

MESOTHELIOMA UK

Mesothelioma UK Nursing 2020 - 2023 Strategy

Foreword

The Mesothelioma UK National Resource Centre was launched in 2004 with financial support initially from Macmillan Cancer Support and latterly from industry, the Mick Knighton Mesothelioma Research Fund and generous private donations.

The Mesothelioma UK Charitable Trust was established in 2009 and immediately became fully responsible for securing sufficient income to support the resource centre activities. This truly is an NHS success story.

Our vision is:

- To be a 'Mesothelioma Essential One Stop Shop' for up to date mesothelioma support, information and education.
- To support the NHS to drive up standards and ensure equitable access to world class treatment, trials and care.
- To help the UK to lead the way in making mesothelioma history through world class audit, research and clinical trials.
- To raise the profile of mesothelioma to help prevent future cases of asbestos related disease.

Our nurses are integral to this vision and we continue to forge ahead developing a 'Hub and Spoke' approach to providing Mesothelioma Nurse Leaders and Mesothelioma Clinical Nurse Specialists across the United Kingdom. This strategy has been devised to help us to achieve this vision.

In the UK approximately 2700 people are diagnosed with mesothelioma each year and the number is rising. Many patients have complex physical and psychological issues with a heavy burden of symptomatic disease. Our aim is to establish and fund the



availability of Mesothelioma UK Specialist Nursing Services in key locations covering the UK including every Cancer Alliance within England and in Wales, Scotland and Northern Ireland. Mesothelioma UK usually funds these specialist nurses for two days per week and each nurse has local, regional and national responsibilities. Prior to Mesothelioma UK investment there were no specialist nurses working exclusively in mesothelioma (MCS 2017). As a charity, Mesothelioma UK is committed to further address this imbalance and to ensure that those living with mesothelioma have access to specialist support.

Mesothelioma UK's 'hub and spoke' approach to nursing is having an incredible impact on driving standards of care across the UK. This is vital to embed high quality nursing care for this group of patients in all healthcare settings. As we move towards achieving our goal of having 38 Mesothelioma UK Clinical Nurse Specialists by 2023, it is important that the nursing workforce develops, sharing skills and reflecting knowledge and expertise. The demonstration of competence and support required is fundamental to the roles of our nurses and the high level of respect in which they are held.

A handwritten signature in black ink that reads "L M Creech".

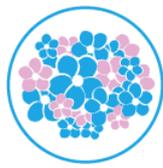
Lorraine Creech

Head of Nursing



Mesothelioma UK Clinical Nurse Specialist Strategy Goals

- 1) To devolve the Mesothelioma UK Nursing leadership to the Mesothelioma UK Head of Nursing and to clarify the Mesothelioma UK Head of Nursing and Mesothelioma UK Nursing Team Leader / fixed term project leads roles.
- 2) To identify where additional Mesothelioma UK Clinical Nurse Specialists and Welfare Rights Workers are required to meet the specific regional needs and incidence of people with mesothelioma.
- 3) To establish by 2023 a Mesothelioma UK footprint of 38 specialist mesothelioma nursing posts including one in every cancer alliance in England and in Wales, Scotland and Northern Ireland and sub specialising nurses such as those working in the Armed Forces Project, Peritoneal and Thoracic Mesothelioma Nursing.
- 4) For Mesothelioma UK Clinical Nurse Specialists to identify and develop small scale research and audit studies to improve outcomes.
- 5) To create a culture and support mechanisms to recognise and support the voice of Mesothelioma UK Nursing.



