

Impact of COVID Pandemic on UK people living with Mesothelioma

Abstract

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 is desperate. This national survey captures their voice through the responses of 64 people either living, or caring for someone, with mesothelioma.

Summary of findings and recommendations

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 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 a 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 (11).
- Gratitude and admiration for the NHS and concern for health care workers was expressed throughout the survey.

Key recommendations

- Avoid and minimise hospital visits particularly for our most vulnerable cancer patients (elderly/co-morbidities)
- Getting Cancer Treatment back on track for all is essential. Consider home treatment services particularly for our most vulnerable cancer patients.
- Telephone consultations are acceptable (video may be preferable) and should be considered routinely post COVID pandemic. Time for family members/carers should be provided. Adapt communication skills for non-face to face consultations and ensure follow up calls for support is provided. Patients may not be familiar and so will need support with virtual meeting platforms.
- Relaunch of SPL with clearer guidelines and access for patients and health care professionals.
- Hospital and community prescriptions to be compatible. Consider home delivery service for prescriptions.
- Continue with NHS England Conference calls for charities to maintain information provided to the public through virtual and on-line support.
- NHS to reassure cancer patients with incurable tumours that they matter and COVID-19 treatment capacity does not exclude them.

Introduction

Mesothelioma UK is a national charity, embedded in the NHS and dedicated to all matters relating to mesothelioma.

Mesothelioma is a preventable, treatable but sadly incurable cancer that predominantly affects the pleural lining of the chest cavity and it is commonly caused by exposure to asbestos. The UK has the highest incidence of mesothelioma in the world with 2500 people dying each year (CRUK 2020).

The COVID pandemic has had an unavoidable and possibly immeasurable effect on cancer treatment and care. The effect on those people living with mesothelioma is profound; almost unfathomable. Mesothelioma UK and our team of dedicated nurse specialists have been supporting individuals and families in some desperate situations.

The charity has been relaying stories, situations and our understanding of issues as widely as possible to hopefully inform the nations fast-changing response to these unprecedented times. On behalf of the UK Mesothelioma community the charity would like to thank all keyworkers, care, hospice and NHS teams and those at the helm of our country's response.

This survey provides some insight into the effect the COVID pandemic has had on our most vulnerable cancer patients, those living with an incurable, life limiting cancer and their desperation to get care, treatment and support **SAFELY** back on track.

Method

The survey was designed to be brief and direct to minimise the time and intrusion required to complete it. For speed the survey was developed on Survey Monkey and the link distributed via Mesothelioma UK social media platforms and website. A PDF downloadable version was available on request. There were 12 questions in total, 6 required a yes or no response but allowed responders to leave comments and 6 were open ended questions. Narrative responses were thematically analysed. The survey was released on Thursday 28th April. This provisional interim analysis is based on responses received in the first 5 days.

Results

Over a 5-day period 64 people responded to the survey. 35 patients and 29 carers. Current status in terms of treatment, fitness, social circumstances were not requested. A full list of the narrative responses is provided (Appendix 1)

1. Treatment Schedule

50% (32) said their treatment schedule had been affected by the COVID-19 pandemic but it is not known how many responders were in the process of receiving or planning treatment. 23 responders offered insight which included postponement of their chemotherapy or entry into a clinical trial, stopping of treatment early, cancelling of surgery or radiotherapy. Interestingly 2

responders said they were private patients and their treatment schedule had continued.

There were a number of comments from responders about the emotional impact felt: -

He feels he has been relegated to the back of the queue by the NHS

I feel in limbo

I am not able to proceed with my treatment and I feel I have been left in the lurch regarding the way forward

I'm very anxious as I have been thrown a lifeline then it's been taken away.

It's daunting as it's such an aggressive disease

He felt anxious that because continuation of the trial had been postponed, or indeed stopped, that this would impact on his survival

He feels quite anxious about this because he's worried the cancer will progress

2. Impact on hospital appointments and scans

64% (41) of responders said their scans or outpatient appointments had altered. 13 responders added comment about how their CT scans had been cancelled or postponed. Whilst for some this caused anxiety others expressed relief as they were worried about going to the hospital and exposing themselves to greater risk of COVID. 20 responders provided insight into the changes to their appointments which were now by telephone call. This was accepted, and people felt 'ok with it'. A carer commented they found it hard as they could not easily ask questions as the call was to the patient, another missed the face to face contact. Two describe receiving bad news, including receiving a diagnosis by phone which was a difficult experience. A carer described the 'steep learning curve' for her 87year old father having to grapple with skype for the first time. One responded suggested using video conferencing instead of the telephone to allow for some face to face contact.

3. NHS Shielding Patient List [SPL] (formerly known as vulnerable patient list)

Mesothelioma UK have received a number of calls from people struggling to decide if they should be shielding, whether they should be on the NHS list and how to get on it. Understandably mesothelioma does not appear in the risk criteria for the SPL however having spoken to a number of clinical experts we advised patients to seek entry on to the SPL as mesothelioma fits into point 3 of the criteria – *people with severe respiratory conditions*. In supporting contacts to the charity Mesothelioma UK specialist nurses and benefits advisors did experience some initial confusion and difficulties with the SPL.

52% (33) of responders automatically received a letter or text advising them they were on the SPL. For those that didn't a proportion either presumed or were advised by a health care professional they didn't meet the criteria and the patients therefore presumed they didn't need to shield. Others tried themselves to be added to the list or approached a member of their health care team to do it for them. Once the necessary form filling or phone calls had been made some experience a delay in receiving a letter of confirmation.

4. Struggle to get shopping or essential items

28% (18) of responders had struggled to get shopping and essential items such as prescriptions. Many had taken steps to seek help with this including registering on the SPL, accepting support from local community initiatives or from family and friends. Sadly, there was evidence that some patients or their carers were taking risks and continuing to meet their own shopping/errand needs.

One particular difficulty with prescriptions that could perhaps be easily remedied was that hospital issued prescriptions have to be dispensed by the hospital pharmacy. Patients would prefer to avoid/leave the hospital setting and source their drugs, where possible, at a local pharmacy.

5 & 6. Contact with Health Care Team

80% of responders had received contact from a member of their health care team. For a proportion this was routine and in keeping with their usual contact frequency. 24 responders said they had received additional calls from their hospital or community health care team to check how they were or offer COVID-related advice.

61% of responders had contacted a member of their health care team themselves. For a majority (12) this was for advice on symptom management, for others (11) it was for routine matters relating to their care. Advice on hospital appointments (9) and shielding (5) were also reasons people contacted their health care team. One person was particularly distressed to receive a call from their GP purely to discuss Do Not Resuscitate decision making.

7. What have patients done to combat the negative effects of shielding.

Patients and their families describe engaging in a range of activities whilst shielding. Use of social media to keep in contact with family and friends was popular with 19 responders. Other activities included catching up on household chores (12), hobbies such as knitting, gardening, writing (12) and trying to keep fit and taking exercise (11). Trying to establish a routine was important for some responders (5). The quiet time was also used by 2 responders to prepare memory books for grandchildren or writing personal accounts of their life's adventures to give to children.

