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# The Military Experience of Mesothelioma Study (MiMES)

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# Contents

|  |    |
|--|----|
| <b>Acknowledgements</b>                              | 3  |
| <b>Project Summary</b>                               | 4  |
| <b>The Military Experience of Mesothelioma Study</b> | 5  |
| 1. Introduction                                      | 5  |
| 2. Background  | 6  |
| 3. Method  | 8  |
| 4. Findings  | 11 |
| 4.1 National data                                    | 11 |
| 4.2 Patient experience data                          | 14 |
| <b>Discussion</b>                                    | 26 |
| <b>Conclusion</b>                                    | 30 |
| <b>References</b>                                    | 31 |
| <b>Appendix</b>                                      | 32 |

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# Project Summary

## The Military Experience of Mesothelioma Study (MiMES)

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### Background

This mixed method study explored the veteran experience of living with mesothelioma. The purpose of MiMES was to generate insights into the experience and health/support needs of British Armed Forces veterans with mesothelioma and identify how best health professionals and support agencies can support them.

### Methods

Quantitative data were derived from three data sources, the record of claims for compensation through the War Pension Scheme, a national dataset of clients receiving services from Asbestos Support Groups in the UK, and the Mesothelioma UK run Mesothelioma Outcomes, Research and Experience (MORE) survey.

Semi-structured interviews were conducted with 13 veterans living with mesothelioma and one person living with mesothelioma who was contracted by the Ministry of Defence (MOD). We also conducted interviews with ten family members of veterans living with mesothelioma and 8 staff members. Interviews were carried out by three researchers between December 2018 and September 2019. Interviews ranged in duration from 24 to 99 minutes and were digitally recorded and transcribed verbatim. Analysis of the data was carried out using thematic analysis (Braun & Clarke, 2006).

### Findings

The findings presented in this report have been divided into four themes. These are:

1. Asbestos exposure
2. Coping with a diagnosis of mesothelioma
3. Preferences for care and support
4. Claiming compensation through the War Pension Scheme

Key messages and implications for practice focus on the legal, medical, financial and support needs and preferences that veterans and their families may have. Perceived inequalities in regard to access to non-NHS funded treatment and the amount of compensation received compared to civilians were reported by participants\*. Changes are required to address these inequalities of care.

Veterans and their families often have to navigate complex civil and military systems. Some reported receiving excellent support from services such as Veterans UK and charitable organisations. The findings highlight that it is essential for veterans living with mesothelioma to have access to professionals who are experienced, sensitive and knowledgeable in the navigation of both civil and military systems. Involvement of these professionals has the potential to improve the care provision for UK Armed Forces veterans and their families.

### Conclusions

MiMES provides valuable insight into the experience of UK Armed Forces veterans living with mesothelioma. The aim is that the findings and implications from the MiMES will provide some guidance and support for professionals working with veterans, and their families, living with mesothelioma.

“.. it is essential that veterans living with mesothelioma have access to professionals..”

\* Veterans with mesothelioma exposed to asbestos pre-2005 can claim an enhanced pension or a lump sum (up to £140,000) payment under the War Pension Scheme. This was referred to as compensation by participants.

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## The Military Experience of Mesothelioma Study (MiMES)

# 1. Introduction

**This report presents an overview of the Military Experience of Mesothelioma Study (MiMES). A background section provides a summary of the context within which the study was conducted. This is followed by a brief description of the methods, findings and a discussion. This report concludes with key messages and implications for practice to be considered by key stakeholders.**

The study was conducted by a research team at the University of Sheffield, Division of Nursing and Midwifery. It was funded through Mesothelioma UK as part of its Supporting Our Armed Forces initiative.



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## 2. Background

**Mesothelioma is one of the most challenging of all cancers, described by a sufferer as ‘being at the edge of the human predicament’ or as ‘a place without hope’ (Sweeney, Toy and Cornwell 2009). Mesothelioma mostly affects people over 65 years of age and is more prevalent in men, with only 17% of mesothelioma patients being women (Cancer Research UK 2020). The majority of mesothelioma is pleural, but a small percentage of people experience mesothelioma in the peritoneum and testes. The only known cause is exposure to asbestos which has usually occurred 15-40 years prior to a diagnosis (Health and Safety Executive 2019). All asbestos used in the UK has been imported; the mineral is not naturally found in UK soil.**

With approximately 2700 new cases diagnosed each year (Cancer Research UK 2020) the UK has the highest incidence of mesothelioma in the world. Annually, the numbers are increasing and there is a direct correlation between this incidence and our nation’s historical use of asbestos (Rake et al. 2006).

Despite the industrial basis for the disease, those diagnosed with mesothelioma come from all types of backgrounds. This is likely to be due to the ubiquitous use of asbestos in the UK. Increasingly, this has involved workplace and environmental exposure in addition to occupational exposure. Within this report, workplace exposure is defined as that which occurs whilst working. Examples include being exposed to asbestos when in a work environment, e.g. working or living in a building whilst renovations are being undertaken. Environmental asbestos exposure is that which occurs in any public building e.g. school, hospitals. Occupational asbestos exposure is that which occurs when the person is exposed through working directly with asbestos. Para-occupational exposure is a term used when people (usually a family member) are exposed to asbestos due to someone else’s occupational exposure, for example someone washing their partner’s work clothes with asbestos on them.

### Care needs related to mesothelioma

Mesothelioma is associated with a range of life-limiting, debilitating disease-related symptoms including breathlessness, pain, cough, lethargy, weight loss and sweating. Mesothelioma is treatable but not curable (British Thoracic Society 2007). Often patients enter into lengthy and complex treatment programs resulting in a range of side effects with no guarantee of benefit. With or without treatment, survival is usually measured in months. Median survival from diagnosis is between eight and fifteen months (Bibby & Maskell 2018). Approximately 60% of people diagnosed with mesothelioma will die within a year of learning they have the disease. Three year survival is only 10% (RCP, 2020).

The industrial nature of the diagnosis means, in addition to navigating health care systems, patients and their family members have complex benefit and compensation claims to process (British Thoracic Society 2007, Darlison & Whitston 2006). For military personnel, whether serving or retired, the process has previously always been more complex as the law protects the Ministry of Defence (MOD) from being sued for compensation for illness or injury caused before 1987. Once diagnosed, there is a risk that a patient would be referred to a benefits advisor with little insight into industrial cancer or war pension entitlements. Exploring all options and deciding on the most appropriate benefits or compensation to pursue adds considerably to the burden of being diagnosed with an incurable cancer.

The mesothelioma experience is surrounded by injustice; from how the disease is contracted, to benefits and compensation but most of all the variation and limited nature of available treatment. However, in the last twelve years, many research trials have investigated new treatments as first and second line therapies for mesothelioma (Bibby & Maskell 2018). New drugs, surgical procedures and radiotherapy techniques offer hope and promise in terms of length and quality of life. As these treatments start to be rolled out into practice, it is vital equitable access is ensured and everyone living with mesothelioma has the opportunity to be considered for them.

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## Mesothelioma in Armed Forces personnel

The incidence of mesothelioma amongst UK military personnel has historically not been recorded or reported. Previous epidemiological studies have focused predominantly on construction workers (Rake et al. 2009) and asbestos industry workers (Harding & Darnton 2010). In the USA it is suggested that 'mesothelioma disproportionately affects veterans and it is estimated that veterans make up one third of all mesothelioma patients' (Mesothelioma Veterans Center 2019). It is therefore important to understand more about the relevance and incidence of mesothelioma amongst British Armed Forces veterans from a public health perspective, but also to understand how better to meet the needs of those at risk of developing the disease, and those newly diagnosed.

In April 2016, the MOD amended the rules regarding compensation for veterans with a diagnosis of mesothelioma. Those diagnosed after 16th December 2016 and exposed to asbestos before 2005 have the choice between a one-off, tax-free lump sum of £140,000 or a pension payment under the War Pension Scheme (Ministry of Defence 2016). The Veterans Welfare Service (VWS), run by Veterans UK, provides advice and support to veterans eligible to claim the lump sum or pension. Claims need to be made in life. Given the symptom burden and limited survival associated with mesothelioma, this increases the importance of the swift, timely and effective partnership working between health, legal and charitable organisations in order for a veteran with mesothelioma to make the right and a timely decision for them regarding a claim.

There is an additional, dual exposure, complication for people with mesothelioma with a military background with occupational exposure. If there is uncertainty about whether their exposure occurred during or after their military service, or both, they need expert support in reviewing their occupational history and deciding whether to make an application through the War Pension Scheme or a civilian compensation claim. The difficulty of these processes and decisions are heightened in the context of living with a life-limiting diagnosis with challenging symptoms and treatment decisions.

