

**Personalising follow up pathways in the NHS for mesothelioma patients: the patient perspective**  
**(250 words max)**

**Introduction**

Across the UK, the follow-up care pathways for mesothelioma patients differ across NHS Trusts, with variation in the services offered.

**Aims**

This study aimed to explore mesothelioma patients' experiences of care in three NHS trusts with different models of follow-up care, to produce recommendations for policy and practice.

**Methods**

The study consisted of three phases: 1) documentary analysis to collate key service documents relating to mesothelioma patients' follow-up pathways 2) interviews with mesothelioma patients to explore their experiences of follow-up and 3) consultation meetings with stakeholders.

The documentary analysis and interview phases took place at Oxford University Hospitals, Royal Berkshire and Buckinghamshire Healthcare NHS Foundation Trusts. NHS HRA ethical approvals were obtained. Three consultation meetings were subsequently held.

Twenty-one interview participants were recruited through Mesothelioma/Lung Cancer Nurse Specialists and the local Clinical Research Network. Documentary and interview data were thematically analysed. Subsequent consultation meetings involved patients and carers, Mesothelioma UK specialist nurses and local lung cancer specialists and commissioners. Written informed consent was obtained from participants.

**Results**

Five key themes emerged from the interview data; these related to people, place, purpose, process and perception of care. Themes were presented at consultation meetings where stakeholders prioritised the findings.

**Conclusions**

Study findings were used to produce recommendations for policy and practice that have been informed by patients, carers, healthcare professionals and commissioners. These recommendations promote consistently high standards of care for mesothelioma patients, by advocating for, and making suggestions for improving, best practice to enhance patient experience and personalise care.

## **Mesothelioma patients' experiences of follow-up care across three NHS trusts (300 words max)**

### **Introduction**

Across the UK, the follow-up care pathways for mesothelioma patients differ across NHS Trusts, with variation in the services that are offered. This study sought to explore mesothelioma patients' experiences of care in three NHS trusts with different models of follow-up care.

### **Methods**

This study consisted of three phases: 1) documentary analysis to collate key service documents relating to mesothelioma patients' follow-up pathways 2) interviews with mesothelioma patients and 3) consultation meetings with stakeholders.

The documentary analysis and interview phases took place at Oxford University Hospitals, Royal Berkshire and Buckinghamshire Healthcare NHS Foundation Trusts. NHS HRA ethical approvals were obtained. Three consultation meetings were subsequently held; two in Oxford and one in Blackpool.

Interview participants were recruited proportionately, in line with the numbers of patients treated at each trust. Participants were recruited through Mesothelioma/Lung Cancer Nurse Specialists and the local Clinical Research Network. At least five stakeholders were invited to each consultation meeting. The first invited patients and carers, the second Mesothelioma UK specialist nurses and the third local commissioners.

Twenty-one individual face-to-face interviews were conducted. Each interview lasted approximately 60 minutes, was digitally recorded and transcribed by a local transcription company. Written informed consent was obtained from participants.

Documentary and interview data were thematically analysed using the Framework method.

### **Results**

Four key themes emerged from the interview data: 'efficiency versus time', 'building relationships', 'information' and 'linking services'. The interview data were presented at each of the consultation meetings where stakeholders identified the findings they felt were priorities for improving mesothelioma patient care.

### **Conclusion**

Study findings will be used to produce recommendations that have been agreed by patients, carers, healthcare professionals and commissioners. These can promote the use of consistently high standards of care for all mesothelioma patients in the UK, by advocating for, and making suggestion for improving, best practice to enhance the patient experience of the care pathway.

## **Mesothelioma patients' experiences of follow-up care across three National Health Service hospital trusts in the United Kingdom (500 words max)**

### **Objectives**

The study aimed to explore mesothelioma patients' experiences of care in three National Health Service trusts in the United Kingdom with different models of follow-up care: Oxford University Hospitals, Royal Berkshire and Buckinghamshire Healthcare National Health Service Foundation Trusts. By comparing three different hospital trusts we hoped to identify any commonalities and differences in follow-up approaches between them.