8. Deterioration in fitness or mental health

The survey asked responders if they had seen a deterioration in fitness or mental health through the period of social isolation or shielding. There were 17 responders who felt there had been a deterioration in fitness and 11 who describe a lowering in mood level, feeling depressed or increase in anxiety.

9. Most worrying issues brought about by the COVID pandemic.

When asked what the most worrying issues there were varying responses. Missing family and not being able to have or give a hug was difficult. The most common (20)

was worry about treatment and whether or not their mesothelioma getting worse. Responders (18) were also very worried about being exposed to and catching COVID-19 and even more devastating there was genuine fear expressed by 11 of not being treated if they contracted COVID-19. Individuals felt they wouldn't stand a chance and describe feeling helpless, unimportant and relegated to the back of the queue. Sadly, responders (6) describe sadness and frustration at having to spend possibly their last months in lockdown, unable to see loved ones and make memories, worried the mesothelioma will lead to their death without seeing their family.

*Being terminally ill I do think sometimes it would be better getting the virus hoping it finished me of quick
Being told my husband (the meso sufferer) would not be treated with a ventilator if he caught COVID-19.
Not a lot.....honestly feel like it doesn't matter that much if I get the virus or not!
Missing my family during the remaining life I have left. Cheated but can accept why.
I may not have long to live and lockdown could be the way I spend the rest of my life.
The last months when I feel well, I can't do what I enjoy, and I will die unable to be with my family.
Treatment postponed has caused loss of hope, loss of opportunities to memory make with family - feels like a
loss on top of loss on top of knowing your life is limited*

10.What has been most helpful or supportive.

Family presence and support was found to be the most helpful (20). Contact from health care professionals (11) and the updates, support and information provided through the UK's online mesothelioma community (11) were also appreciated. Help from local community or council initiatives particularly with organising prescriptions (6) and access to on-line shopping including supermarket priority lists (5) were included in the narrative responses.

Just one negative comment was made about a lack of support – *“Nothing [was helpful or supportive] as absolutely no support received”*.

11.What priority, as part of the COVID-19 response would you like the NHS to address?

Responders had a number of suggestions for the NHS to address as part of the COVID-19 response. The most common request (17) was for cancer treatment to resume as soon as possible. They also requested (7) the SPL were reviewed to ensure it was more efficient and perhaps user friendly. Reassurance from the NHS that cancer patients matter (3) and are not “bottom of the pile” and receiving telephone contact (3) from the hospital were suggested too.

Responders were keen to see NHS staff and service needs, with particular attention to PPE, were addressed (10) and the search for effective COVID-19 treatments (10).

12. Responders were invited to add any other comments they wanted to share.

This general question saw more comments about confusion with the SPL and concern about access to treatment. There was a comment too about being seen as an individual and not to generalise. It also, without prompting, contained a number of comments expressing gratitude. Thanking Mesothelioma UK for completing the survey and

hoping it led to their voices being heard. There was also gratitude for the NHS as a whole and how care has been managed through the most challenging of times.

In the most desperate times, the NHS has ever faced, you have served us with immediate professionalism and the highest level of care and attention. My Dad died of Mesothelioma at the end of March at home as he wished for, in no pain, with no distress and with dignity and I will forever be grateful to you for this.

Acknowledgements

Thank you to all those that took the time to complete the survey. Thank you to Mavis Nye for her help with the survey content and distributing the survey.

References

<https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/mesothelioma>

Appendix 1

Impact of COVID Pandemic on UK people living with Mesothelioma

1. Has your treatment schedule been affected by the COVID-19 pandemic?

No 51% Yes 49%

Patient	Carer/ Family Member / Friend
<ul style="list-style-type: none"> • Face to face consultations have been replaced by telephone ones. No problem. • District nurses have had to train my wife to drain my chest, in order to avoid visiting the home and risking infecting us. No face to face contact with oncology, HASAG, Macmillan or my GP so far. - Diagnosis given on 16 March. All contact by phone. Chemo treatment could be dangerous at present. • Trial cancelled for the time being. No CT scans being done so don't know my present condition. • I have completed the first part of the treatment, 3 rounds of chemotherapy and after a laparoscopy have been recommended as suitable for 2nd part of treatment which is an operation. I have been told that the operation is very successful and can lead to remission of the cancer. The operation has been put on hold indefinitely due to Coronavirus and I am worried about my future. • 3 monthly appointment with Lung Specialist & CT scan postponed. • Denim trial suspended • I was due to have some radiotherapy but it was cancelled. • Chemotherapy has been stopped until further notice • Port main treatment pain management, no face-to-face meetings with Palliative Care team. • Chemotherapy postponed. • Not on treatment • My trial has been stopped until this is all over • we are private patient so this is probably why nothing has changed • As my tumours have grown I was going to have radiotherapy and chemotherapy. • Last scan showed progression. Oncologist rang to say I would be called back in 8wks. Very vague phone call • Scans have been cancelled • I was supposed to start a new trial at Leicester, the signing was cancelled 3 weeks on the trot then the trial date ended. Now waiting for a call from Derby about putting me on a holding drug for a while.....that's nearly 3 and 1/2 weeks ago . 	<ul style="list-style-type: none"> • Been in hospital 3 weeks with no visitors allowed and nothing to do and as result really deteriorated • Chemotherapy and planned scan were cancelled • Following surgery mum would usually have been assessed for follow up chemo but has been told this will not happen • Treatment postponed - reason give Lyn is that the risk of catching Covid-19 is high in the hospital • The cancer is currently stable but my grandfather will not receive monitoring for the foreseeable future • Chemotherapy stopped as the result of mesothelioma • All appointments are tel calls now No relatives allowed to attend chemo sessions Husband had severe infection + no beds available in hospital so acute nursing team visited daily to give intravenous antibiotics Has not seen a doctor for months Surgery and pharmacy hours restricted + tel requests only • Taken into hospital six weeks after fourth chemotherapy at end of February. - lack of follow up care from any medical professional. Had become bedridden and had virtually not eaten. Ten days in hospital - eating by end and start to walk with zimmer frame and help. Moved to community hospital for three weeks and having physio ever day. As a result of ward being needed for Coronavirus moved to a nursing home where and physio now stopped so progress to get some quality of life back will be very slow and possibly will deteriorate as will need draining and will need to shield so difficult to move or have these treatments. • No. Sadly my father was told his treatment wasn't working and there was no more they could do. As we entered lockdown Dad was able to remain at home and he received everything he needed by our incredible NHS before he sadly passed. There were no delays in getting Dad anything he needed including a hospital bed. • on private immunotherapy on 3 weekly cycle but now changed to 5 weekly cycle • Due to recommence treatment but all appointments post phoned. We were due a phone appointment from palliative care at Guys but they failed to contact both times the appointment was set • Should have received face to face meetings with palliative care, but these were cancelled. Although husband has occasional chats about his medication adjustments there has been no real informative chat for all of us involved. • Unable to see my clients and friends or run my support group face to face • Mesothelioma diagnosis delivered by phone, rather than face to face. No counselling eg specialist nurse. Dr who made the call was kind but obviously busy so my dad and I didn't feel at liberty to ask more questions. Since then my dad has had no one call on him personally. One phone call made only after I rang the meso nurse for advice about his breathing. Similarly my dad's legal claim had to be done via Skype; a steep learning curve for an 87 year old recently diagnosed with a terminal disease.

