



# MESOTHELIOMA UK

## COVID Impact Survey 2 - September 2020

### Summary

The UK has the highest incidence of Mesothelioma in the world.

It is an avoidable Cancer; treatment is not curable and those living with mesothelioma have a short window of opportunity to access potentially beneficial treatments. Sadly, with the COVID-19 pandemic, mesothelioma patients and their families are amongst our most affected cancer patients. For some the situation has been desperate.

Mesothelioma UK completed COVID Impact Survey 1 in May 2020. Responders (35 patients and 29 carers) candidly described the impact the pandemic was having, they shared their fears, worries and the practical difficulties they were experiencing. This second survey approached the same issues but through Mesothelioma UK's team of 27 nurses.

Each Mesothelioma UK nurses is based in an NHS hospital and each has worked tirelessly through these first 6 months of the COVID pandemic to support patients, minimise the impact of the pandemic and adapt services to ensure continuity has been maintained as much as possible.

Twenty Nurse completed the 18-point survey and they described in detail the challenges, fears and major concerns that have been directly derived from their experiences of caring for people living with Mesothelioma through the COVID pandemic.

There was considerable overlap between the findings of both surveys and a number of recommendations have been reiterated and new ones made.

The key recommendation focuses on cancer treatment: -

Getting Cancer Treatment back on track **for all** is essential.

- All UK NHS trusts, GPs and Primary Care Services to be given deadlines for achieving 100% return (with necessary adaptations) to pre-covid service provision.
- All clinical trials to be risk assessed and re-opened where possible.
- Consider home treatment services particularly for our most vulnerable cancer patients.
- Less immuno-suppressing treatment regimens to be made available swiftly
- Bespoke guidelines and advice to be made available that address unique circumstances of cancer patients with a terminal diagnosis.
- Continue with public reassurance that Cancer patients matter and COVID treatment available for all cancer patients

## Background

Following the outbreak of the COVID pandemic, to maximise individual's safety and meet the health care demands COVID created, inevitably there was extensive disruption to our national cancer services.

In May 2020, to capture the impact of this on Mesothelioma patients and their families, Mesothelioma UK completed a survey focused on patient and carers' early pandemic experiences. This was summarised in a report sent to NHS England directly and it also contributed to extensive feedback co-ordinated by Cancer 52 and a COVID Cancer Intel initiative established by the Cancer Charity Forum.

## Mesothelioma UK COVID Impact Survey 1 (May 2020)

### Summary of Key Findings

- *Mesothelioma patients are frightened of attending hospital, they are concerned about exposure to COVID-19.*
- *50% described that treatment had been postponed or cancelled. Not all responders were on treatment.*
- *64% of responders said their scans or outpatient appointments had been altered.*
- *Responders used the following terms to describe how they have felt "frightened, abandoned, anxious, left in the lurch and in limbo".*
- *Patients miss having face to face consultations but despite this telephone consultations have been readily accepted. Ad-hoc calls to check on them are appreciated.*
- *Family members/carers can miss out on communication opportunities with health care professions with phone consultations.*
- *There was variation in which patients were automatically included on the NHS Shielding Patient List (SPL). Lack of automatic inclusion on the SPL lead people to presume they didn't need to shield. Health care professionals and patients experienced significant confusion in how to register for the SPL.*
- *Family support, charity and community services meant people generally didn't experience difficulty with shopping or essential errands.*

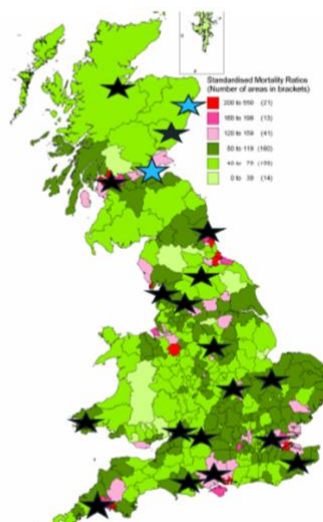
- *Hospital prescriptions are problematic in that they can only be used within the hospital.*
- *Establishing a routine, exercising, hobbies and catching up on household chores all helped combat the negative effects of social isolation.*
- *Using social media to keep in touch with family and friends was helpful but challenging for those who haven't used it before.*
- *There was evidence of frequent communication from and to hospital, community and palliative health care professionals.*
- *Patients' fitness and mental health have deteriorated.*
- *There were a number of worries expressed: -*
  - *mesothelioma progression whilst treatment is stopped*
  - *fear of exposure to COVID-19*
  - *ability to endure COVID-19 on top of mesothelioma*
  - *an assumption that treatment for COVID-19 would be withheld due to underlying mesothelioma*
  - *spending limited life remaining in lockdown instead of with family and loved ones.*
- *Presence and support from family and friends was the most appreciated but community initiatives, on-line shopping and contact from health care professional were also commented on.*
- *The UK Mesothelioma community (Warriors, Asbestos Support Groups and Mesothelioma UK) was useful and updates were informative to many responders.*
- *Gratitude and admiration for the NHS and concern for health care workers was expressed throughout the survey.*