### **Methods**

This study consisted of three phases: 1) documentary analysis to collate key service documents relating to mesothelioma patients' follow-up pathways at the three trusts 2) interviews with mesothelioma patients to explore from their perspectives what they liked about their care pathways and what they felt could be improved 3) three consultation and priority setting meetings with key stakeholders, including patients, carers, specialist nurses and commissioners.

The documentary analysis and interview phases took place at Oxford University Hospitals, Royal Berkshire and Buckinghamshire Healthcare National Health Service Foundation Trusts. National Health Service Health Research Authority ethical approvals were obtained. Three stakeholder consultation meetings were subsequently held; two in Oxford, United Kingdom, and one in Blackpool, United Kingdom.

Interview participants were recruited proportionately, in line with the numbers of patients treated at each trust. Participants were recruited through Mesothelioma/Lung Cancer Nurse Specialists and the local Clinical Research Network. At least five stakeholders were invited to each consultation meeting. The first invited patients and carers, the second Mesothelioma UK specialist nurses and the third local commissioners.

Twenty-one individual face-to-face interviews were conducted. Each interview lasted approximately 60 minutes, was digitally recorded and transcribed by a local transcription company. Written informed consent was obtained from participants. Documentary and interview data were thematically analysed using the Framework method.

### **Results**

Four key themes emerged from the interview data: 'efficiency versus time', 'building relationships', 'information' and 'linking services'. The interview data were presented at each of the consultation meetings where stakeholders identified the findings they felt were priorities for improving mesothelioma patient care.

## **Conclusion**

Study findings will be used to produce recommendations that have been agreed by patients, carers, healthcare professionals and commissioners. These can promote the use of consistently high standards of care for all mesothelioma patients in the United Kingdom, by advocating for, and making suggestions for improving, best practice to enhance the patient experience of the care pathway.

The number of new mesothelioma cases in the UK per annum is relatively small (~ 2700), compared with lung cancer (~47,000). 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. 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.

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-one 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.

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 has been published in BMJ Open. A second paper detailing the development of the recommendations arising from the study is currently under review with BMJ Open.
- 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.

**Mesothelioma patients' experiences of follow-up care across three NHS trusts: interview study**  
**(249/250 words max)**

**Aim**

To explore mesothelioma patients' experiences of follow-up care. It will explore what mesothelioma patients' follow-up pathways 'look like' in three separate NHS Trusts with different models of follow-up care.

**Design**

This qualitative interview study was part of a larger study consisting of three phases: 1) documentary analysis to collate key service documents relating to mesothelioma patients' follow-up pathways 2) interviews with mesothelioma patients and 3) consultation meetings with stakeholders.

**Setting**

The study took place at three NHS Trusts in the Thames Valley; Oxford University Hospitals, Royal Berkshire and Buckinghamshire Healthcare NHS Foundation Trusts. NHS Health Research Authority ethical approvals were obtained

**Sample**

Recruitment was proportional across sites, in line with the numbers of patients treated at each trust. Participants were recruited through Mesothelioma/Lung Cancer Nurse Specialists and the local Clinical Research Network.

**Data collection**

Twenty-one individual face-to-face interviews were conducted. Each interview lasted approximately 60 minutes, was digitally recorded and transcribed by a local transcription company. Written informed consent was obtained from participants.

**Data analysis**

Data was thematically analysed using the Framework method.

**Findings**

Four key themes emerged from the interview data: 'efficiency versus time', 'building relationships', 'information' and 'linking services'.

**Implications for policy or practice**

Study findings will be used to produce recommendations that have been agreed by patients, carers, healthcare professionals and commissioners. These can promote the use of consistently high standards of care for mesothelioma patients, by advocating for, and making suggestions for improving, best practice to enhance the patient experience of the care pathway.