- Although my fathers CT scan showed a small increase in thickening attending hospital for more chemo outweighs the benefit and chemotherapy side effects are also closed.

2. Have your hospital appointments for scans or outpatients changed or altered because of the COVID-19 pandemic?
 No 36% Yes 64%

Patients	Carer/ Family Member / Friend
<ul style="list-style-type: none"> • Now having consultations by phone and have had CT scan postponed • I was on the Confirm trial but just prior to the lockdown had had the two weekly treatments suspended due to side effects. Subsequent pre treatment appointments were then changed to telephone consultations with continued suspension of treatments. I also had a CT Scan just as the lockdown was being instigated, this showed some growth which when coupled with the side effects resulted in me being taken off the trial. While I expect that the outcome would probably have been the same I felt the lack of any face to face discussions with the consultant, trials team or Mesothelioma nurse, during these significant treatment changes, was most undesirable. I am aware that specific questions would have been answered over the phone but still feel I would have got a lot more out of meeting face to face, questions often come to mind during discussions. • My visit to Leic Glenfield for consultation after ct scan was changed to a telephone appointment. • Felt in limbo but have had calls from the cancer sister • I am not able to proceed with my treatment and I feel I have been left in the lurch regarding the way forward . No one seems to have any idea when regular treatment will commence. I'm very anxious as I have been thrown a life line then it's been taken away. • Postponed - unavoidable as can not chance catching virus. • 5th Chemo cancelled as denim trial suspended • Scans and meetings all cancelled • Telehline appointment. • Put back for 2 months relieved as worried about going into the scan unit and als having a blood test • Delayed appointment/review, Accepted in view of the circumstances. • No CT scans or face to face appointments • I have an appointment for a scan but I will have to stay in my car and they will phone me when Im ready then I have to go to a ward where they will take my bloods I was told this when I have a phone call from my Doctor • only the palliative care appointment as this is on the nhs • Now having consultations by phone, I'm ok with it it just means you miss the personal touch and forget about things you were going to ask but feel a bit rushed on the phone. • I get three monthly scans to keep track of progress .I'm in early stages so I'm worried about not having these scans • Scan results took 2 months to be read. Appointments are now over phone • Consultation is given over phone now • Phone appointments 	<ul style="list-style-type: none"> • Next mri been cancelled • Hospital appointments cancelled phone appointments now Scans being done at a local Radiology group instead at the hospital • Phone call instead of going to hospital. Thought it was a go idea maybe a video call instead of a phone call if its just a check up with no problem. We often go in between scan appts to see Dr this could be done over the phone then go in if you have problems • My wife has not had any consultation, chemotherapy or scan since the beginning of March. She feels abandoned • Been told we will have telephone consultations for the foreseeable • All treatment postponed- trial information is unclear • His scans won't be as regular. He feels quite anxious about this because he's worried the cancer will progress • He felt anxious and concerned about visiting hospital due to the virus I felt anxious that because continuation of the trial had been postponed, or indeed stopped, that this would impact on his survival as chemotherapy was stopped • Tel appointments only • Draining will be delayed. There was virtually no follow up from main consultant/hospital anyhow so don't think that will alter as they were not doing much anyhow. • Hospice nurse home appointment cancelled, felt anxious about not being in face to face contact. • Told to stay at home and be discharged from oncology and to contact gp if needed. Told no scans will be done • Cancelled until further notice • Consultants appointments via phone, blood test done outside hospital in the 'cancer treatment bus'. • 3 monthly CT scan done at private hospital with no other patients around and segregated from other departments. Feel happy that infection prevention was key. • Due to recommence treatment but all postponed. Quite daunting as it's such an aggressive disease • Phone consultation only before chemotherapy. Very hard for me to ask questions as the wife/carer as the phone call is to the patient only. • My clients report face to face meetings Some clients chemo is still going ahead Some clients scans are delayed • Nothing offered to my dad. See previous response. • My dad attended his scan. He had a telephone call with the results. Usually this is something I support him with as he doesn't always understand everything. Obviously this could'nt happen. If the appointment was by video conference I could also listen in.

3. Did you automatically receive a letter or text advising you were on the NHS Shielding list?

No 48% Yes 52%

If No, What action did you take ?

Patient	Carer/ Family Member / Friend
<ul style="list-style-type: none"> Have gone into respite care for twelve weeks so wasn't worried. I completed the NHS feedback form but have had no reply Told my palliative nurse who arranged for me to receive a letter. Spoke to the palliative care nurses and my GP surgery and .gov. Still have not received the official letter from NHS England. I registered on line . delayed letter receive. Entered on line and rang the doctor twice,said there was a backlog so still waiting!! I was advised by my nurse that as I was not having treatment I was not classed as hi risk, so I registered on the government site who also said I was not classed as high risk. Yes not easy as not having chemotherapy or radiotherapy although still having cancer I registered online , then I got the government letter I live in Glasgow was told the shielding list was for england only I registered myself online about 2 weeks ago but still have not had any letter from the government. However I do know that my name is registered as I have had emails from supermarkets giving me priority online shopping slots for delivery. The supermarkets said they got the info off the government's register for vulnerable people. I have used this service and found it very useful. Anybody know if you can check the register yourself? 	<ul style="list-style-type: none"> We were not aware he should have got a letter and presumed the drs must think he was ok. Yes ,I went on line and registered her. This was quite easy Filled in the local authority form He took action but it took quite a while for us to sort this out. It wasn't easy and he was very stressed about it We didn't. We felt as Dad had been told none of his treatment was working and there was no more that could be done for him, there was no reason to send him a letter. As it was then only a matter of time before we were going to lose him i guess he was exempt from receiving the letter. Yes I added my mum to the list via the governments website Registered through Government website I called the doctor the receptionist said he my husband should be on the list but as he is under palliative care maybe this is why he hasn't had a letter !! Many of my clients haven't been sent the letter No, I just assumed, looking through the list of vulnerable cases, mesothelioma patients weren't included. In Wales it took much longer than England

4. Have you struggled to get shopping and essential items eg: prescriptions?

If yes, what actions have you taken ?

