lay mans terms. Please try to limit to 1 A4 sheet. Please include detail of any deviations from the original proposal.

The number of new mesothelioma cases in the UK per annum is relatively small (~ 2700) [3], compared with lung cancer (~47,000) [4]. People from both patient groups often enter the same follow-up pathways, with an assumption their care needs are the same. However, there is increasing recognition that some of mesothelioma patients' care needs are unique to their condition [5 6]. Little published research has explored the specific needs of mesothelioma patients. A recent systematic review compared the psychological care needs of patients with mesothelioma and advanced lung cancer. It identified the need for separate assessment and care pathways to be developed to address some of the experiences that may lead to distress for mesothelioma patients [6].

This study explored mesothelioma patients' experiences of follow-up care in three NHS trusts: Oxford University Hospitals (OUH), Buckinghamshire Healthcare (BHT) and the Royal Berkshire (RBH). The study involved a documentary analysis (phase 1), interviews (phase 2) and consultation meetings (phase 3).

Phase 1: Key documents - reports, guidance, policy documents - relating to mesothelioma patients follow-up pathways at the trusts' were sourced to establish what services are in place, enable comparisons between trusts and to inform the interviews.

Phase 2: Twenty mesothelioma patients receiving follow-up care were interviewed to explore their experiences of follow-up, the type and frequency of support received from health professionals and how this aligns with their treatment pathways and symptom control. Key findings highlighted a need for patients to have access to a specialist mesothelioma team within a streamlined mesothelioma care pathway. This 'pyramid of care' consisted of a mesothelioma specialist nurse, respiratory consultant, multidisciplinary team members (including oncologists and lung cancer nurse specialists), community and palliative care teams, support services and support groups.

Phase 3: Consultation meetings with stakeholders were held to discuss the findings, make recommendations for policy and practice and to propose a preferred, patient focused, follow-up service that is evidence-based, collaborative and inclusive. The first meeting was with patients/carers, the second with Mesothelioma UK nurse specialists; the third with local commissioners and clinical leads.

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

This study has demonstrated impact in the following ways:

- Findings have been/will be presented at numerous international and national conferences including Mesothelioma UK Patient and Carer Day, Blackpool 2019; NLCFN, 2019, IMIG 2020 (postponed due to Covid-19), BTOG 2020 and BPOS 2020.
- One paper detailing the study process and findings is currently under review with BMJ Open. A second paper detailing the development of the recommendations arising from the study is in preparation for submission to Qualitative Health Research journal.
- In collaboration with Meso UK we have developed a set of recommendations to help ensure mesothelioma patients are provided with high quality care pathways following their diagnosis and to sign post towards optimal care pathways.
- An infographic has been designed for use of postcards/posters/online to disseminate these recommendations at a national level (Meso UK and Oxford Brookes badged).

The above has helped create impact by influencing policy and practice and raising the profile of mesothelioma patient care pathways, highlighting best practice standards required for high quality patient care.

How has this research grant helped you?

The grant has enabled me to establish mesothelioma research networks with fellow researchers and clinicians interested in this area of practice. It has also paved the way for a follow-on study (currently in progress) which explore clinical decision making in mesothelioma (currently paused due to Covid-19).

## 5. Budget

Have there been any major deviations from the budget proposed at the start of the project?	No. Funds are still left at present which it has been agreed will be used to pay for Open Access costs for the publications arising from this study, as well as future international conferences (Covid-19 permitting).
If the budget is delivered directly from Mesothelioma UK, please provide a spending report with this document.	To follow. I have requested this from our finance team.

## 6. 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
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<p>Have you disseminated any results from this study to date:</p> <p>If Yes, please provide details and references. (publications, conference papers, newsletters etc)</p>	<p>Yes.</p> <p>Please see section above for details of publications (submitted to BMJ Open and Qualitative Health Research) arising from this study.</p> <p>Conference details as follows:</p> <p>‘Mesothelioma patients’ experiences of follow-up care across three NHS trusts’; International Mesothelioma Interest Group, Brisbane, Australia, March 2020 (postponed due to Covid-19).</p> <p>‘Mesothelioma patients’ experiences of follow-up care across three NHS trusts’; British Thoracic Oncology Group, Dublin, Jan 2020.</p> <p>Mesothelioma patient pathways: changing policy and practice; BPOS, Edinburgh, Feb 2020.</p> <p>‘Mesothelioma patients’ experiences of follow-up care across three NHS trusts’; National Lung Cancer Forum for Nurses, London, Nov 2019</p> <p>‘What is the best practice for patient follow up care?’; Mesothelioma UK Patient and Carer conference, Blackpool, Oct 2019</p> <p>In addition, the work has been disseminated in:</p> <p>Darlison, L, Gardiner, C, Henshall, C, Tod, A (2020) Making Mesothelioma Patient Research Happen: The UK Experience. IASLC Lung Cancer News. Available at <a href="http://www.lungcancernews.org/June2020">www.lungcancernews.org/June2020</a></p> <p>Study updates have also been disseminated in previous Meso UK update newsletters, through communications with Sandstar.</p>
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## 7. Declaration

Signature of Principal Investigator:	
Print Name:	Catherine Henshall

Date of Submission:	03.07.20
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