## The Military Experience of Mesothelioma Study (MiMES)

There has been no experience-based research to better understand the health and support needs of Armed Forces veterans with mesothelioma and their families. Clinical experience and anecdotal evidence from health professionals indicate that this group may encounter particular challenges in recognising and reporting early symptoms, getting a diagnosis and accessing care and support, including financial help. Little is known about how structural factors, attitudes and barriers interact to influence diagnosis and care needs for people with a military background. We need to understand more about experiences of patients, family members and health and support staff in order to enhance diagnosis and care provision.

MiMES aims to start to address this major evidence gap regarding mesothelioma in Armed Forces veterans. The main study aims are:

1. To explore research approaches to establish the incidence and prevalence of mesothelioma amongst British Armed Forces veterans.
2. To understand the health and support needs of British Armed Forces veterans with mesothelioma, and their families.
3. To identify how health professionals, legal professionals and support agencies can best meet these care and support needs.

MiMES was conducted in partnership with Mesothelioma UK as part of its Supporting Our Armed Services (SOAF) initiative. Mesothelioma UK received Government funding through the LIBOR scheme to establish SOAF, a specialist UK wide service for patients and families with mesothelioma who have a military background. SOAF and MiMES are supported by an Advisory Group (henceforward referred to as the Advisory Group) with representatives from Asbestos Support Groups (ASGs), Veterans UK, patients and family members and health services.

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# 3. Methods

**MiMES is a mixed method study exploring the understanding and support needs of veterans living with mesothelioma. Completion of the first research aim enabled some insight into the incidence and prevalence of mesothelioma amongst British Armed Forces veterans along with some descriptive statistics related to patient experience. Methods related to this aim are presented here first, followed by a summary of the qualitative methods.**

## 3.1 National data

To determine prevalence and incidence of mesothelioma in people with a military history is difficult in the UK. No complete record is kept by any relevant organisation, for example, the health service, Ministry of Defence or Asbestos Support Groups (ASGs). With this in mind we present a partial picture using data from the number of claims made through the War Pension Scheme. In addition, analysis of data from two other sources is presented. These sources are a national dataset of clients receiving services from Asbestos Support Groups in the UK, and the Mesothelioma Outcomes, Research and Experience (MORE) survey conducted by Mesothelioma UK (Mesothelioma UK 2020). Descriptive statistical analysis was performed using SPSS and Excel. The findings are summarised below.

Although they do not provide a complete picture, the findings provide some context for the qualitative study. They give an indication of the numbers of people with mesothelioma who have a military background. However, the true numbers are likely to be much larger than those presented here. Our figures only reflect those accessing services, or responding to survey requests, not the actual numbers of people. Where geographical distributions of people are presented in the findings these are based on only the first four postcode digits.

### War Pension Scheme claims for mesothelioma

Summary data was provided by the Ministry of Defence regarding all people with mesothelioma who submitted a claim for the War Pension Scheme. At the time of writing this report (July 2020) data from the final year was not available. It is anticipated that this will be available in Autumn 2020. We are therefore presenting data from April 2016 to March 2019. This is not the complete number of people with a diagnosis of mesothelioma with a history of military service, but merely those who made a claim. It is impossible to know what proportion of people do not make a claim.

### Supporting Our Armed Forces (SOAF) database

As part of the Supporting Our Armed Forces (SOAF) project, Mesothelioma UK and HASAG Asbestos Disease Support worked together to form a national database of people with a new diagnosis

of mesothelioma and a known background of UK military service. Referrals to the SOAF database were received from health professionals, Asbestos Support Groups (ASGs) and other stakeholders working across the UK. Anyone diagnosed with mesothelioma and any Armed Forces experience was eligible. This database took some time to establish. Annual entries to the database went up year on year. However, it is not a complete record as some nurses and ASGs did not refer their clients.

This database took some time to establish. Annual entries to the database went up year on year. However, it is not a complete record as some nurses and ASGs did not refer their clients.

### Mesothelioma Outcomes, Research and Experience (MORE) survey

The MORE survey was conducted by Mesothelioma UK in 2019 (Mesothelioma UK 2020). MORE is a UK based observational prospective cross-sectional survey where data was collected directly from patients on their experience of mesothelioma, their health-related quality-of-life and current clinical management. Recruitment was conducted via Mesothelioma UK via its website, social networking groups/links and specialist nurse network. The participant completed an online survey which was then validated by a specialist nurse.

## 3.2 Patient Experience Interview Study



the qualitative, interview-based component of MiMES was conducted. This includes how participants were recruited, who took part and how the data was collected and analysed.

### **Recruitment**

Invitations to participate in MiMES were circulated to veterans and family members via Mesothelioma UK and ASGs. Information was distributed by Mesothelioma UK using newsletters and social media. People were asked to contact the Mesothelioma UK information line if interested in participating. When contacted, the information line staff discussed the study. They liaised with the research team if people were interested in participating. Additionally, advice workers from

ASGs discussed the study with veterans living with mesothelioma and then liaised with the research team if the veteran or family member was interested in participating. An information sheet and consent form were then sent via post or email for the person to consider.

Staff members were recruited via Mesothelioma UK, ASGs and their existing contacts. Staff were chosen for their ability to provide insight into the support needs of veterans living with mesothelioma and their families.

### **Data collection**

Interview topic guides were developed from the available literature and findings from previous research undertaken by the research group. These were used to guide

interviews. The project advisory group also supported topic guide development. Topics included the participant's service history, their experience at diagnosis and living with mesothelioma and the financial/legal implications of living with mesothelioma as a veteran (a full topic guide can be viewed in Appendix 1).

Semi-structured interviews were undertaken with veterans, their family members and professionals supporting veterans. Interviews were undertaken by the research team between December 2018 and September 2019. Interviews lasted between 24 and 99 minutes and were audio recorded. Twenty interviews were conducted over the phone and three interviews were conducted in person. Using telephone interviews enabled people to participate from across the UK. This method proved more convenient for interviewees and less burdensome.

### **Sample**

The final interview sample consisted of 13 veterans living with mesothelioma, plus one person living with mesothelioma who was contracted to work on an Armed Forces base for most of his working life. In addition, the sample included ten family members (Table 1 and 2) and eight staff participants. At the participants' request, four of the interviews were conducted jointly with both the person living with mesothelioma and the family member present.

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The veterans' ages ranged from 61 to 89 and the family members' ages ranged from 36 to 74. Time since diagnosis ranged from three weeks to four years. While we attempted to recruit and interview women veterans, all veteran participants were men.