No 72% Yes 28%

Patient	Carer/ Family Member / Friend
<ul style="list-style-type: none"> At the start it was so hard to get a slot but I was able to then book one for 3 weeks ahead. This has now stopped so when I want shopping I have to keep going in with first thing in the morning or late at night and the release the next days slots Its in between when I just want a loaf or milk so My husband chances it and goes when our local shop is quiet. Friends and family have bought food for us Have been speaking to the dr It has been difficult to get on line shopping deliveries but luckily I have family who have been helping out. I do not want my wife to go as she is shielding me. The supermarkets seem to have got more organised and 	<ul style="list-style-type: none"> My father has been delivering food and medication to my grandparents Supermarkets were using gov priority lists but initially only in England. It was only a worry initially when people were panic buying + when daughter had to isolate due to displaying symptoms. Morrison's home delivery of essential is excellent on 03456116111 ext 5 Althou we are able to shop online, there have been times when we couldn't get iy delivered and prescription have been slightly erratic due to the pharmacy being inundated with work. Eventually daughter has had to step in and deliver items etc. Her husband is asthmatic so she has been trying to avoid shopping etc herself

<p>shopping deliveries seem to have been better this week.</p> <ul style="list-style-type: none"> • Prescriptions issued by the hospital have to be dispensed at the hospital pharmacy, which on one occasion meant a family member having to make a 90 minute round trip to collect. On a second occasion the pharmacy sent items by post but they took a week to arrive. Sending the prescription electronically to a local pharmacy would be much more efficient. • Re-registered on gov website and I eventually received emails from supermarkets offering me priority slots. Even then some didn't have any slots available even for vulnerable people 	
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5. Have you been contacted by any of your health care team (GP, District Nurse, Meso UK Nurse, Specialist Nurse, Palliative Care Nurse)?

No 20% Yes 80%
If Yes, Who & why?

Patient	Carer/ Family Member / Friend
<ul style="list-style-type: none"> • Just my GP to talk to me about that dreadful Government DNR. Im so pleased they have stopped doing that now. My wishes are at my local Hospice and my family know my wishes • To suspend my chemo • The lung nurse from my local hospital has recently phoned to check out how I am feeling but I have had no contact from the specialist nurse at the specialist hospital where I am due to have the operation . • Meso Nurse to say that she might be redeployed but the helpline would remain open. GP surgery to check if I needed any help. • Sam at Meso UK • Liz Darlison. This was an arranged telephone consultation regarding a proposed CT scan. Karen Lord. This was a telephone call enquiring about my general health and well being. Also she invited me to take this survey. I have nothing but praise for the NHS staff and this praise goes back many years long before the current crisis. • GP - regarding medication for pre-existing arthritic condition and pain relief. HASAG - discussion about forms to be filled. District nurses - about chest drain. MacMillan nurses - about support. Oncology nurses - contact details. Oncology doctor - letter confirming telephone discussion. • General call about my pain management. • My oncologist and my Meso nurse to check on my condition • Letter informing me I was at risk. Also blood test carried out at home on 3 occasions. • My GP called to check up on me And my lung nurse arranged my port to be flushed and CT scan to still go ahead on the day planned • Letter from GP to self isolate • I took it upon myself to call my cancer nurse and gp • I contacted my GP with a bad cold (I think ???) starting with a sore throat and cough for 4 days then 3 weeks of runny nose severe head aches and tiredness that kept me bed/sofa bound. GP's rang me back and were rather unhelpful and was told to contact them if it gets any worse. • Oncologist for my usual regular consultations prior treatment • Cancer sister but nothing fro Hospital doing the trial. • District nurse phone every week to see how Im doing 	<ul style="list-style-type: none"> • The palliative care nurse has been fantastic • Specialist nurse scheduled a welfare check in • Dad's Palliative nurse visited him at home as usual before he passed away during the lockdown. We also had a home visit from a district nurse. Dad's GP called the house to check how he was and since Dad has passed she's also called my Mum to see how she was coping - amazing! All of this has been absolutely incredible and we will forever be grateful to the NHS for how Dad was monitored from home to ensure he had everything he needed and was experiencing no pain and relatively little discomfort. • Meso nurse just to confirm the ct appt • Just checking in • District nurses come out, GP is going to do a telephone consultation. • We see them regularly anyway • Dr, and Hospice at Home. Only on palliative care as all treatment given from diagnosis as of beginning of June 2015 had been given. There was nothing else that could be given as of 11th of September 2019. Now only had whatever time left. Slow deterioration from this date until became very poorly. Coughed up blood doctor and Hospice @ Home Team decided Hospice best option. 29th of February 2020 went into a hospice. First of its kind in the country where wife as prime carer Was able to do everything. 2 & 1/2 weeks later the Hospice had to close due to the shortage of staff due to the Coved 19 virus. Moved to mother Hospice and was cared for with Wife being able to stay at all time. Passed away on 12th of April 2020. From Epithelioid Mesothelioma. No virus involvement. • Hospital where surgery took place have been in touch advising chemo would be stopped as the result of virus...scan will be arranged at later date • District nurse and local hospice check in with us to see if we need anything • Routine contact with all of them as part of treatment schedule. • Practice nurse from surgery to check everything • Clinical nurse specialist at guys- Rachel, to check in • Hospital appointment consultation call

- Palliative Care Nurse phone to check on my pain, adjusted medicine, type and dose sizes. Feed this to my GP OK and getting these OK from pharmacists.
- Consultant to see how I was doing, discuss treatments and advise about blood results. GP to advise about medication change from Consultant. Consultant from hospice has made three telephone consultations after I was referred before the lockdown by my GP. Meso Nurse regularly texts/rings to see how I'm doing. DNs were coming in weekly to dress/flush PICC line. Surgery Receptionist to advise how to request meds and see if there was anything I needed.
- GP surgery and specialist team rang to check how I was feeling and if I needed anything
- Meso nurse new phone number and nice little note hope your ok and if i need any help. Someone else. Husband took call, said recorded message, but couldn't remember who.
- I had a call from the lung nurses to see if I was ok
- GP- phone appointments following blood tests, has discussed corona generally Meso UK nurse as routine follow up
- Palliative care nurse is available and checked how I was. No contact from GP

- I think they called to check he understood the current advice in his treatment.
- His specialist nurse advised him that he was more at risk and should stay indoors
- Macmillan nurse Angela Charles has been amazing. Due to infection acute nursing team daily for 2 weeks. Oncologist appointment by tel. Hospital dietician
- After phone call to them, Palliative care called to check on his medication and how he was managing. Husband had to instigate contact though.
- District nurse called as we done a chest drain rang to see if we were ok
- Meso nurse, consultant, GP. Just to check in following op and make sure she had help

6. Have you contacted any of your health care team (GP, District Nurse, Meso UK Nurse, Specialist Nurse, Palliative Care Nurse) ? 9 hospital appointments. 5 shielding list/advice 12 symptom management 11 GP/DNs for routine care matters.

No 39% Yes 61%

If yes -Who? And What for?