The survey results led to a number of recommendations and Mesothelioma UK used the findings to design and increase the support provided through the charity's many patient and family facing services, in particular through the team of dedicated NHS based Mesothelioma Clinical Nurse Specialists that the charity funds.

## **Mesothelioma UK Clinical Nurse Specialists**

The charity funds 27 dedicated Mesothelioma Nurse Specialists in NHS trusts from Inverness to Plymouth, Kent, Wales, Cambridge and many locations in between. When we received the further request for cancer charities, in their advocacy roles, to feed back as much detail as possible about anything relating to patients ongoing issues and experiences, we decided to canvass the insight and experience of our specialist nurses.

1. Leicester x 3
2. Cambridge
3. Wales
4. Portsmouth\*
5. Manchester x 2 (1 adopted)
6. Sheffield
7. North East x 2\*
8. Oxford
9. Glasgow
10. Plymouth
11. London x Guys\*
12. London Barts\*
13. Southampton\* (Armed Forces Post)
14. Kent x 2\*
15. Liverpool
16. Inverness x 2(Adopted)
17. Lancashire x 2 (Adopted)
18. Dundee
19. West Midlands\*
20. BASINGSTOKE
21. Aberdeen
22. Yorkshire



## Mesothelioma UK Clinical Nurse Specialist Team Locations

### Survey 2

#### Method

Mesothelioma UK put together a second survey (Appendix 1) specifically for our nursing team. The survey was designed to capture detail and highlight what is happening to our cancer services from a Mesothelioma patients' perspective and also to capture the challenges the nurses and their clinical teams were continuing to have.

The survey was circulated in late August 2020, to 25 Mesothelioma CNS's by a member of the charity's operational team. The Head of Services and Head of Nursing were not included. Responses were returned by email, anonymised and collated. The survey had 18 questions, 13 of which requested narrative responses. Responses were categorised to establish emerging themes.

#### Results

Responses were received from 20 of the 25 nurses contacted. A full response was not expected given that a number of the nurses work in teams of 2 or more and may therefore have opted for a collective response. Also, the survey request was circulated during summer holiday time with a short turn around.

#### Diagnostics and Referral

There was a variation in experience with diagnostic services. The nurses identified that referral numbers were decreased, and the number of patients being diagnosed was lower than usual. Nurses (3) described the difficulties patients experienced accessing their GP services and the added challenge of no face to face consultations. It was

highlighted that more patients were probably being diagnosed via initial presentation at A&E rather than GP referrals.

Three nurses said they didn't have any disruptions to their diagnostic services. The disruptions the others experienced was across all areas. Access to CT scans, thoracoscopy and biopsies were delayed and, in some cases, stopped for a period, in addition the procedures took longer to arrange and perform. Despite being more than 5 months into the pandemic a number of nurses were still, at the time of the survey completion, having to work with ongoing disruption. Access to thoracoscopy (3 nurses), CT Scanning (7 nurses) and Surgical Biopsy (1 nurse) were all highlighted as still being affected. As teams looked to recover and restore services the repatriating of diagnostic services from centralised hubs unfortunately added in additional delays.

### **Patient and Carer Fears or Worries**

Overwhelmingly the most common fear expressed to CNSs by patients was about contracting COVID and not wanting to attend hospital which they considered to be high exposure risk area. 13 nurses cited this as a key concern.

The second worry the nurses highlighted was concern and worry about disease progression with 6 nurses identifying that delayed treatment, stopped treatment or trials was something patients were fearful of.

Patients reported feeling neglected, abandoned and frustrated. Nurses said patients had told them they felt they had been sent home to die alone and conversely others were also worried about dying alone, without any visitors, if they were admitted to hospital.

### **Priority for Improving Current Cancer Services.**

The nurses were asked what they thought their patients and their carers would say was their number one priority for improving the current cancer services situation. The overwhelming priority identified was access to treatment and clinical trials and generally getting treatment options back on track. The nurses also suggested that patients are happy with virtual/telephone appointments, but they really value and missed face to face appointments. The nurses felt face to face appointments should be reinstated as an option as soon and as widely as possible. One nurse also said patients need clearer information, likely to dispel the myths, about risks regarding treatment and coming into the hospital environment.