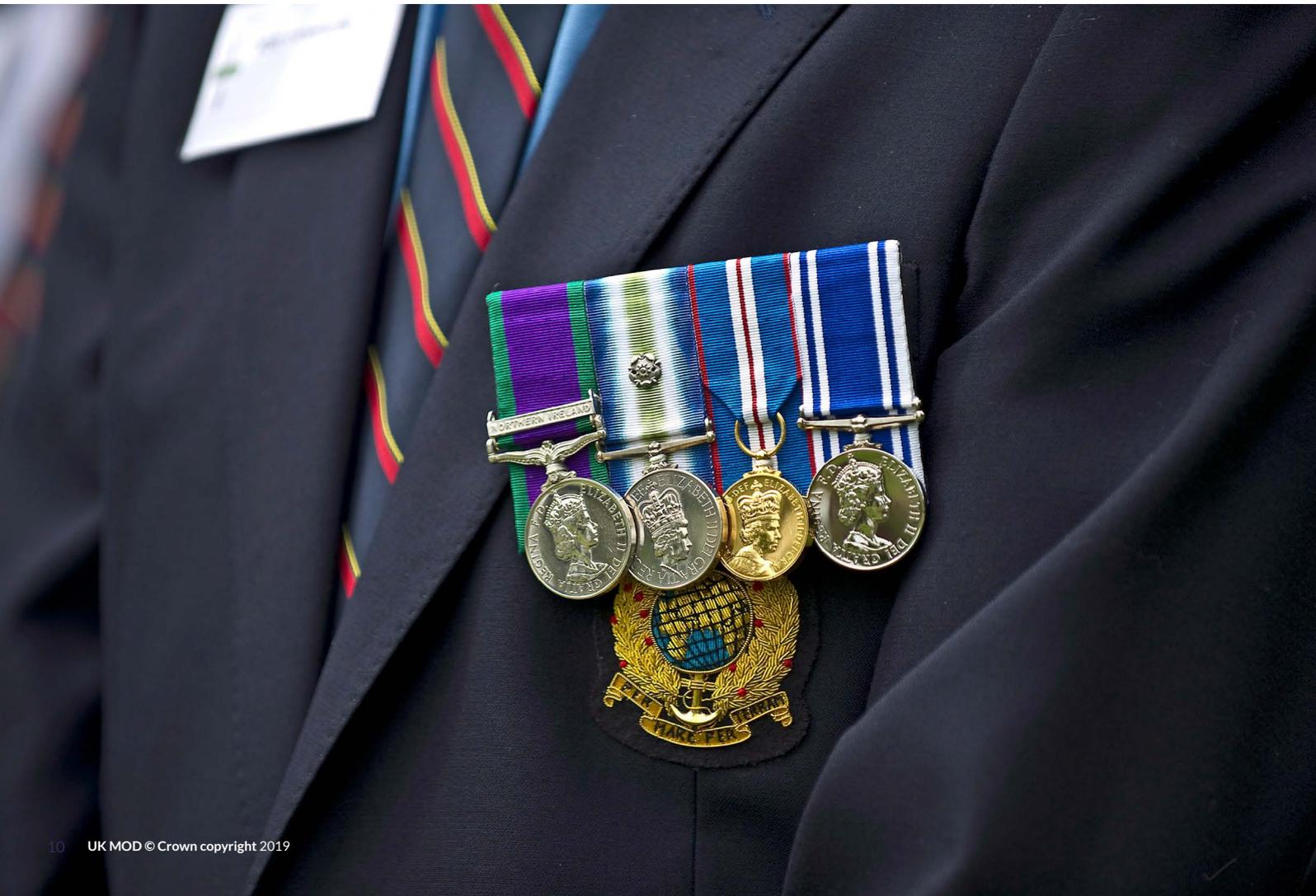
#### Data analysis

The anonymised interview transcripts were uploaded into QUIRKOS (a qualitative analysis software package). QUIRKOS was used

to manage and search the data. Thematic analysis methods were used to ensure a systematic and rigorous progression through six analytic phases: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing a report (Braun & Clarke 2006).

The data were analysed by the research team. Data were discussed at regular intervals and consensus

was achieved through discussions with research team members. The developed themes were also challenged and verified by discussing them at meetings with Mesothelioma UK Clinical Nurse Specialists, ASG staff and the family members of people living with mesothelioma. The findings of this report presents the themes which have been developed. These themes support the key messages and implications for practice developed from MiMES.



# 4. Findings

MiMES findings are presented here in two sections: national data and patient experience. First the findings from the analysis of National data is presented. This is mainly descriptive in nature, although analysis from the MORE data does allow some comparisons in responses between respondents with and without a history of military service. Following this, the more in-depth findings from the interview based qualitative study are presented.

## 4.1 National data

### War Pension Scheme (WPS) compensation claims

There has been a total of 340 WPS claims from people

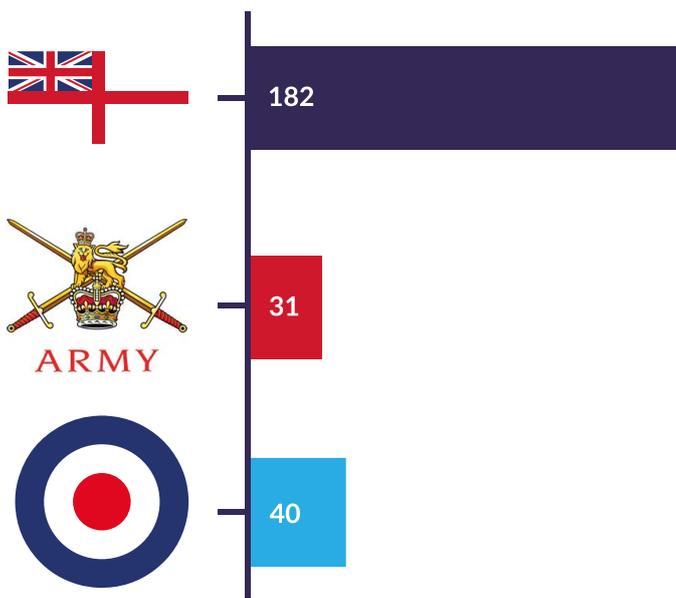
with mesothelioma between April 2016 and March 2020. The first year had the highest number of claims (147) followed by a drop in years two and three (92 and 84 respectively). However, 2019/20 saw another increase, this time to 108 claims.

We do not have a breakdown of this final year of claims. However, the previous year indicates that the vast majority opted for the lump sum rather than the enhanced pension payment. Only four of the 340 claims were reported as being rejected (two in 2017/18 and two in 2018/19).

In terms of service history and gender breakdown of claimants we only have data from April 2016 to October 2018. In that time there were 261 claims, 257 were from men and four from women.

| Year                | Rejected      | Lump Sum      | War Disablement Pension | Total |
|---------------------|---------------|---------------|-------------------------|-------|
| 11/04/16 - 31/03/17 | 0             | 119           | 28                      | 147   |
| 01/04/17 - 31/03/18 | 0             | 85            | 5                       | 92    |
| 01/04/18 - 31/03/19 | 2             | 78            | 4                       | 84    |
| 01/04/19 - 31/03/20 | Not available | Not available | Not available           | 108   |
| <b>Total</b>        |               |               |                         | 431   |

Table 1. Summary of WPS Claims



Data on service history is also incomplete. We do not have data for the period after October 2018. In addition we have been informed that this information was not initially recorded. From 243 claims in that time **182** veterans had served with the Royal Navy, **31** with the Army, and **40** with the RAF. The vast majority were therefore from the Royal Navy.

During the MiMES project, various stakeholders who work with veterans with mesothelioma have informed us that anyone making a claim with sea-going service during and after World War 2, up to the early 1970s, will be presumed to have been asbestos exposed. Their WPS claims are likely to be successful. Claims from people who served in the Army and RAF may have a higher level of scrutiny. This raises a question about whether people from the Army or RAF may presume they were not exposed to asbestos in their service. There is a possibility that they were discouraged from applying for the WPS because their service was not in the Royal Navy.

#### Supporting Our Armed Forces (SOAF) database

Data were collected by HASAG between December 2016 and January 2020. In total 92 veterans were included in the database. See Figure 1 for the distribution of clients. In

order to protect the anonymity of clients, only the first 4 postcode digits have been used.

All veterans included on the SOAF database were male and living with pleural mesothelioma. The veterans' average age was 80 (range 56-92). Forty-seven (51%) veterans had a spouse and 43 (47%) did not have a spouse. For 2 (2%) of the veterans their marital status was not reported. 10 (10.9%) of the veterans had served in the Army, nine (9.8%) had served in the RAF and 73 (79.4%) in the Navy. Whilst the database was based on a UK sample, the majority of the veterans included were from the South coast, near naval docks, which may explain the high proportion of participants from the Navy.



Figure 1. Distribution map of ASG Armed Forces clients, 2016-2020

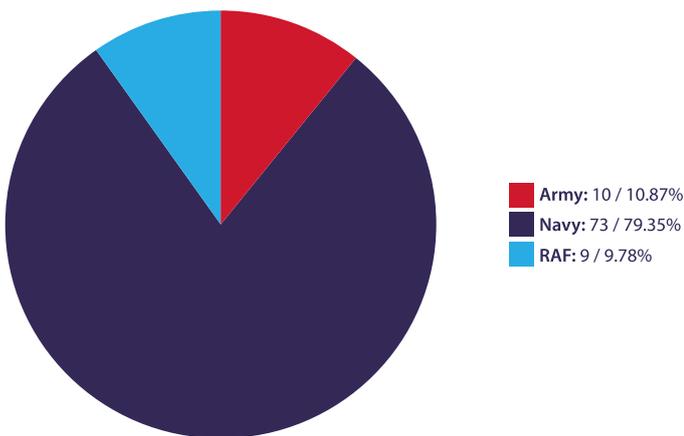


Figure 2a. Branch of service map of ASG Armed Forces clients, 2016-2020

The average length of service was 7.5 years in the Army, 9.6 years in the Navy and 21 years in the RAF.

91 (99%) of the veterans opted for the lump-sum payment and only one (1%) chose the monthly pension.

80 veterans (87%) on the database had been exposed to asbestos as a result of their military service only while 12 (13%) were exposed to asbestos in both military and civilian life. These same 12 veterans reported dual exposure. When an individual has been exposed during their Armed Forces service as well as whilst working in a civilian job, this is called dual exposure (Mesothelioma UK, 2018).

All veterans with dual exposure had the opportunity to seek advice from a solicitor and explore the possibility of a civilian claim. A third (4) of these 12 veterans pursued a claim as a civilian alongside their claim as a veteran to the MOD.

It is understood that a solicitor would only take on a case for a civilian claim if they believed they had a strong chance of being successful, and that the outcome would be in the veteran's best interests. For example, if the total civilian claim was unlikely to exceed £140,000 (the military lump sum payment) then it was arguably not in the client's best interests to pursue it. If someone had

been awarded a WPS claim and was then successful with a civilian claim, the client would only keep the excess amount. The £140,000 military lump sum payment would be repaid.