Patient	Carer/ Family Member / Friend
<ul style="list-style-type: none"> • About 3 times trying to get answers. • Contacted doctor to ask why I wasn't on High risk list • District nurses & GP - supplied chest drain dressing leaks in shower. • District Nurses re PICC dressings Consultant re blood results • GP by phone ref: pain in area of plural effusion. • I have today emailed the specialist nurse to see if she has any update on my operation. • Jenny at darent valley hospital to discuss scan appointment on the 30 May • Lorraine Meso UK and my GP. I also called Mcmillan nurses about appointments with my oncologist • Meso nurse specialist on advice over hospital appointment • My cancer nurse and GP. • My GP to Get more than a months supply of meds • Only my oncologist cancer sister • Palliative Care Nurse to check on my pain and the path to trying to ease it. She is trying to get consultant to make any suggestions. • Palliative care Nurse who I asked regarding appointments. • Re medication and dressings • Sam Westbrooke Meso UK peritoneal nurse to quiry some of my symptoms following my cytoreductive & Hipec surgery. • Seek advice re appointment • To arrange a ct scan due to pain in my lower Chest 	<ul style="list-style-type: none"> • Advice on supporting those who are shielding. • Anxiety control for end of life care • Before lockdown I rang to check if I should self-isolate and they said yes. • Complications after surgery with regard to wound...district nurse visited • District nurse for catheter as having problems with it but told they are bot coming out • District nurse for pain/sickness medication and for pressure sores. • Gp for continually bleeding nose • GPS to request different meds/pain relief. Macmillan nurse for advice Triage nurse at hospital who advised ringing doctor. • I was concerned about my dad's breathing • Medication adjustments • Meso nurse checking when we get the results • Meso Uk nurse to inform her of the passing of husband and to obtain biopsy information for coroner. • Nurse for advice • Once it was obvious there were changes in Dad's behaviour (2 days before he passed) we spoke to his Palliative Care nurse who arranged for a district nurse to visit Dad at home. • Specialist nurse to go through changes in symptoms • The GP to organise medication • To arrange telephone consultation with oncologist

- To ask about the official NHS England letter to say that I am on the at risk list.
- Trials Nurse to arrange medication.
- Yes to ask why I am not high risk

7. Please tell us about anything you have done to try and combat the negative effects of shielding and social isolation?

Patient	Carer/ Family Member / Friend
<ul style="list-style-type: none"> • As I am also a carer for my daughter who has learning disabilities I have had to find things for her to do like gardening and stone painting puzzels cooking ect, and show her how to do these things • Done a lot of work at home and picked up my second novel trying to finish it. • Exercising more than usual. Trying to get a daily routine • Gardening , built an outside Onsen (Japanese hot tub) so we can soak and watch the stars Growing vegetables Cooking more and less pre prepared meals Maybe enjoying more beer than usual Relaxing in the sun Spending time I never thought I'd have with my wife (she is shielding with me) Writing my life's adventures for my kids Zoom(ing!) with kids & parents Quizzes on Microsoft teams Learning to knit ! • general keeping busy sorting jobs around the house skyping family • Hav'nt been out for 5wks only 2wks ahi travelled to Leicester for 1st chemo and hav'nt felt well enough to do much • Have done Zoom with family, church group and book club • Having to keep ones distance from family and friends is strange but necessary but on the plus side it means I can get with my many and varied jobs. I keep telling the car that this easy life it is having won't last. A good sense of humour helps. • Hobbies, gardening, walking and keeping in touch with family. • I have been trying to keep fit by gardening and using an exercise bicycle. I am eating a healthy diet. I like to read and have an iPad. • I have stuck to a routine and Spring cleaned the house and tidied the garden. I go for a walk now and again around my park. I keep in touch with the family by phone. Social Media keeps me in touch with the world. • I walk Around my small garden 100 times a day. I also FaceTime my kids • I'm a distance from my family. Unfortunately have to be alone in lockdown. Phone contact every day • Just trying to stay positive and busy .I live alone so it's a bit daunting .just face timing family and friends and walking round the garden but find night time very lonely • Keeping busy. • Kept busy as much as possible • Kept busy at home • Kept in regular contact with family/friends via text/phone/FaceTime Pottered about doing jobs that I'd put off. Started memory books for my Grandchildren. Gardening Cooking • Listen to BBC radio 3 music. Go for walks up hill to expand collapsed lung - as advised by consultant 	<ul style="list-style-type: none"> • As a family we have made sure there is always a zoom meeting, WhatsApp quiz and daily video contact - support with shopping ensuring essential items and treats - sending photo videos of previous memories • Cant have visitors as in nursing - a time in your life when you need people and you cant see or be with them • Face time family and friends regular phone calls • Face time family. Waved at granddaughter through window whilst family were on a walk. • Follow mavis nye on fb. Keep in touch with family/ friends by tel + WhatsApp but husband too poorly to bother • Going out for a walk every day. • Gone for walks • Got husband to play scrabble at last! What's app video grandchildren more • Had to make most of time in the environment both of us were living in. Was like being in lock. Down within lock down as in the hospice . • Have had family stay • He has been in regular contact with the rest of our family • Husband is building a model boat at the encouragement of our son. Missing going out for walks - although don't think we'd manage much now. • I haven't been able to do anything • I phone every day. My daughters also phone, Skype, text, email. I do my dad's shopping every week and collect his prescription. • I try to keep my husband positive because his cough has gotten worse it makes him anxious • Keeping busy with the garden • Keeping in touch with family via video chat • Lots of phone calls and video calls :) • My husband has Mesosthelioma but has not ventured into any sort of establishment during the lockdown period. I have done the shopping, prescriptions etc for him • No negative effects, at home with immediate family we are all shielding together. Happy to have the time together. • Now have dad and mum living with us so can care for dad rather than him being forced into a home • Speaking to friends on the phone • Switch off the news. In a distressing time as it was, the news has been all consumed by stories of death and suffering which we had to try and avoid as much as possible. • Tried to keep a routine • Trying to work from home and keep a routine • Use of video calls Doorstep deliveries of hot meals for my dad. He liked to eat out a lot and doesn't really cook much so I know he appreciates some meals Encouraging my dad to take on some cleaning activities around the house. This overcame the negative impact of no longer being able to have a cleaner. It also encourages him to get up and do some light exercise so actually this is good. Obviously he can only do this whilst he is well enough but does give him some thing else to occupy his time

<p>surgeon. Enjoy wild flowers in woods - fragrance of bluebells.</p> <ul style="list-style-type: none"> • My wife and I have a renewed interest in our garden and we have had visits from our children albeit from a safe distance • My wife has done all the jobs and I have been self isolating • Not a lot....I honestly feel like it doesn't matter that much if I get the virus or not! • On line social media and quizzes to keep in touch with family and friends.oh and of course the long list of jobs that my wife has given me when I looked remotely better. • Regular hand washing and limited contact to my wife. All shopping left on door step. Wash hands after receiving post. • Spent time with my dog, done some gardening and tried to have a structure to my day • Spring cleaning staying positive lots of FT with grandchildren reading to them and the older ones reading to me • Stayed at home away from friends and family but keep in touch through video call • Supervising diy jobs that the husband continues to do, giving useless advice and tips while he does it! 😊 • Try to keep busy but difficult not being active • Trying to maintain reasonable fitness • Walking and learning new skills. • Working from home provides routine and structure and contact with the outside world Gardening, knitting, cooking all help to relax 	<p>Shopping and medicine deliveries Waving and chatting at his window</p> <ul style="list-style-type: none"> • WhatsApp video calls to family. <p>19 social media 12 Catch up on household chores 11 hobbies 11 Exercise 5 routine</p> <p>Not a lot.....honestly feel like it doesn't matter that much if I get the virus or not!</p>
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8. Do you feel you have deteriorated through this period of social isolation/shielding particularly in terms of your fitness or mental health?

