MESOTHELIOMA UK

University of Sheffield

MINNOW:

The Mental Health Implications of a Mesothelioma Diagnosis and Developing Resources to Optimise Wellbeing Study

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The Mental Health Implications of a Mesothelioma Diagnosis and Developing Resources to Optimise Wellbeing Study (MINNOW)

1. Introduction

The MINNOW study used a mixture of interview and survey methods to understand the mental health implications of a mesothelioma diagnosis and to develop resources to optimise wellbeing. We wanted to explore how people with a diagnosis of mesothelioma and their informal carers were affected. The study was funded by Mesothelioma UK.

In this report, the term “informal carers” means those who provide unpaid care for a person living with mesothelioma, e.g., partners, spouses, family members, friends and neighbours. We use the term “interventions” to mean strategies and techniques which are used to help mental health and wellbeing.

Mesothelioma

Mesothelioma is a type of cancer which has only one known cause: asbestos exposure[1]. It mainly affects the linings of the lungs and the abdomen[1]. Symptoms do not appear until many decades after exposure[1]. Mesothelioma is not currently curable and life expectancy for those with the disease is usually very limited[2]. The symptoms of mesothelioma, such as breathlessness, cough, fatigue and pain, can be burdensome and difficult to control[3].

Mesothelioma and mental health and wellbeing

Living with incurable cancer can mean that patients and their informal carers are at greater risk of problems with their mental and physical health. They can also be impacted socially and financially. Receiving a diagnosis of incurable cancer can be traumatising, with the uncertainty harming patients’ quality of life. When cancer patients have pain, they may experience depression and anxiety, and feel dissatisfied with their healthcare.

There are several aspects of a mesothelioma diagnosis which potentially combine to make this disease impact strongly on mental health and wellbeing, for both patients and their relatives and friends[4]. The news that someone has this terminal diagnosis can come as a terrible shock. The long lead time from exposure can mean the diagnosis is hard to process, and it often brings difficult questions about relationships with former employers. Mesothelioma may be classed as an industrial injury, with complicated legal implications, such as coroner involvement and compensation claims, often continuing after the patient has died.

The MINNOW study

The aims of the MINNOW study were to:

- Find out what evidence there already is about interventions used by patients living with mesothelioma and their informal carers to manage their mental health and wellbeing (MHWB).
- Understand how mesothelioma affects the mental health and wellbeing of patients and informal carers living with mesothelioma.
- Explore what interventions they are using to manage this.

We designed our study to answer these research questions:

- How does mesothelioma impact on patient and informal carers' mental health and wellbeing?
- What is the scale of mental health conditions in patients and informal carers living with mesothelioma?
- What current psychological interventions are being used by patients and informal carers living with mesothelioma and which do they find most helpful?

The methods we chose to best answer these questions are outlined in the following section.

2. Methods and analysis

MINNOW was a mixed methods study. Before the study began, we arranged ethical approval and agreements for sharing data. In this section, we present the different methods we used to collect and analyse our data.

- Phase 1 was a review of the existing research literature, plus an internet search to find out what online information and interventions people living with mesothelioma had available to support their mental health and wellbeing.
- Phase 2 used a survey.
- Phase 3 used interviews.
- In Phase 4 we joined with practitioners and people living with mesothelioma to develop resources and recommendations. Members of the Mesothelioma UK Research Centre's Patient and Public Involvement (PPI) Panel were involved throughout all stages of the study.

Phase 1: Systematic review

We carried out systematic searches of five research databases to find all the relevant studies published between 2002 and 2022. We evaluated the quality of these studies. We then drew together all the evidence presented by the studies and wrote a summary of our findings.

We also conducted five online Google searches, using convenience sampling, for content on mesothelioma-related organisations' websites mentioning and/or recommending MHWB interventions. We then summarised the findings of these searches.

Phase 2: Survey

The source of data for this part of the study was a one-off survey of mesothelioma patients and their informal carers. A summary of the results is given below. When combined with the interview data, these statistics help to provide a rounded picture. Information about the survey was publicised via the networks and social media of Mesothelioma UK, The Mesothelioma UK Research Centre and UK Asbestos Support Groups. Participants completed the survey either online or on paper.