Figure 2b presents the occupation of the veterans whilst they were in the Armed Forces. The three most common occupations were electrician 12 (13%), engineer 23 (25%) and seaman 26 (28%). These are all occupations with risks of higher levels of asbestos exposure. 29 (32%) were recorded as working in occupations where they may not have been exposed to the same level of asbestos exposure as those working in the high risk occupations but, would have been exposed at lower levels. Sometimes this may be due to work, living or training environments.

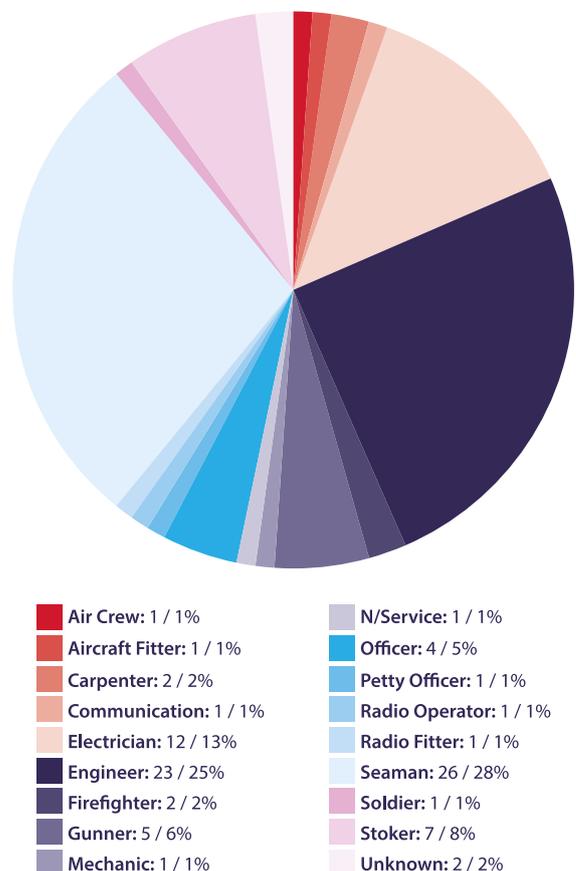


Figure 2b. Occupation of the 92 veterans on the SOAF database.

### Mesothelioma Outcomes, Research and Experience (MORE) survey

The MORE survey generated responses from 503 participants. Of these 74 (15%) had served in the Armed Forces. We report here the range and duration of service. More advanced analysis comparing veteran MORE participants to civilians is planned during 2020/21.

| Branch of Service | Number    |
|-------------------|-----------|
| Royal Navy        | 15        |
| Royal Air Force   | 19        |
| Army              | 39        |
| Other (Unknown)   | 1         |
| <b>Total</b>      | <b>74</b> |

Table 3. MORE participants branch of service

In contrast to the AFCS and SOAF data, the majority of veterans from the MORE data were from the Army. As mentioned above, this difference may be due to the location of the SOAF database participants. In addition, it may reflect the fact that MORE participants were self-responders to a survey, rather than on a database because they were accessing a service or compensation payment.

The WPS and SOAF datasets are more likely to contain people accessing their systems because they are seeking compensation and so contain mainly people from the Navy. In contrast, MORE responders may include a larger proportion of people who did not pursue compensation because they did not think they were likely to be successful because, for example, they were not in the Navy or an occupation at higher risk of asbestos exposure.

Length of time in the service varied enormously, with the majority (45, 60.8%) serving five years or less. However, there were eight (10.8%) veterans who had been in military service for over 20 years.

### 4.2 Patient Experience Interview Study data

The sample characteristics of the patients, family members and staff interviewed are presented below. A pseudonym has been allocated to each participant to preserve anonymity.

The following section presents findings from the qualitative data analysis. They are arranged using the key themes to emerge from the analysis. The subheadings used to organise the key themes are asbestos exposure, coping with a diagnosis of mesothelioma, preferences for care and claiming compensation are explored. Anonymised quotes from patients, family members and staff have been included to support the findings.



| Participant pseudonym and ID | Service    | Telephone or face-to-face interview | Relative present (Yes/No) |
|------------------------------|------------|-------------------------------------|---------------------------|
| Albert P1MN                  | Navy       | Telephone                           | No                        |
| Bob P2MA                     | Army       | Telephone                           | No                        |
| Callum P3MR                  | RAF        | Telephone                           | No                        |
| Derek P4MR                   | RAF        | Face-to-face                        | No                        |
| Errol P5MR                   | RAF        | Telephone                           | No                        |
| Fred P6MC                    | Contracted | Face-to-face                        | Yes                       |
| Graham P7MR                  | RAF        | Telephone                           | No                        |
| Henry P8MA                   | Army       | Telephone                           | Yes                       |
| Ian P9MN                     | NAVY       | Telephone                           | No                        |
| James P10MR                  | RAF        | Telephone                           | No                        |
| Kevin P11MA                  | Army       | Telephone                           | Yes                       |
| Leo P12MN                    | NAVY       | Telephone                           | Yes                       |
| Martin P13MN                 | NAVY       | Telephone                           | Yes                       |
| Neil P14MR                   | RAF        | Telephone                           | No                        |

**Table 4. MiMES patient participant characteristics** | First character: P= Patient, Second character/s: Interview number, Third character: M=Male, Fourth character: Branch of service. For example, Albert P1MN = Patient, Interview 1, Male, Navy.

| Family Members | Telephone or face-to-face interview | Relationship to person living with mesothelioma |
|----------------|-------------------------------------|---|
| Sian F1FC      | Face-to-face                        | Wife  |
| Paul F2MM      | Face-to-face                        | Widower   |
| Violet F3FC    | Telephone                           | Wife  |
| Naomi F4FC     | Telephone                           | Wife  |
| Theresa F5FC   | Telephone                           | Daughter  |
| Josie F6FC     | Telephone                           | Widow   |
| Neville F7MM   | Telephone                           | Widower   |
| Simon F8MM     | Telephone                           | Son   |
| Orla F9FC      | Telephone                           | Wife  |
| Laura F10FC    | Telephone                           | Wife  |

**Table 5. MiMES family member participant characteristics** | First character: F= family member of a veteran, Second character/s: Interview number, Third character: M=Male, F=female, Fourth character: C= civil, M=military. For example, Sian F1FC= Family member, Interview 1, Female, Civil

| Staff | Telephone or face-to-face interview | Work role                              |
|-------|-------------------------------------|--|
| S1    | Telephone                           | Solicitor specialising in asbestos.    |
| S2    | Telephone                           | Asbestos charity worker                |
| S3    | Telephone                           | Military charity worker                |
| S4    | Telephone                           | Military charity worker and researcher |
| S5    | Face-to-face                        | Mesothelioma nurse specialist          |
| S6    | Face-to-face                        | Mesothelioma nurse specialist          |
| S7    | Telephone                           | Mesothelioma nurse Specialist          |
| S8    | Telephone                           | Mesothelioma nurse specialist          |

**Table 6. MiMES staff participant characteristics** | First character: S = member of staff working at a professional organisation. Second character/s: Interview number

### Asbestos exposure: The nature of exposure and awareness of asbestos-related diseases

There were a range of situations in which the participants had been exposed to asbestos. In many cases veterans had not been aware of the dangers of asbestos until many years after the exposure had occurred. Ongoing exposure to asbestos was also highlighted as a concern. The implications of dual exposure, in both military and civilian life, is also discussed.

### Patients and family members findings

- **Awareness of exposure to asbestos**

Most patient participants were aware of exposure or suspected that they had been exposed to asbestos during their time in service. However, many had been unaware of the dangers of asbestos at the time they were exposed. Awareness had developed later through attending health and safety courses, hearing about the dangers of asbestos in the news or seeing their colleagues diagnosed with asbestos related diseases. For some, this had led to great concern and even an expectation that they would get an asbestos related disease:

“some naval veteran participants reported resignation rather than shock at diagnosis”

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“You’ve always had this [asbestos exposure] in your mind, haven’t you?” **Sian F1FC**

“Ever since we started going on the [health and safety] training courses I realised that I’d probably had more than my fair dose of exposure.” **Fred P6MC**

“I think...he [her father] had a sense of, I thought this was going to happen anyway...my [other family member] has got asbestosis because he worked alongside my dad” **Theresa F5FC**

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This emerging expectation that they would get an asbestos related disease was particularly notable in accounts related to naval veterans. The analysis of the national SOAF dataset showed that 73 (79.4%) of the veterans were from a naval background. Some of the naval participants interviewed knew of other naval veterans who had died of mesothelioma or were living with asbestos related diseases. The high percentage of naval veterans may mean that there is a greater awareness of asbestos related diseases in veterans who have worked in this branch of service. Having an expectation that they will develop an asbestos related disease, may in part explain why some naval veteran participants reported resignation rather than shock at diagnosis. This finding is in contrast to the feelings of shock reported in a study exploring the impact of a mesothelioma diagnosis for civilian patients (Taylor et al. 2018).