Patient	Carer/ Family Member / Friend
<ul style="list-style-type: none"> • A bit. • Am terminal and getting weaker. Miss family & hugs. Mentally ok but feel it's wasting time I have left. • Definitely fitness as I can't risk going out. I don't have much time and I'm Stuck In when I need to see my kids • Definitely not keeping fit has had an effect on my health and wellbeing. • every day is different but in general ok • Fitness a little • Fitness has suffered a great deal, trying to get mobile is a big problem. • Fitness is a big challenge. I keep loosing weight unless I eat very large portions of carbohydrates. Possibly related to arthritic condition. • Fitness is OK, Menttal health may be deteriorating. • Haven't felt any deterioration but scan will show any different. Go for walk everyday but keep a safe distance from other people • Mental health yes • Mental health. Being told that you have a terminal cancer then being told you have to stay indoors whilst you still have the energy go out and live the rest of your life is difficult to come to terms with. • No deterioration noted, although it is nice to have peace of mind 	<ul style="list-style-type: none"> • As the carer yes as I have lost my beloved husband. • Definitely. Fitness; not doing enough exercise or walking, normally walking 1 mile per day but nothing now. Mental health ok but not talking enough or interacting. • Fitness is a struggle, walking is so important, especially in woodland for the fresh air. • He has been feeling quite down because he can't see the rest of our family • I think my mum has become much more anxious yes • I think that my husband (the patient) has. • It is hard to keep motivated and busy but yoga and gardening helps • My Dad feels lonely and no doubt dwells more on concerns because there is little else to distract him. His natural predisposition is optimistic, so this helps to thwart the downward spiral • My husbands mood can be much lower than normal because he can't get out and about and feels trapped and anxious at times • No. More time to keep an eye on health and fitness. • No. Recovering from op anyway • Not being able to see my family and grandchildren and do the things we planned like fell walking. • Not yet! • Oh yes, son and I are watching the deterioration and feel we can't go much to help. Husband spends a lot of time

<ul style="list-style-type: none"> No I'm trying to keep my fitness up and keeping a clear positive mind No in fact have felt really good No neither , but my cancer is growing and I know I'll need treatment but I'm loving being at home with my wife and dogs, No, but as everyone concerned with future No. No. Luckily I am feeling quite well. I am an active member of our local church and people have been phoning and emailing me. The family keep in touch regularly by FaceTime etc. Not at present. Not really just concerned that everything has been put on hold to accommodate coronavirus it's as nothing else matters. Physical activity is difficult anyway, but I try to get out and about as much as I can with family/friends which I haven't been able to do, so this has had some effect on both my fitness and mental health. Really missing walking and getting out , really missing spending time with my children and family Yes as I was always out and about and travelled a lot, spent a lot of time with family and friends, so mentally I have felt down and physically I have started to feel weaker. Yes have suffered with a lot of anxiety due to not being able to go out and walk the dog or visit my children don't get enough exercise to be able to sleep well at night Yes Im loosing muscle power in my legs. I feel so shut in and very lonely. I hate not seeing my family. I dont understand why I couldnt go out in the car to have a small walk in the country or sea if there was no one else around. I cant imagine doing this till December that just is not fair Yes, limitation of fitness follow surgery. Not been able to exercise fully. 	<p>asleep and is in a lot of pain when awake. We both feel helpless.</p> <ul style="list-style-type: none"> Personally for me now having lost my amazing Dad, it's tough not being able to really get out and about to occupy my mind. I've also been away from my partner now for 6 weeks as I moved home as the lockdown was enforced. My partner was also unable to attend the funeral which is incredibly sad. Probably mental health has been affected, and feel Coronavirus has taken residence over cancer patients and their families Yes- my dad is stuck at home and does like to chat with people and potter around the town and shops Yes, fell more anxious and depressed. Am sitting more so have the sores and now cannot control pain, and I am being told different things by different people. Yes, fitness and motivation- worry about going for a short walk Yes, not walking has really had impact but lucky to live right on beach so see people + hear waves
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9.Particularly because you have mesothelioma what has been the most worrying issue for you caused by the changes brought about by the COVID pandemic?

Patient	Carer/ Family Member / Friend
<ul style="list-style-type: none"> Appointments, treatment delays. Now thinking when we get back home getting supplies in. Will the care package have broken down? Because I have been unwell not being able to get to see a professional doctor for a proper consultation and therefore not knowing if you have or have had the virus Controlling my chest pains. Fear of catching the virus and not being treated/treated aggressively because of my Meso and having a DNR in place. Worry of DN's etc coming into my home with no PPE and possibly infecting me with the virus. Worry of effects postponement of chemo/treatment would have on my Meso. Fear of dying on my own and being cremated with no family members present. Follow up appointments and scans could be effected. Having a worse chest and death sooner than with just meso. Being low priority If admitted to hospital as I have a terminal disease. I feel I am between derby and Leicester hospital in a black hole. 	<ul style="list-style-type: none"> Anxiety Being more likely to be poorly with respiratory problems and needing hospitalisation. Not seeing granddaughter is so hard Catching it Catching it Cessation of treatment and not been able to have a scan Feeling helpless and unimportant He is particularly concerned about being at even higher risk because of the disease, despite being otherwise relatively fit and healthy I am worried about my dad catching the virus and not recovering. I am also worried about his quality of life for the 12 weeks particularly as this could be what is left of his life or at least a significant amount of his life. If Dad was still going through treatment I would have been desperately concerned about any pause in this. I was worried if Dad needed any urgent assistance there may be delay due to the issues our country is enduring, however,