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NHS Cancer Networks and Alliances

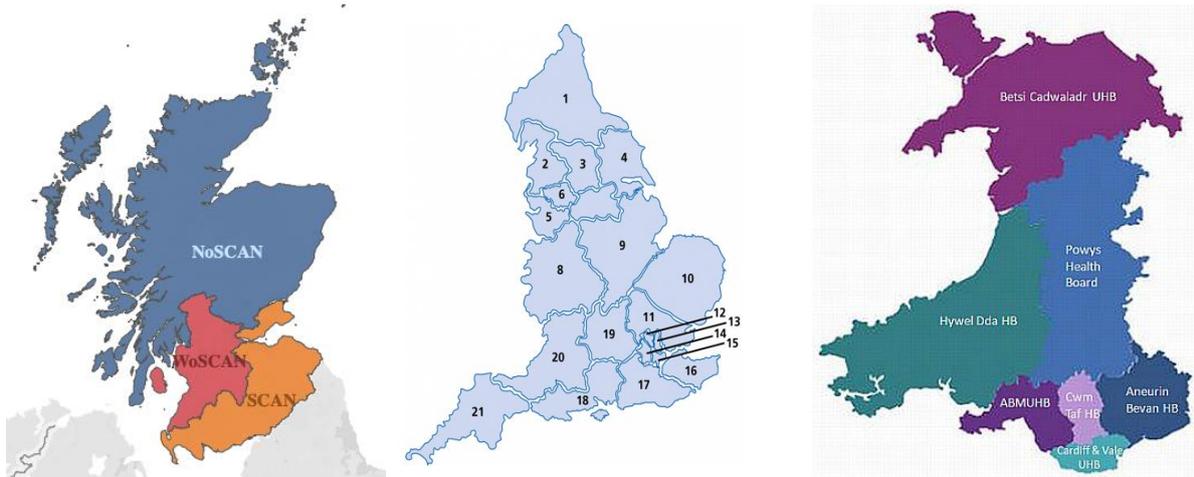
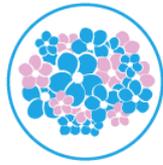


Image of NHS Scotland, England and Wales Cancer Networks and Alliances taken from NHS England.

Mesothelioma UK currently

- Funds 21 Mesothelioma UK Clinical Nurse Specialists in 19 Hospital Trusts in the UK
- Has adopted 5 Mesothelioma UK Clinical Nurse Specialists in 3 Hospital Trusts the UK.
- Fosters 2 Nurses in the UK offering them support and guidance in 2 Hospital Trust in the UK.
- In total currently 26 Clinical Nurse Specialists gain financial support from Mesothelioma UK.



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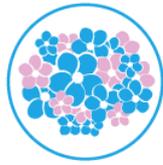
Mesothelioma UK Clinical Nurse Specialists

1. Leicester (3 total including Head of Services and Head of Nursing)
2. Portsmouth (Team Leader)
3. Manchester (2 including one adopted)
4. Sheffield
5. Newcastle (Team Leader)
6. Oxford
7. Glasgow
8. Wales
9. Plymouth
10. Cambridge
11. London 2 nurses total
12. Kent
13. Liverpool
14. Southampton (Armed Forces Specialist)
15. Basingstoke (Peritoneal Specialist)
16. Morecambe Bay (2 adopted)
17. Inverness (2 adopted)
18. Dundee
19. Aberdeen

Each of the Mesothelioma UK Clinical Nurse Specialists is funded under a 2-year service level agreement and this is usually the extension of a lung cancer nursing role. For the adopted posts funding is provided to allow the Clinical Nurse Specialists to extend their expertise in mesothelioma and be included within Mesothelioma UK training programmes. Fostered posts are affiliated with Mesothelioma UK to develop pathways for joint working and support.

Each Nurse has a local, regional and national remit to their roll, outlined below.

Local	Regional	National
Caseload	Support CNSs	Information Line
Support Group	Support Group	Audit/ Research
MDT	Education	Education
Resource	Trials	National Projects
Trials	Meso Profile	



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Training, Support and Coaching

- The Head of Nursing and the Team Leaders provide support and coaching.
- The Mesothelioma UK Clinical Nurse Specialist Professional Forum is held three times a year and contributes to the development of Mesothelioma UK nursing and the delivery of mesothelioma nursing services throughout the UK.
- The Forum assists with sharing best practice, developing nurse leadership, sharing information, peer support and is a clinical interface between the charity and the NHS/ clinical setting.
- The Forum assists Mesothelioma UK in the implementation and delivery of its Strategy “Dedicated to Making Mesothelioma Matter” and “Mesothelioma UK Audit and Research Strategy. Mesothelioma A Problem to be Resolved.”