Also contrasting with civilian experiences was the nature of exposure that veterans from across the services recounted. Their exposure reflected the varied nature of military work and life. Living accommodation, combat experiences and extensive travel were identified as potential sources of exposure to asbestos.

- **Living Accommodation**

Some of the examples of asbestos exposure provided by the participants include Nissen huts, living on board ships and living in old factories. Some participants mentioned accommodation during training in particular. This indicates that domestic exposure for military veterans is

distinct from domestic exposure for civilians. For those in military service, the employer (MOD) would often have been the provider of the accommodation and therefore responsible for providing a safe living environment as well as a safe working environment.

- **Combat**

Participants also described examples where combat may have exposed them to asbestos, for example “searching bombed out” buildings, bomb blasts and searching for ammunition in old buildings/factories. Some participants discussed actually working in buildings that had been bombed. This is a type of exposure which would not usually need to be considered when conducting a civilian occupational history. This illustrates how having an Armed Forces background may create specific challenges when undertaking an occupational asbestos exposure history.

- **Extensive travel**

Most of the veterans had experienced extensive travel during their service, both nationally and internationally. This meant, pinpointing the exact location of exposure was not always possible:

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“I’ve been to a lot of places to work, and by the nature of my job in a number of them, I went to visit an awful lot of places as well.... I didn’t know that I ever worked with asbestos... I was all over the place” **Callum P3MR**

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When asked about exposure, some veterans could not recall having handled asbestos. However, many could recall having been in buildings and vehicles that potentially contained asbestos. This makes a distinction between workplace and environmental risk rather than occupational risk. Some veterans may underestimate the contact that they have had with asbestos throughout their working and service lives because it was environmental rather than occupational. This illustrates why asbestos and occupational histories should be taken by a professional with experience of working with veterans and knowledge of service life in relation to mesothelioma.

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- **Ongoing exposure to asbestos**

Some veterans and family members described how exposure to asbestos had been ongoing over years, despite evidence of the harm that it can cause. Concerns were expressed about Crown properties, which still contain asbestos, falling into disrepair.

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“I could take you to probably thousands of crown estates properties from airfields to ships, from ships to army training centres, from army training centres to aircraft, stately homes, public buildings, even to the Palace of Westminster itself, which has an acute problem of asbestos.” **Paul F2FM**

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### Staff findings

- **Awareness of asbestos exposure**

The findings from staff contrast to those of patients and families in relation to awareness of asbestos exposure. The patient and family participants did demonstrate a developing awareness of asbestos exposure over time. However, the staff participants referred to patients’ lack of awareness of asbestos exposure, even when their exposure had been very high. Examples included patients who remembered sleeping next to ‘big dusty pipes’, but who had been unaware that these pipes were made of asbestos. Other examples included a patient had been cleaning after a fire on board a ship that was built using asbestos. He had not linked this work to his asbestos exposure until after his diagnosis and had an occupational history taken.

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“they [patients] say, as punishment we were sent down in the ship to deal with all the asbestos sacking but I wasn’t exposed to asbestos” **S5 (Mesothelioma nurse specialist)**

“it’s interesting because a lot of, sometimes Armed Forces in the Navy, believe that they’ve never come into contact with asbestos.” **S2 (ASG worker)**

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The patient findings show that some veterans may be aware of sources of asbestos exposure. However, looking

at the patient and staff findings together shows that we cannot assume that all military patients are aware of the nature and source of their exposure to asbestos.

- **Dual exposure**

Staff participants also recognised the high probability of dual exposure for some veterans.

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“you can imagine, somebody comes out of the services, 30s, 40s, they will do another job, and often that involves exposure as well.” **S6 (Mesothelioma nurse specialist)**

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The possibility of dual exposure again emphasises the importance of accurate occupational history taking and expert advice regarding the best strategy for seeking compensation.



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### Coping with a diagnosis of mesothelioma

Within this section, findings relating to the strategies used to cope with a diagnosis of mesothelioma are presented. The importance of family members is also discussed.

#### Patients and family members' findings

- **Coping strategies**

Participants' accounts revealed how veterans adopted strategies to help them cope with their diagnosis. These often had links back to coping strategies they had developed during military service. Examples included deference to hierarchy, such as following the consultants' orders:

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"I'm going to fight it. And the way to fight it is to be a soldier. Do as you're bloody told." **Bob P2MA**

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Participants made comparisons between challenging experiences whilst serving in the Armed Forces and living with mesothelioma. These memories drove them to proactively cope with, rather than be subdued by, their mesothelioma diagnosis:

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"...I think you just get on with stuff because you're thrown into the deep end a lot of times when you're in the forces, one way or another, whether it be physically, mentally, and you just get on with it." **Henry P8MA**

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Being physically and mentally strong and independent was important to many veterans. Maintaining an image that projected the appearance of physical and mental strength and independence was also valued. Participants also communicated a belief that they were responsible for themselves and they did not like to be a burden to others. These factors meant that the participants were often reluctant to express their needs or recount negative

experiences in detail. This was particularly noticeable if the experience was emotional for them, as talking about emotions was not encouraged during their military service.

- **The importance of family members**

Family members often expanded upon and clarified needs that the veteran touched upon but did not explain in great depth. An example of this was the importance of family members in helping veterans to cope with a diagnosis of mesothelioma and, potentially, seek help when necessary. In the scenario below the patient participant had been upset when told by a consultant that his mesothelioma symptoms could "blow up at any time". His wife had been instrumental in making sure he spoke to and was reassured by the specialist nurse.

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"And we thought, we know that, we don't need to hear it, you know. And that really upset him and when we came home, he was really, really, you know, almost hanging himself depressed. And so I rang the specialist nurse and he talked to him [P11MA] and put his mind at rest." **Naomi F4FC**

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Whilst family members often played a key part in seeking help for their veteran family members, some felt that veteran's families should deal with their emotional needs independently. This again was attributed to the time in service when spouses of Armed Forces personnel were expected to cope without seeking support:

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"I think it's a military thing...when [patient's name] was off in a submarine for months on end, I was at home with a baby and a toddler, you know? ...you would never actually want to admit, especially being a senior officer's wife, I can't cope, because they would say, well, what's wrong with you?" **Josie F6FC**

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## Staff findings

### ● Coping strategies

Aligning with the findings from the patient and family member data, staff participants viewed veterans as stoic, resilient and proactive with a reserve of coping mechanisms to draw upon.

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“they [military patients] almost know how to deal with it, although, you know, I don’t want to say cope because I don’t think anyone can cope with it, but at least they can function with it.” **S5 (Mesothelioma nurse specialist)**

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Alongside these examples of mental strength, staff participants also recognised the potential stigma for military patients in relation to showing emotions. In addition, several participants expressed concerns about how to support military patients who may have experienced mental distress linked to their military service.

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“I think some of the things about the stigma of mental health are just like, you don’t want to show weakness, you don’t want to seem vulnerable. But I think that’s amplified, probably, in the military because part of your training is around mental strength, resilience, all of those things.” **S4 (Military charity worker and researcher)**

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This indicates that people providing care and support to military patients require the skills to provide sensitive, holistic care. This includes knowledge of when veterans and their families appear to be coping, but in fact may benefit from emotional or physical support. Little mention was made by staff regarding the family members’ emotional and physical needs in relation to living with mesothelioma.

### Preferences for care and support

The data from patients, family members and staff showed that veterans and their families required support throughout their mesothelioma journey. Who is best placed to provide this care and support is also discussed in this section.

## Patients and family members findings

### ● Support to facilitate independence

The patient and family member participants indicated their preferred sources of support. These included other veterans, health care professionals and asbestos support groups. Support appeared to be more acceptable if it helped them maintain their independence, as this was prized by several veterans. The importance of maintaining independence was attributed to their time in the military:

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“...it’s the way I lived for 12 years [as a serviceman], I’ve always been independent...that’s what they teach you in the military, don’t they, to stand on your own feet and get on with it.” **Ian P9MN**

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### ● The military family

While veterans often avoided discussing their own physical and emotional needs, they also expressed a sense of responsibility for caring for other veterans. The strong bonds that were formed from the shared military experience was important to many participants. The shared history facilitated connections, communication and trust. This meant some participants sought support from other veterans and were keen to provide support also.