- Having to enter hospital for treatment knowing there are cases of covid within hospital, but glad treatment continuing.
- I am worried the cancer is spreading and I will no longer be a suitable candidate for the operation.
- I have this disease in my lungs and believe if I got covid I would not survive, but still not classed as high risk. I put a DNR in place for my illness but feel if i got covid i would not be treated like others without the disease or DNR
- I worry about the staff who are looking after me and hope that they come through this unhurt.
- If I deteriorated would treatment be available .
- If i got ill i wouldn't get a lot of help, as i am old (68) and got cancer
- Just hospital appointments
- Lack of treatment and lack of communication, in my position being terminally ill I do think sometimes it would be better getting the virus hoping it finished me of quick. I can't see how keeping someone with terminal cancer away from hospital helps...apart from the NHS of cause.
- Lack of treatment available
- Missing my family during the remaining life I have left. Cheated but can accept why.
- My progression has been ignored and no treatments have been offered
- No ongoing treatment or CT scans
- No treatment.
- Not being able to give grandchildren a hug
- Not having my scans is a big worry for me and my family at this time
- Not having treatment is my main worry. I was stable but dont know now and that is fearful. I know if I get the virus I dont stand a chance but Im terminal and this is wasting what time I do have to spare.
- Not hugging or seeing my children (One is a nurse) Trying to quarantine deliveries
- Scared in case you get this virus as it affects your lungs.
- still attend some hospital appointments which involve a 2 hour train journey. I worry being in contact with people also i worry that i may not have long to live and lockdown could be the way i spend the rest of my life.
- That if I catch COVID I probably won't survive it.
- That it I become infected it would mean death
- The fact that I feel so vulnerable yet there's little I can do about it.
- The knowledge that Mesothelioma can be aggressive and fast growing if no treatment is being administered
- To much of an uncertain time left being wasted.
- Weaker immune system and what would happen if I caught Covid
- When Ive felt low not being able to get out and walk my low mood off
- Worried meso hasn't got worse! Last chemo Friday but who knows anxiety sets in
- Worrying about trial continuing Worry should I have to go into hospital

there were absolutely no issues or problems for us which we're incredibly grateful for.

- I'm not the patient but as carer feel we have been left in limbo for support and understanding of where we are in respect of the progression of the illness. Husband was released back to GP and palliative care when the isolation and lockdown started
- **Inability to go out and see family**
- Isolation and health professionals are busy dealing with a Coronavirus. Reluctance to contact anyone in hospital because you are aware their time is taken up with a Coronavirus ..at the same time being very concerned about your own personal circumstances
- My husband who was the patient worried about the family and wanted them to stay home and stay safe. He never worried about himself. I and family were his main concern.
- Not being able to see anyone, dying at home rather than hospice
- Only issue that has concerned us, is being told my husband (the meso sufferer) would not be treated with a ventilator if he caught COVID-19. Seeing as he is good health and a peritoneal patient seems very odd. Apart from stable meso he is fit and in good health.
- That he is missing out on treatment and the opportunity to discuss his concerns with experts and socialise with others in the same situation. He feels he has been relegated to the back of the queue by the NHS
- That my husband has deteriorated so quickly
- The fact that the symptoms are so close to mesothelioma it can be worrying at times
- The fear of catching it / the fear of bringing it home to my mum - as a result I have had to be in total isolation with her and my brother and boyfriend not going to work or shops etc in order to look after mum safely. We are all adults.
- The fear of getting covid husband was in hospital as the lock down started and was told he wouldnt survive
- The high risk to my mum given she is more likely to develop serious symptoms or worse if she catches it
- The last months when I feel well I can't do what I enjoy and I will die unable to be with my family.
- Treatment postponed has caused loss of hope, loss of opportunities to memory make with family - feels like a loss on top of loss on top of knowing your life is limited
- Very aware that he would not recover from COVID = fear facture in general life.
- What will happen if I test positive
- What's going to happen next, the disease progressing
- Worry that if he comes in direct contact with the virus it may further affect his lung capacity

20 worried about disease getting worse, treatment being stopped,
18 fear being exposed to and catching COVID-19
11 were frightened of not beng treated if they contracted COVID-19, individuals felt they wouldn't stand a chance, describe feeling helpless, unimportant and relegated to the back of the queue.

Sadly many responders describe sadness and frustration at having to spend possibly their last months in lockdown, unable to see loved ones and make memories, worried they will die without seeing their family.

10. Particularly because you have mesothelioma what has been the most helpful or supportive thing for you through the COVID pandemic period to date?

Patient	Carer/ Family Member / Friend
<ul style="list-style-type: none"> • Community • Contact with health professionals • Continued treatment and contact from hospital. • Creative ways to keep in touch - was able to make a birthday very special- didn't think this would be possible- family coming together • Daughter keeping in touch and sorting shopping etc • Family in constant touch with sufferer, if no family contact would have felt unimportant...as whole country has been discussing virus, and resources taken up with this ...but at what impact to people who are seriously ill • Getting prescriptions delivered. • Having family close by to help • Internet grocery shopping • Keeping up with the scans • Macmillan nurse has been brilliant • Mavis's facebook groups :) • Medical staff have been so helpful and caring • Mesothelioma uk questions and answers • My wife and hospice staff and knowledge of love of all family were the help and support. • N/A • Not having to go into large public hospitals • Nothing • Nothing and no one outside of our home • Phone call from council to see if we needed any help • Prescriptions now delivered • Supermarket priority list • Thanks from clients who appreciate my support • The initial phone contact from Alison Squib and her help in getting my dad the benefits advice to which he is entitled. • The NHS has continued to serve us fully without delay. Not once were we concerned for the safety of Dad. If he needed anything it was delivered fast - we we're given everything we needed without any stress or worry. • To continue with the chemotherapy. 	<ul style="list-style-type: none"> • Apart from the loss of some of my personal freedoms it hasn't affected me greatly but knowing that these wonderful people are there if I need them is all I need. • Being with my husband my carer and my little dog, and sitting out in a bit of sunshine in the garden, keeping in touch with Meso warriors on Facebook • Dealing with it all myself and keeping positive • Easy access to my treating Consultant and Meso Nurse. • family and friends, weekly shopping slot online • Family! • Following mesothelioma groups on twitter and the support of my family. • Friends and family checking in on me on a daily basis • Getting a regular priority delivery slot from Asda! • Going for walks. • Going out once a week on a Thursday to clap for the NHS as a man sings in our road and I do meet up with neighbours. We space out and I wear a mask and it is wonderful to have company for just half an hour • Had trouble ordering shopping on line but got there in the end oncologist been great and hospital and lasag • Help from lots of people and family • I have found the Tuesday morning question and answer sessions on Facebook with the designated nurse really helpful. It enables me to keep in touch and I don't feel so alone with this problem. • Meso UK • Mesothelioma uk social media groups and live chats. My wife and children • My family • My family. • My palliative nurse and my family & friends phoning. • My son and his partner staying with us and working from home • My wife • My wife , my neighbours , and food parcels from the government • My wife and also the mesothelioma uk updates have helped me along with being able to talk to a newly diagnosed patient being treated in a Barcelona hospital on chemotherapy prior to an operation and provide him with a bit of encouragement. • My wife and children. • My wife and my dog • Nothing as Absolutely no support received • Our respite which allows me to maintain physical health with swimming and walking. • Positive attitude and support of family • Regular communication from DAST • Regular Skype meetings with support group • Social media, Mavis Nye very informative pages & Meso UK social media and live stream. • Staying in touch with our family and friends and keeping up with the news etc regarding the pandemic • The daily updates and help and support from husband • Though not fully controlling the pain, it good to have good contact with my Palliative Care Nurse and she can get action from my GP. • Updates keeping us Meso warriors informed especially the video link

11. Particularly because you have mesothelioma what priority, as part of the COVID-19 response would you like the NHS to address?