Four Work Streams

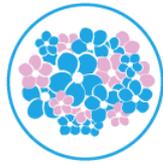
The Nursing Strategy will focus on four main workstreams, identified below.

1. Increasing the number of Mesothelioma UK Clinical Nurse Specialists and developing team leadership

- Increase the number of clinical nurse specialist posts to 38.
- Establishing the Mesothelioma UK Head of Nursing post.
- Develop an additional Mesothelioma UK Clinical Nurse Specialist Team Leader Post in England.
- Develop a new Mesothelioma UK CNS Team Leader post in Scotland where a further a ‘hub and spoke’ approach to mesothelioma nursing is developing.
- Develop a project lead post in Wales to develop a ‘hub and spoke’ approach to nursing within Wales. This would be a two year fixed contract with the ultimate goal of becoming a Mesothelioma UK team Leader post within Wales.

2. Strengthening service level agreements

- It is important to ensure that Mesothelioma UK Clinical Nurse Specialist posts are set up within Trusts which meet all aspects required in expressions of interest.
- Tighter evaluation of posts by full submission of data to the Mesothelioma UK Dashboard, production of an annual report and collaboration with



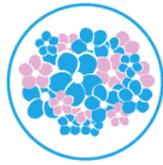
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Mesothelioma UK Clinical Nurse Specialist Team Leaders at the biannual renew process of the service level agreement.

- Attendance at the Mesothelioma UK Clinical Nurse Specialist Forum and regular contact with the Mesothelioma UK Clinical Nurse Specialist Team Leader to feedback and have a two way dialogue about matters arising within the Mesothelioma UK and the host Trust.

3. Securing engagement for ongoing projects, research and audits and the dissemination of the findings.

- Mesothelioma UK Clinical Nurse Specialists to identify research questions and develop small scale research and audit studies.
- Mesothelioma UK Clinical Nurse Specialists to be aware of the Mesothelioma UK Research Strategy and engage with the Mesothelioma UK Centre for Research
- Engage with others to secure ongoing funding for research. Mesothelioma UK Clinical Nurse Specialists should engage with projects such as the Armed Forces Project. Continual engagement is required particularly for this very important project which ceases funding in September 2020.
- In 2019 The Mesothelioma Outcomes Research and Experience (MORE) survey was undertaken and it was the Mesothelioma UK's second large scale survey (the initial one was conducted in 2012) seeking to comprehensively capture patients' experience. The charity will share and disseminate findings to improve services, resources or any aspect of mesothelioma experience, treatment or care. The findings will be disseminated enabling the Mesothelioma UK Clinical Nurse Specialists to deliver data regionally by cancer alliance or devolved administration and nationally.
- A proposal for a new digital health research service is being set up - the Mesothelioma Companion and Digital Assessment Xchange (Meso-DAX) in partnership with a collaborative healthcare research partner, DASH Global. The Mesothelioma UK Clinical Nurse Specialists will be integral to offering and consenting patients to enrol into Meso-DAX during clinical consultations. This data platform will allow for review, analysis and evaluation throughout the patients care throughout their disease trajectory.



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4. Maintaining the stability and the wellbeing of the Mesothelioma UK Clinical Nurse Specialist workforce

- Consider devolving the Mesothelioma UK Clinical Nurse Specialist Professional Forum to more regional events.
- Consider the inclusion of team building events to assist with wellbeing.
- Consider online meeting formats.
- Conduct a job satisfaction survey following the COVID-19 pandemic and repeat in 2 years' time.

Reference:

Cancer Workforce in England. A census of cancer, palliative and chemotherapy nurses and support workers in England in 2017. Macmillan Cancer Support