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“...you’d be talking with people who have all worked in the same industry together...So who have everything in common and talk the same language...” **Albert P1MN**

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There was discussion about whether a support group for veterans living with mesothelioma would be advantageous. However, the geographical spread of veterans living with mesothelioma within the UK meant participants saw this as impractical. Additionally, some expressed that the specific condition that the veteran was living with was less important than the military camaraderie. This suggests that veterans may have a preference for other veterans to support their emotional needs regardless of the specific health conditions. Generic veteran organisations may therefore have an important role to play in supporting veterans. Mesothelioma UK has

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an existing Facebook group dedicated to Armed Forces personnel, veterans and their families.

With regard to professional support, veterans discussed the importance of knowing who to turn to when they needed information or support. One or two key points of contact was preferred over several as this was easier to navigate. Having a key professional to contact, such as a nurse specialist, helped veterans to overcome barriers and access complex health and military systems.

“Having a key professional to contact, such as a nurse specialist, helped veterans to overcome barriers and access complex health and military systems.”

#### Staff findings

- **Point of contact**

Staff participants highlighted the significance of two specific sources of support. One of these was the Clinical Nurse Specialist (CNS) who provided information and support regarding clinical issues. The second was an asbestos support group (ASG) advice worker who guided patients and their families through the medico-legal process.

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“...they see you [the specialist nurse] as the expert in navigating the system really.” **S6 (Mesothelioma nurse specialist)**

“So basically, you know they use me as central point. So if the support groups are having problems or there is delays, I get an authority and I can speak directly with a patient or the actual welfare officer involved.” **S2 (ASG worker)**

Access to these points of contact varies across the country. Although the number of mesothelioma nurse specialists is increasing, areas of the UK remain without access to this expertise. Similarly, ASGs across the UK vary in terms of size, funding and levels of activity. While the need for access to specialist services is not unique to veterans, the specialist support services required for veterans means that access to these services may sometimes be challenging.

- **Partnership working**

One of the strongest messages across the staff interviews was the importance of successful partnership working and the linking together of services. Predominantly, this was discussed in relation to the importance of joint working between the CNS, ASG worker and Veterans Agency. Such efficient partnerships enabled professionals to help veterans and their families navigate services. Thus, both specialist mesothelioma knowledge and organisational knowledge were important.

In order to pursue a claim against the MOD, the claim documentation has to be signed by the claimant and authorised by the Veterans Agency. It cannot be done posthumously, therefore timely communication between services is essential. Once a patient has received a diagnosis, the CNS either provides contact details so that the patient can contact their local ASG or alternatively they ask the patient’s permission to refer them to the ASG. The latter was the preferred option by participants who appreciated the need for efficiency in making a claim. The ASG then contacts the Veterans Agency who arranges to meet with the patient to initiate the claim and ensure the necessary signatures are in place on the DS1500. The DS1500 is a form that allows people living with a terminal illness to claim benefits. Staff commented that having a complete DS1500 appears to help a War Pension Scheme claim to be processed efficiently.

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“It’s really important that if someone has mesothelioma that they are visited well hopefully within a week or so by the Veterans Agency” **S1 (Solicitor specialising in asbestos)**

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“...the lovely Mesothelioma UK run nurses will provide me with a medical report with the DS1500 and then I send that straight through to the welfare office.” S2 (ASG worker)

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These networks appear to be well established and working smoothly in the areas where staff participants worked. Nevertheless, the benefits of this coordinated way of working highlights the implications if effective and timely communication links do not exist.

- **Rapport**

Several staff participants described patients with a military background as cautious and reluctant to show their emotions and express their feelings regarding their diagnosis. Sometimes this made it more difficult for staff participants to build rapport, especially for those who were unfamiliar with military culture.

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“...they take a little time to warm up, not warm up but they take a little time to open up to you... I think they are more cautious and they want to make sure that they are politically correct and they’ve got everything correct and everything is right.” S2 (ASG worker)

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Building rapport is especially important when supporting a veteran with mesothelioma. For example, the nature of asbestos exposure may be a particularly sensitive topic for mesothelioma patients with a military background. When asbestos exposure occurred during military service, talking about this can be difficult. Armed service experiences can be a topic that veterans think they should not talk freely about. This requires a more delicate approach and emphasises the importance of good rapport between patients and professionals.

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“I think it’s just building up a bit of a rapport with them to get them to open up and then talk about the exposure really.” S2 (ASG worker)

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Having an awareness of military culture and using this in practice can help to identify military patients and

provide appropriate and sensitive care and support. This awareness is generated through experience of serving in the military, living with someone who has served or experience of working with military communities. This highlights the importance of people with mesothelioma having access to professionals with experience of working with veterans for veterans.

- **The military family**

Staff participants recognised that some people from a military background may find it more difficult to talk about their diagnosis, particularly their emotions, with people who don’t share the Armed Forces experience. Aligning with the patient and family member data, the analysis of the staff interviews found that veterans may prefer to access support from others with shared lived experiences. This illustrates the value of both mesothelioma and military support groups and clubs for this group of patients.

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“...it goes back to a sense of this commonality, shared experience that they’ve had before” S7 (Mesothelioma nurse specialist)

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Nevertheless, it is important to remember that not all mesothelioma patients with a military background identify themselves as a veteran. Indeed, as always, each patient must be supported in the most person-centred and family-centred way possible.

- **Claiming compensation**

The War Pension Scheme provides veterans and their families with access to compensation. However, veterans, family members and staff participants all identified perceived inequalities when comparing the Armed Forces scheme with civilian compensation. These inequalities are explored in this section.

- **Sources of claim information**

Asbestos support groups, mesothelioma nurse specialists and other health care professionals were described as valued sources of information regarding eligibility for and the process of applying for compensation. Prior to discussions with these key professionals, many veterans

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were unaware that they were eligible for compensation.

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“[The Asbestos Support Group Advisor] turned round and said, do you know you can get a claim for this. I said, you what? I haven’t got a clue what you’re talking about. He said oh, we’ll help you.” **Bob P2MA**

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The War Pension Scheme provides two financial compensation options to veterans diagnosed with mesothelioma. These are first a one-off, tax-free lump sum of £140,000 or second, an enhancement to their existing pension payments (Ministry of Defence 2016). Deciding which option is best for them can be challenging so soon after receiving a devastating diagnosis.

All veterans interviewed had applied for and were successful in obtaining the lump sum. Most were impressed by the speed at which their claim was approved and processed. However, there were mixed reports regarding the standard of information and support provided around the claim process. This suggests that standardised information for veterans living with mesothelioma may facilitate their decision-making process regarding compensation.

“Navigating these systems and making an informed decision can be challenging and specialist advice is therefore required.”

The national data shows the widespread uptake of the War Pension Scheme and all veterans interviewed were aware of the scheme. However, there was a lack of awareness regarding the possibility of claiming compensation for dual exposure. Dual exposure was

discussed in staff interviews but seldom brought up in patient and family member interviews. This indicates that more can be done to raise awareness of the risk of dual exposure for veterans and the implications that this may have for claiming compensation. Navigating these systems and making an informed decision can be challenging and specialist advice is therefore required.

- **Perceived inequalities between civil and military claims**

Several of the veterans and their family members were grateful that the War Pension Scheme existed. They also commented on the speed of the process when no complications were encountered. However, several perceived inequalities between civil and War Pension Scheme options were identified in interviews. These included the fact that the War Pension Scheme does not include payment for non-NHS funded treatment, is not index linked and, sometimes was thought to award the smaller amount of compensation.

Veteran participants that were undergoing non-NHS funded treatments reported spending a significant amount of their WPS compensation on these treatments. There was concern about how they would pay for this treatment in the future, and other living costs, if their Armed Forces compensation ran out. Veterans and their families were aware that some civilian compensation claims set aside payment for non-NHS funded treatment:

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“I will, in a little while, push the question rather harder, towards MOD, what are you going to do about paying for treatments not available on the NHS?” **Callum P3MR**

“So we’re using the compensation money, the £140,000, to pay for it [immunotherapy], and it’s £6,000...Every three weeks, so we’re already well into £40,000. Okay, and then we had a telephone call and they’re putting it up...So now it’s gone up to £7,537 or something every three weeks...As soon as the compensation runs out, then what happens? Then what do we do? Do we sell our house and move into a god knows what? I don’t know.” **Henry P8MA**

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Veterans were also concerned because they had an impression that the amount of compensation was lower than for civilians and that it was not index linked:

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“...it’s a great thing that the option is there, but actually, it should be made that it’s linked to inflation, so that at least it maintains its value” **Callum P3MR**

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“...the compensation, for one, is a lot higher, I believe for personnel who are in the private sector.” **Albert P1MN**

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#### Staff findings

- **Smaller amount**

Staff participants also had a perception that the sum received via the MOD claim tended to be less than the sum received in an equivalent successful civil claim. Veterans were therefore likely to receive a smaller amount of compensation than civilian patients.