### **Nurses Most Challenging or Saddest Issue**

The lack of face to face contact with patients was felt to be the most challenging and saddest issue for the nurses with 9 of them describing how this made them feel. There was also concern that the lack of face to face contact meant patients were not adequately assessed, communication skills and training could not be followed, bad news was not delivered as well over the phone and it was much harder to build up a relationship with the patient and their family.

End of life care, the ability to spend time with loved ones and lack of visitors at end of life was found to be challenging and difficult with 6 nurses describing situations. Patients and their families felt very cheated that they weren't able to spend time together particularly with such a short life expectancy.

Nurses felt they had an increase in number and complexity of telephone calls with patients and families during this time. They also were far more pro-active about reaching out to patients to make sure they were supported. Nurses found it hard to keep patients spirits up via telephone and virtual contact only, particularly those that were shielding, who were cut off from family.

Nurses also spoke about the effect on them personally. One nurse wrote; *"It has had a real impact on me – more than anything has I think throughout my career. Sometimes I felt I couldn't have another one of those conversations – that I didn't have anything left."* Another nurse described how she just felt she was continually delivering sub-standard care.

In general terms 9 of the nurses said it took considerably more effort to support patients and 5 said slightly more. With less face to face contact nurses were spending more time on the phone to provide the support needed. The stopping and pausing of services and treatments and keeping up to date with what treatment and trials were running was hard. There were more calls to radiology than usual and arranging CT scans was sometimes difficult.

### **Implement 1 Thing to Help**

The nurses were asked if there was one thing you would like to do or change to help the current situation, what would it be. They responded they would like to ensure face to face consultations are once again available. They would like to see clinical trials re-opened and access to less toxic drugs ensured. The final thing the nurses would implement would be to allow family to visit and accompany mesothelioma patients in the hospital setting.

## New Ways of Working

The nurses and the teams they work in have adopted a variety of new ways to work. Virtual clinics using telephone (11) and video (6) being the most common. In addition, there have been virtual support groups (10), virtual MDT meetings (11) and team meetings (10). One nurse had been able to work from home and another had established new nurse led patient care services. It was widely expected that most new ways of working virtually will continue even after the pandemic.

## Experiences of Virtual Communication with patients (Video and Telephone)

A number of advantages and disadvantages of virtual working with patients were identified.

<b>Advantages of Virtual Working</b>	<b>Disadvantage of Virtual Working</b>
No need to attend hospital	Difficult to pick up on non-verbal cues
More frequent contact with CNS possible	Not able to examine patients
Increased continuity of care	Patients feel anxious as not seeing doctor
Reduced travel time	Harder to assess Performance Status
Meets patients' COVID exposure anxiety	Hard to give bad news/have difficult conversations
Well patients seem to prefer it	Need to have access to technology
Quicker to get a virtual appointment at services I refer patients to	Difficult for people with hearing difficulties
No parking issues or costs	Hard to offer support to patient who is upset
Health Care Professional can work from home	Can't do blood tests or x-ray
Patient more at ease in their own home	
Carers can be involved via speaker phone or 3-way conversation if not in same room	
Easier to offer more frequent follow up	

## Understanding of Shielding Advice

The first COVID survey Mesothelioma UK conducted in May 2020 revealed the significant confusion regarding shielding. The nurses confirmed that patients have continued to struggle with the complexity of the shielding advice, and they felt the initial 'Dunkirk spirit' waned over time. As patients felt the ongoing isolation, missed their family, friends and particularly their grandchildren, nurses observed that the 'we can get through this' attitude decreased. The impact on mental health and confidence,

the feelings of isolation and some would say abandonment took its toll. This was all the more complicated for people and families living with mesothelioma because of the poor outcomes and survival. People clearly felt there was little point in shielding if they hadn't got long to live, they wanted contact with their loved ones during this time and many thought they wouldn't be offered treatment if they did contract COVID because of their underlying mesothelioma diagnosis. Some patients chose not to register for shielding because of this and some avoided briefings and advice as they found it distressing.

The nurses have identified ongoing confusion about shielding. One nurse asked the question in her response if patients should still be shielding highlighting that health care professionals are confused too. Another explained that advice circulated since shielding stopped, has further added to the confusion.

Access to social media and/or the internet seemed to make it easier for patients to keep up to date.

Despite patient concern, confusion and sometimes reluctance to shield the nursing team encourage patients to adhere to the guidance and reassured them it was safe to attend hospital when requested to.