Patient	Carer/ Family Member / Friend
<ul style="list-style-type: none"> • A cure for the virus • A safe environment for appointments and consultations when needed • Continue with mesothelioma patients treatments • Continuing treatment for cancer patients • Everyone is classed as priority if they catch this virus maybe Meso sufferers need a higher level of priority • Get cancer patients treatment in virus free centres • Get cancer treatments and trials back on track as soon as possible. • i did have a scare a few weeks ago where i nearly collapsed . My wife rang bleep 500 and was told they would get back to us. They did but it was 2 hours later. Fortunately this time i was okay, • I think they are doing a great job • I would like the NHS to have separate centres for COVID-19 and cancer etc so diagnosis and treatment for other health problems can continue. • If anything, these past few weeks have shown that more funding needs to be directed to social care, mental health and our front line workers • Lack of letter to high risk people....still not got one! Delays in wheelchair repair and Community Nurse response. • Let them know I exist at this point in time. • Maintaining treatments • More testing • No priority expected • Not getting trials or treatments stopped • Nothing at the moment. • Ppe for all carers and staff for the nhs • Put me on a trial that is up and running also to be able to have a CT scan to see if it shows it has progressed or not. • Rapid vaccination program once vaccines have been developed, • Research into vaccine. (Not really NHS) • Saving life's of the infected, but also carry on with the treatments and investigation of these suspected of cancer. • Testing levels • The government register to work better and inform people, not so much for myself but for more lonely mesothelioma sufferers • The priority is look after the staff, give them masks, gowns, gloves, whatever they need and when this is all over remember what they did! • There was a lot of scare mongering in the early days with lots of cancer patients, but in particular those with lung cancers, believing that we were going to be the bottom of the pile when it came to be treated/have access to ventilators should we 	<ul style="list-style-type: none"> • A vaccine • As a friend of sufferer, lam extremely concerned that health professionals have weighed up risk of contracting virus against overall survival rates of sufferers. I feel this is alarming as sufferers have gone through extreme anxiety on getting diagnosis, and followed a treatment plan/surgery, only for this to be stopped or postponed. This could ultimately have catastrophic impact on survival • As patient died there is no answer. • Assessing patients on an individual basis and not a sweeping statement about all patients. • Choice to continue treatment • Ensuring PPE is available to all as there are shortages especially in hospices • Extended lockdown to eradicate a chance of a second peak as seen in other countries • For treatment to still be on going • How can treatment continue Whilst Mak to g a low risk of exposure to coronavirus. • I think a call from specialist / cancer nurse just to check all is well would have gone a long way for my husband as he already feels he is a pain now he feels even less important • I think the NHS is coping as best they can, it is the government that need to address the support they give the NHS • Issuing face masked and gloves • Mental health • More ppe for care homes • More ppe for front line staff, for trials to restart • N/A • No answer • Not being able to have treatment • Resuming treatment for lung cancer patients • Some acknowledgement that he isn't forgotten. A letter or a phone call now and again just to reassure him. • That there are other medical problems beside COVID • The issue of correct medical face mask covering • The NHS did everything for us that we needed. In our opinion the're no more they could have done for us in such desperate times. We felt the NHS treated us as a priority and we were responded to as one every single time we needed them. • To be able to have family round to visit if they are in self isolation as well, so no chance to spread the infection. • Vacinen

<p>catch the virus. I feel the NHS should have addressed our concerns from the onset.</p> <ul style="list-style-type: none"> • They are too busy so I don't feel they can address anything just keep getting them the right PPE and make sure the correct figures are put through to the Government. Fast track and vaccines as they say we are not going to be unlocked until they find a vaccine. Well we know how long it takes to get Trials done so just keep making that a priority. But thank you NHS for all you have done x • To address the situation where treatments are being stopped/put on hold. • To carry on treating cancer patients, they can say what they want but I know of a lot of people that are not being seen as normal. • To get a call to see how we are coping from hospital would have been nice • To keep their staff safe, they do so much for me already • Vaccination research • Why I'm not high risk when I have a severe lung condition and covid would probably kill me. Whether I was having treatment or not. 	
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12. Please feel free to add any other comments you would like to share. Thank you again for completing this survey.

Patient	Carer/ Family Member / Friend
<ul style="list-style-type: none"> • Because of Covid-19 I feel mesothelioma patients have been ignored and to a certain extent left to their own devices • I am worried that many people in the UK will not get the diagnosis and treatment for serious conditions due to corona virus • I don't need to add anything, you will have gathered from my previous comments how much respect I have for the NHS and the people in it. • I have found my whole experience with Mesothelioma to have been well managed . • I have peritoneal meso. I recently had surgery, but am not undergoing treatment. I have been sent the shielding letter, but it's not clear if I should be included. • I hope that everyone is keeping safe with or without mesothelioma • I thought I would have been on the shielding list and my GP agreed but nothing has been suggested or done about • I would like to know of any trials I can go on as the one I am due to go on hasn't been approved I believe. It is as though we all have been forgotten. • Just thanks for what has been done and just maybe improvements can be identified and acted on! • My husband has shielded with me because he was so scared of bringing the virus back into our home with him if he hadn't. Expecting us to distance from one another in the house was near impossible, but being on top of one another day in and day out also causes problems. The guidelines could have been clearer. • Pleased I don't require any treatment at this time • Thank you for this survey it helps to find out just what patients are going through. The main concern was 	<ul style="list-style-type: none"> • As the carer/wife through COVID-19 this has been a most difficult time as due to Mesothelioma. It has taken a long time for coroners to receive all relative information to be able to pass to me so that I could have an interim death certificate to make a funeral. Now trying to make a funeral and everything having to be done over the phone and only been able to have a handful of people and not to be able to grieve with them is most difficult. But I and they have to do what is best and stay safe. • Husband's hospital appointments is not for another few months but would be extremely worried about attending if lockdown still in place • In the most desperate times the NHS has every faced, you have served us with immediate professionalism and the highest level of care and attention. My Dad died of Mesothelioma at the end of March at home as he wished for, in no pain, with no distress and with dignity and I will forever be grateful to you for this. Thank you so much. x • Keep up the great work Mavis X • N/A • Obviously as this virus is unprecedented, resources have been prioritised. I feel strongly however, that each individual who has a health concern, or worse, a mesothelioma diagnosis, then these patients should have had an equal chance of health priority. Each life is precious, especially to fathers, mums, husbands and children and grandchildren • See people as individuals not as one group • Thank you to mesothelioma UK for their amazing support • What a terrible time for anyone to have been delivered the bad news about mesothelioma. I try to support my dad, and he's not a complainer by nature, but I do wish there could be more contact made with him

getting on the list the Government was slow working that one out

- Thank you NHS
- Thanks
- Took ages for gov and doctors to know I am shielded didn't hear a thing until I informed them still waiting for gov food
- Was told by my oncologist consultant that may not get all treatment necessary should I contract covid19 due to meso diagnosis, since heard may not be true but worrying at time
- With the weather like this it's like being on Holliday , so wonderful to hear the birdsong and see spring arrive