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“It’s just unfair... it’s so unfair. Because they [the veterans] are aware that a civilian working alongside them, refitting that ship or working in that army base of RAF base, would be able to claim a lot more. And that’s not fair, not when they’ve served their country.” **S6 (Mesothelioma nurse specialist)**

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- **Non-NHS funded treatment**

Staff participants recognised the inequality veterans faced regarding access to non-NHS funded treatment, such as immunotherapy. Patients pursuing a civilian claim can access additional funds to use on non-NHS funded treatments but this is not available to those via the MOD claim route.

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“...so immunotherapy, generally that would never be covered under any kind of MOD claim because the cost you can’t even predict” **S1 (Solicitor specialising in asbestos)**

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- **Posthumous claim**

The inability to make a posthumous claim when pursuing a lump sum under the War Pension Scheme was something all staff participants recognised as problematic. Under the WPS, there is an option of a spouse submitting a claim for widow(er)’s benefits, provided the mesothelioma lump sum was not already awarded. This was seen to be different to a civilian compensation claim that can be pursued by family members after someone has died of mesothelioma.

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“The war widow’s pension or the lump sum, that’s not available after you die, you only get a pension, a small percentage. Which is actually quite insulting if you know that you could have nominated and got 140K in life, if you just, you know, then you lose the chance” **S1 (Solicitor specialising in asbestos)**

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The findings indicate that it is essential that professionals work efficiently and quickly when supporting an application for the War Pension Scheme, because the claim must be signed by the claimant in life. When reflecting on this process, staff participants presented a sense of urgency regarding broaching the topic of 'medico-legal issues' and referring the patient to their local ASG and Veterans UK. Managing the speed of referrals and gathering appropriate evidence adds an additional layer of complexity and organisation when supporting a veteran in comparison to a civilian mesothelioma patient.

- **Loyalty**

Staff participants recognised that pursuing a claim can cause feelings of guilt for patients, conflicting with the loyalty they carried for their employer. However, this can be intensified for veterans due to the nature of their job, and loyalty to the service.

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*"They're always proud of their service, so they kind of don't want to sue, don't want to be seen as rocking the boat, you know"* S6 (Mesothelioma nurse specialist)

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This internal conflict can be difficult to manage for patients. It is important that professionals working with patients and their families understand this conflict in order to provide effective support.

### **Findings summary**

The national and patient experience data have provided novel understanding of the experiences of UK veterans living with mesothelioma. The national data has provided insight into the incidence and prevalence of mesothelioma in UK veterans. It has also highlighted variations in the datasets regarding prevalence in veterans across all three services. There was also a significant number of veterans with mesothelioma from the RAF and Army, not just the

Navy. These figures are not the true figures of people with mesothelioma and a military background. The WPS and SOAF data reflect those accessing advice (SOAF data was collected by HASAG) and compensation (WPS and SOAF). It will not include people from all services who do not want to access advice or think their chances of having a successful compensation claim are low. The number of people in the MORE data who have an army background indicates that this current population may be underrepresented in current estimates. This also shows that asbestos exposure and mesothelioma awareness and prevention is important across all three services. The analysis also highlighted the wide range of occupations that veterans undertook (within the Armed Forces). The patient experience data explored the health and support needs of UK Armed Forces veterans living with mesothelioma. Building on the analysis of the national data, the patient experience data showed the range of occupational settings in which veterans were exposed whilst working for the MOD. Furthermore, participants expressed their concerns about current Armed Forces personnel being exposed to asbestos/asbestos exposure. We have included their concerns within this report in order to encourage those responsible to ensure that the next generation of Armed Forces personnel are not exposed to asbestos.

The findings showed that veterans and their families may adopt strategies that have previously helped them to cope during military service. Also linked to their military service was the preference to support, and be supported by, other veterans. The availability of this type of support may be advantageous for veterans living with a diagnosis of mesothelioma. However, several inequalities between civilians and veterans living with mesothelioma were identified during interviews. These included a perceived disparity in compensation opportunities and the inability to claim posthumously.

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# Discussion

**MiMES is the first in-depth exploration of UK veterans' experiences of living with mesothelioma. The study has generated a unique insight into the experiences of participants and their priorities for care.**

The results from this study raise some useful questions on how to support and care for people with mesothelioma who have a military background. Some of the participants' experiences, and implications for services, are similar to those without a military background. However, MiMES findings do indicate that there are issues that may be specific to, or more prevalent for Armed Forces veterans.

Eight key messages have been devised from the findings. These are summarised below along with reflections on the implications for future care and trials.

**Key message 1 - Challenge assumptions regarding who has been exposed to asbestos whilst in the Armed Forces and raise awareness of the risk of such exposure.**

The findings indicate that there are assumptions regarding who is at risk of asbestos exposure and why, for example naval servicemen working on ships being the predominant high-risk group. Whilst some navy personnel are at high risk of asbestos exposure, MiMES indicates that



other service personnel are also at risk. The nature of asbestos exposure amongst our participants varied enormously. People from across the three services were exposed to asbestos and developed mesothelioma. Exposure was not always in high risk occupations and workplaces. Exposure was sometimes low level and short term, from working and living environments. Increased awareness is required to reduce exposure in the future and to promote early diagnosis.

#### Implications

- Raise awareness of asbestos risk and mesothelioma within the Armed Forces and military personnel community.
- Consider developing asbestos awareness training courses for all Armed Forces personnel. This would allow people to recognise asbestos and know what process to follow if it is found.

**Key message 2 - Occupational history taking requires skill and sensitivity for patients with an Armed Forces background. This is especially true for people who have experienced combat or trauma during their military career as the diagnosis may trigger emotional distress.**

Identifying the source of asbestos exposure during military service may be difficult and requires the help of someone with expertise and experience. Veterans, and particularly those deployed to combat zones, sometimes find discussing the sources of their exposure challenging. This discussion may cause them emotional distress. Our findings show that staff working with veterans are aware of the need to be sensitive when taking an occupational history with veterans.

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### Implications

- Consider making veterans and their families aware in advance of having an occupational history taken, that the asbestos exposure interview will be very detailed and that it may require them to remember distressing or difficult military experiences.
- Be sensitive when taking an occupational history and mindful that exposure may have occurred at a time which is difficult for the veteran to discuss. They may need time to develop the trust required to discuss and disclose such event.

### Key message 3 - Veterans' stoic approach may disguise their physical and emotional needs.

Many veterans appeared stoic in the face of a diagnosis of mesothelioma. This may be linked to how they dealt with adversity and challenges during their time in service. Thus, a diagnosis of mesothelioma may have a more significant impact on a veteran than it outwardly appears. Furthermore, our findings show that veterans and their families may not explicitly ask for additional support when they require it.

The military wives who were interviewed were protective over the mental and physical health of their husbands. They were highly attuned to their spouse's emotional and physical needs. The inclusion of family members in discussions around care may therefore be beneficial for the patient. The impact of a mesothelioma diagnosis on

military family members remains unknown and more research is required in this area.

### Implications

- Let veterans and their families know about specific support available in a clear and direct manner.
- Explain how that support would be advantageous to them, for example it may allow them to maintain their independence.
- Further research is being undertaken to understand the psychological needs of veterans' family members.

### Key message 4 - Veterans require access to experts with experience of navigating the relevant health, legal and military systems

Some veterans may have to navigate both civil and military systems. These can be complex. If veterans do not access the right information at the right time, this can have significant health and financial implications. Our findings show that providing veterans with support from key professionals with experience of navigating these systems may be advantageous for their care. Aspects such as occupational history taking, applying for compensation and information about access to support requires professionals with experience of working with veterans. This works best when organisations work in partnership across settings.

Our findings highlight the importance of partnership working between professionals "behind the scenes". In cases when there was clear

communication between Veterans UK, CNS and ASGs, this ensured that the patient received high quality care in terms of receiving information about compensation and support in a timely manner.

### Implications

- People receiving a diagnosis of mesothelioma should be asked if they have served in the Armed Forces. This should be acknowledged and documented.
- Occupational history taking should incorporate, as appropriate, military specific questions. For example, "have you lived aboard a ship? Have you ever spent time in or near buildings after they have been bombed?" From diagnosis, ensure that veterans and their families have access to a finance and benefits advisor who can deal specifically with veterans.
- Ensure that veterans have access to a specialist mesothelioma nurse who can provide specialist advice, and assist the veteran to navigate military and civil legal and financial systems
- Professionals who are not familiar with military systems should refer to Mesothelioma UK for guidance if they meet anyone with mesothelioma and an Armed Forces background.
- Professionals should have access to training on how best to work with Armed Forces personnel, veterans and their families, especially if working in localities with high numbers of current or ex-military personnel.