## **Guidance and Resources**

The survey asked the nurses if they had the guidance and resources necessary to meet the needs of their patients.

The lack of UK wide advice, it being different in each country and the frequency of changes made it hard to keep up to date, to offer advice and follow the guidance. Sources of information included their own NHS trust, government websites, Meso UK, NHSE, CRUK, LCNUK and Cancer One Voice.

Support from line managers and their own NHS trust varied with some saying support from their line managers was very poor. Limited access to PPE and lack of confidence in the guidelines about who should be wearing it caused concern initially. Access to IT equipment to be able to work from home was identified as an issue.

Access to GP and primary care services when trying to refer patients for community support or review has been highlighted extensively.

## **After Death Difficulties**

Mesothelioma UK had received calls from family members about difficulties with funeral arrangements and after death coroner's contact. We therefore asked the nurses if they had a feel for what their patients' family's experiences were. The limited number of people allowed to attend funeral was a definite issue for many. There were



positive comments about how caring and supportive funeral directors have been through this time. There were no comments about death certification or contact with coroners' offices.

### **Benefit and Civil Claim Delays**

All of the nurses responded and none of them were aware of any delays in claiming and receiving benefit or compensation advice, support or payment. There was one exception; a patient who felt their civil claim had been slowed. There had also been one situation where a patient in hospital could not be visited by a solicitor to complete some paperwork.

### **Key Messages from Meso UK CNSs on Behalf of their Patients**

Where there has been little or no disruptions patients have expressed gratitude but going forward, we need to ensure if there is a 2<sup>nd</sup> wave that cancer services, from diagnostics through to treatment, are protected so that services can be maintained. This should be equitable across the country and be coupled with a message, loud and clear that it is safe to still attend the hospital.

GP and primary care services need to get back on track and offer their pre-covid services.

Advice about shielding, who is vulnerable and how to protect yourself needs to be clearer and more consistent.

Some patients felt that coming out of shielding was harder than lockdown. There will be long term effects of the COVID pandemic and patients will need ongoing support. Staff are exhausted and morale is low. Having to deal with other people's anxieties, worries and fears whilst feeling frightened and anxious yourself has taken its toll.

### **Final COVID Related Comments**

Access to GPs was again highlighted as still lacking. The nurses were grateful for the role charity organisations played in terms of keeping people up to date and providing support. It would seem the nurses generally felt that the way the NHS pulled together and responded to the pandemic was really amazing and the public response to key workers was heartening.

### **Conclusion**

There are a number of similarities in the results of the two COVID surveys Mesothelioma UK has conducted despite being completed 4 months apart and having patients respond to the first and nurses to the second.

Fear about contracting COVID, about not being considered eligible or worthy of COVID treatment and continual worry about their mesothelioma progressing whilst treatments were disrupted were overwhelming issues.

Most cancer services are now reinstated although there is a degree of variation meaning some patients still can't access clinical trials or some investigations. Reinstating all cancer services equitably and sustaining them through any future COVID surges is generally considered to be essential and a priority as we move forward with this pandemic.

Confusion about shielding and the emotional and mental burden created by the isolation are still palpable. This is perhaps more apparent in a disease like mesothelioma where patients are living with a very limited life expectancy and have an urgency to immerse themselves in their family, friends and time with loved ones.

Some changed ways of working have perhaps enhanced services. Virtual consultations have added a welcome option but both surveys confirm patients and clinical teams need the option of face to face consultations to maintain essential standards of care, treatment and communication.

Access to GPs and primary care, particularly palliative care services continues to be disrupted and the nurses in this second service prioritise this as needing to be addressed promptly.

There was a plea from the nurses to have visitor and accompanying person rights for people with mesothelioma. Living with a disease that will likely result in the person dying within a year, irrespective of any treatment, surely warrants a waving of the general restricted approach to visiting that has been adopted throughout NHS trusts.

Finally, nurses could still feel the gratitude and support for the NHS expressed widely throughout the pandemic and this is extremely heart-warming. Nurses wanted the effect of the COVID pandemic on them personally to be acknowledged. Morale has been affected, clinical teams are tired and have at times struggled to provide the support needed when they too have had their own personal and family COVID journey to manage, they had each had their own fears and anxieties.

## **Recommendations**

The results from this second survey have supported a number of findings and recommendations from the previous survey that was completed in May 2020.

The following recommendations take into consideration the findings from both surveys.