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**Key message 5 - It is important to recognise and understand the perspectives and support needs of family members.**

Family members are often omitted from studies of veterans. Our findings show that family members form an important part of the veteran's experience of living with mesothelioma. They are key to supporting the veteran and helping them to access support when necessary. Our findings also show that family members may require support themselves. However, due to a background valuing independence and self-reliance they may have difficulty asking for help in a timely manner. Further research is required to explore and understand the needs of the family members of veterans with mesothelioma.

**Implications**

- Professionals should be mindful of the important role of family members and their support needs.
- Further research into the psychological needs of family members of veterans

**Key messages 6 - Veterans living with mesothelioma may prefer to support, and be supported by, other veterans.**

Asking for help can be challenging for some veterans and their families. Maintaining independence may also be a priority for veterans. Our findings suggest that some may prefer receiving support from other veterans, who they see as being part

of the same 'military family'. Some veterans may already be involved in various groups within their military community, but others may benefit from being put in contact with local and national organisations.

Mesothelioma UK Clinical Nurse Specialists have attended Armed Forces and Veterans Breakfast Clubs in order to raise awareness of the disease within the Armed Forces and military personnel community. They have also attended to increase their knowledge of where to refer patients who may require support from their local Armed Forces community.

**Implications**

- Ensure the veteran is aware of local military social groups so that they can attend if they choose to. Examples may include breakfast clubs and local military charities.
- Promote the role of military charities and breakfast clubs in supporting veterans living with mesothelioma.
- Ensure the veteran and their family members are aware of the Mesothelioma UK Facebook group dedicated to Armed Forces personnel, veterans and their families

**Key message 7 - Some veterans see inequalities between their experience of living with mesothelioma and that of civilians.**

Several veterans, family members and staff highlighted perceived inequalities between veterans and civilians living with mesothelioma.

These included the experience of claiming compensation, the amount of compensation received, access to non-NHS funded treatment and the inability for families to pursue a claim once the veteran had passed away. These perceived inequalities frustrated participants and some felt that the "duty of care" had not been fulfilled by the military. These participants considered it important that veterans and their families felt valued by the Armed Services.

There is a particular concern about the fact a War Pension Scheme claim must be made in life. It is not possible for a veterans' families to pursue a claim posthumously.

**Implications**

- Discuss the findings with the necessary stakeholders.

**Key message 8 - There is a lack of awareness regarding asbestos exposure in the Armed Forces and concern about ongoing asbestos risk.**

Although some participants shared in-depth knowledge of their exposure to asbestos, some even anticipating their diagnosis after learning about the diagnosis of fellow servicemen, several staff participants described a lack of awareness and shock amongst veterans diagnosed with mesothelioma.

Alongside this, data from veterans, family members and staff participants presented anger and concern that asbestos can still be found on some

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military premises and buildings. This presents an ongoing risk to military personnel.

#### Implications

- Professionals should not assume that veterans will be aware of their exposure to asbestos.
- Increase awareness of ongoing risk of asbestos exposure for military personnel.

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# Conclusion

The findings from this study reinforce the fact that mesothelioma is a significant problem for UK veterans. It is difficult to obtain accurate figures on incidence. However, 340 claims were made to the AFCS between April 2016 to March 2020. The vast majority were from Royal Navy veterans. However, incidence amongst veterans from the Army and RAF should not be underestimated. Data from the SOAF and MORE databases indicate veterans from all three services are at risk of mesothelioma due to asbestos exposure during their service. Exposure is not always due to high risk occupations but may be due to workplace or environmental exposure.

This study also identified that UK veterans and their families face unique challenges when faced with a diagnosis of mesothelioma. There were many examples of how civilians and veterans' mesothelioma journeys may differ. These included sources of exposure, seeking financial compensation and preferences for type of support.

There were two key areas in which opportunities for best practice were missed. First, perceived inequalities in regards to access to non-NHS funded treatment and the amount of compensation received. Second, situations where professionals lacked experience of working with veterans. These cases significantly impacted on the patient experience. The findings suggest that changes are required to address these inequalities of care. It is essential that professionals working with veterans are experienced, sensitive and knowledgeable about navigating civil and military systems. Involvement of these professionals has the potential to improve the care provision for UK Armed Forces veterans and their families. Furthermore, the findings demonstrate the importance of increasing awareness amongst Armed Forces personnel about the dangers and prevalence of asbestos exposure.

The study highlighted the challenges veteran patients have in regards to navigating complex civil and military systems. However, examples of good practice were provided by patients, family members and staff. These can be used going forward to improve the care provided to veterans and their families living with mesothelioma.

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# Appendix

## Appendix 1 : Patient topic guide used in the individual interviews

### Welcome and introduction

- Provide an overview of purpose, format and length of in-depth interview - topics to discuss, audio-recording, note taking.
- Ground rules of interview - e.g. if you say any names we'll anonymise, if you need to we can stop/pause the interview (e.g. if they are feeling unwell or short of breath), reinforce confidentiality.
- Confirmation of consent. Emphasise that if they have any concerns with participation to let us know.
- Request to tape discussion - Check OK and start recording

### I'd like to start by asking a few things about you

- Age
- Marital status
- Live alone or with family, family nearby
- Home: rural/urban
- Other illnesses
- Length of time since diagnosis

### I'd like to ask you a few questions about your service history.

- Occupation
- Where were you based
- Length of service
- Employment since leaving service
- Are you aware of any asbestos exposure? If so, when? Where? During or after service? Any details.

### I'd like to ask you a few questions about your experience around the time of your diagnosis of mesothelioma

- Journey from first symptom to diagnosis / what happened leading up to your diagnosis? Prompts: symptoms, who you discussed these with at home and in health service, tests and investigations
- Receiving your diagnosis. Prompts: Who, where, what happened, what did people say? Did you take anyone with you (e.g. family member)?
- Explore what people were told and understood about the diagnosis and prognosis, treatment options and legal and financial implications
- Expectations and preferences about information: Prompts: Did you expect to hear the information about your diagnosis of mesothelioma? Did you feel prepared?
- Did you have a preference for how much information you wanted to be given about your diagnosis? Did any of the doctors or nurses ask you about this before you were given your diagnosis?
- Response to and impact of your diagnosis. Prompts: How did you feel (e.g. shock, loss of control, uncertainty, fear, denial, confused)? What did you understand/not understand? Did you get the information you needed (e.g. what is meso, causes, prognosis, treatment,

finance/legal)? What additional information did you need? Family response and needs? Worry about telling family/impact on family)

- What did you expect or hope would happen next? (Prompts: What will happen regarding treatment, care and support?)
- What happened next? Prompts: Immediately after getting the diagnosis. Were you given details of who to contact for further support or information? Have you used these services?
- What was your experience of navigating services? How did you find this? Did your Armed Forces service history affect this? If so, how?
- Claiming compensation. Have you claimed already? Are you in the process of claiming? Can you describe this process? What was your experience of this?
- Sources of support. What sort of support have you needed? What support have you received? What sources of support have your family members needed? What support have they accessed? What support is missing?
- Was there anything that could have been done differently to improve your experience?

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**Next I'd like to talk to you about how you are now**

- What is your health like now? Prompts: Regarding mesothelioma, other co-morbidities.
- What are your current treatment and care and related support and information needs – for you and your family? Prompts: Current needs, are these needs being met? How, who? Where? Explore needs regarding diagnosis and prognosis, treatment options and legal and financial implications
- What are your expectations and hopes for the future regarding treatment and care and related support and information needs for you and your family? Prompts: Explore needs regarding diagnosis and prognosis, treatment options and legal and financial implications. Who will meet these needs?

**Is there anything you would like to add?**

- Additional comments about mesothelioma and the diagnosis?
- Questions about the study?

**Ending**

- Clear reminder of how the information gathered at the interview will be used.
- Would the participant like to receive a summary of what we find at the end of the patient experience study?
- Thank the participant for taking part.





The University Of Sheffield.

**Mesothelioma UK is a national specialist resource centre, specifically for the asbestos-related cancer, mesothelioma. The charity is dedicated to providing specialist mesothelioma information, support and education, and to improving care and treatment for all UK mesothelioma patients and their carers.**

The charity integrates into NHS front line services to ensure specialist mesothelioma nursing is available at the point of need. This is achieved through a growing network of specialist mesothelioma nurses, regionally based in NHS hospitals but funded by Mesothelioma UK.

Mesothelioma UK runs a specialist, UK-wide service for armed forces personnel and veterans, called 'Mesothelioma UK - Supporting our Armed Forces'. Find out more information at [www.mesothelioma.uk.com/armedforces](http://www.mesothelioma.uk.com/armedforces).

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