- Getting Cancer Treatment back on track **for all** is essential.
  - All UK NHS trusts, GPs and Primary Care Services to be given deadlines for achieving 100% return (with necessary adaptations) to pre-covid service provision.
  - All clinical trials to be risk assessed and re-opened where possible.
  - Consider home treatment services particularly for our most vulnerable cancer patients.
  - Less immuno-suppressing treatment regimens to be made available swiftly
  - Bespoke guidelines and advice to be made available that address unique circumstances of cancer patients with a terminal diagnosis.
  - Continue with public reassurance that Cancer patients matter and COVID treatment available for all cancer patients
- Telephone consultations are acceptable (video may be preferable) and should be considered routinely post COVID pandemic but face to face appointments should be available for clinical examination, breaking bad news and at the request of patients.
- Shielding advice and guidelines to be individualised and more detailed.
- Hospital and community prescriptions to be compatible.
  - Consider home delivery service for prescriptions.
- Explore the full COVID impact and long-term support needs of health care workers
- Continue with NHS England Conference calls for charities to maintain information provided to the public through charities virtual and on-line support.
- Identify which COVID induced ways of working (virtual clinics, MDT's' Team Meetings, Support Groups) worked best and establish national guidelines

## Appendix 1

### Mesothelioma COVID Impact Survey 2<sup>nd</sup> August 2020

You will recall back in May Mesothelioma UK completed a survey capturing patient and carers early experiences of the COVID pandemic. This was summarised in a report sent to NHS England directly but also, we contributed it to extensive feedback work by Cancer 52 and a COVID Cancer Intel initiative established by the Cancer Charity Forum.

There has again been a further request for cancer charities, in their advocacy roles, to feed back as much as possible anything relating to cancer patients ongoing issues and experiences.

Mesothelioma UK has therefore put together this survey specifically for our nursing team. We would like to capture as much detail as we can to highlight what is happening to our cancer services from a Mesothelioma patients' perspective and also to capture the challenges you and your clinical teams are continuing to have.

We would like every member of our nursing team to complete the survey. Be as honest and detailed as you can but please keep your responses short as we want to turn this survey around in 10-14 days.

1. Have patients diagnosed over the last 4 months told you about barriers, challenges or difficulties they had seeking advice or getting referred or investigated? Please share details of these here.

2. What is the experience of mesothelioma patients being cared for by your clinical team in terms of accessing:-

Test Intervention or treatment	No disruption there has been access throughout	Initial disruption, now fully back on track	There is still some ongoing disruption	This is still not available to our patients	This was not available pre COVID – N/A
Thoracoscopy					
CT Scan					
Surgical Biopsy					
Surgical Resection (EPD)					
Chemotherapy					
Radiotherapy					
Clinical Trials					
Other.....					

3. What are the most common fears or worries patients and their carers have expressed to you?

4. What impact has self-isolation, shielding and quarantining had on patient fitness?

No impact	Loss of confidence	Performance status reduced	Other

5. What impact has self-isolation, shielding and quarantining had on patients' emotional well-being?

No impact	Loss of confidence	Low mood/depression	Other

6. What would your patients and their carers say would be a No 1 priority for improving the current cancer services situation?

7. What has been the most challenging or saddest issue for you with regard to patient care/contact over the last 4 months?

8. Has it taken considerably more effort to keep patient care, treatment and support on track through the COVID pandemic?

Yes Significantly	Yes slightly	No, just the same effort

If yes, please give examples: -

9. In terms of mesothelioma care or treatment (not COVID), if you could implement one thing now, to help your patients with the current situation what would it be?

10. What new ways of working have you implemented during the COVID pandemic? And which would you like to continue with post COVID?

New way of working	✓	continue with this post-covid (yes or no)
Virtual Support Group		
Telephone Clinics		
Video Clinics		
Telephone/video HNA		
Virtual MDT meetings		
Virtual Team Meetings		
Other.....		
Other.....		

11. What are your experiences of remote communication (e.g. video or phone calls) with patients during the pandemic? Can you share any advantages or disadvantages to this for you, patients and carers?

12. What do you understand about patient's current understanding of the NHS shielding advice and gaining access to the Shielding list?

13. Have you had the guidance and resources necessary to meet the needs of your patients over the last 4 months? Give e.g. where necessary.

14. Have you been informed of any difficulties experienced after the death of someone with mesothelioma in terms of funeral arrangements, death certification and coroners?

15. Have you been informed of any benefits/civil claim delays by patients and their carers?

16. On behalf of your patients do you have any key message you would like to share with the National Cancer Programme Team?

17. Is there any other COVID related matter related to you or your patients that you would like to share?

18. Any other comments?

***Thank you team for taking the time to support this work.***