We collected demographic information (e.g., age, where they lived, type of mesothelioma), plus data on their previous and current use of psychological interventions (e.g., antidepressants, talking therapy). Four questionnaires were used to assess positive and negative aspects of participants' mental health and wellbeing. These were:

- The EQ5D for health-related quality of life
- The Hospital Anxiety and Depression Scale (HADS) for anxiety and depression
- The PCL-5 for psychological trauma (indicating Posttraumatic Stress Disorder)
- The Posttraumatic Growth Inventory for personal growth

Phase 3: Interviews

We carried out interviews, either online or over the phone, with ten patients and 11 carers. We used a flexible set of questions so we could hear what was important to our participants. The interviews, lasting around an hour, were recorded and transcribed. The transcripts were anonymised to keep confidentiality. We developed themes from the interview data in an analysis process involving regular discussions between members of the research team.

Phase 4: Co-production workshops

When carrying out research, it is important to collaborate with those who use it. This enhances the research's relevance and usefulness. So, we held two online workshops. We invited patients living with mesothelioma, informal carers (current and bereaved), clinical nurse specialists and Asbestos Support Group (ASG) professionals. In the workshops we shared our findings and participants shared their mesothelioma experiences.

We explored similarities and differences and discussed areas of shared interest. We considered potential actionable tools that could be used to improve clinical practice and to empower those living with mesothelioma to look after their mental health and wellbeing.

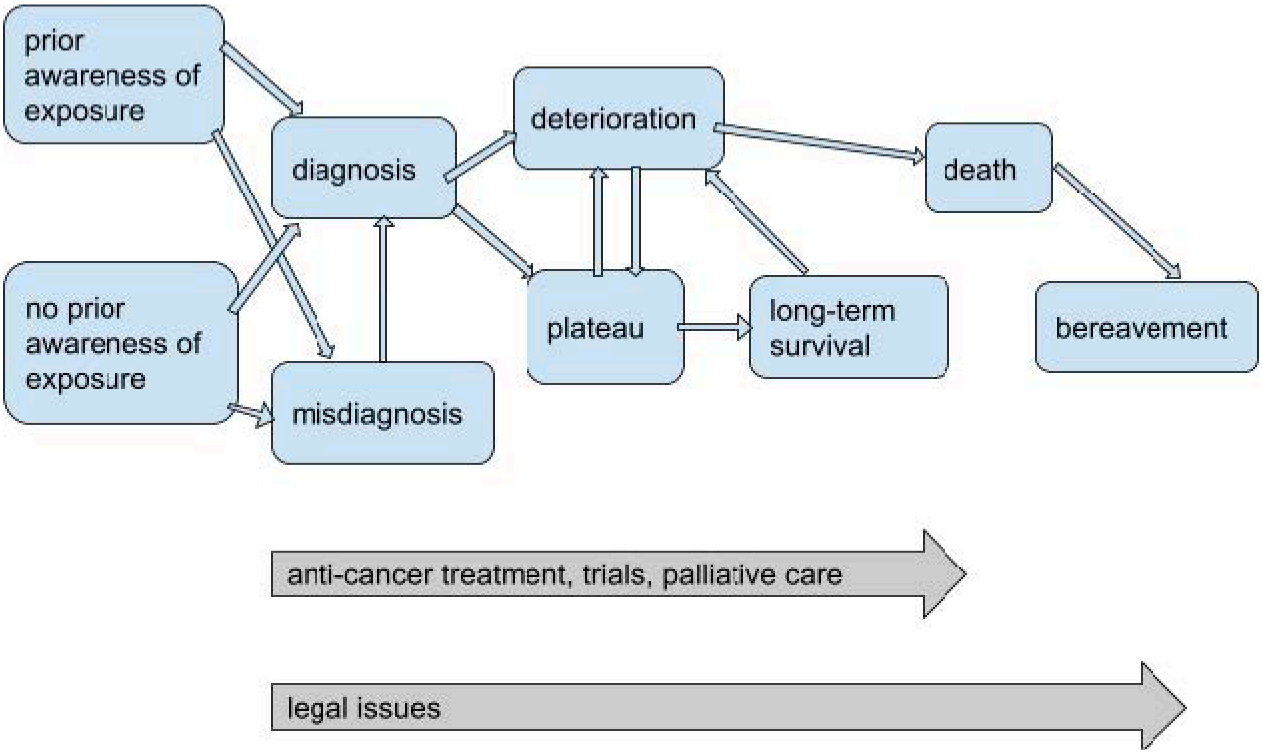
3. Key findings

Phase 1 findings

From the literature searches, we identified 38 relevant articles, mostly from the UK and Italy. Mesothelioma had negative mental health and wellbeing effects on patients and carers, such as trauma and isolation, plus positive effects, such as meaning-making and closer relationships.

The diagram below shows just how complex and variable the journey is for people living with mesothelioma. Any stage in the journey can have an impact on someone's mental health and wellbeing. Knowledge of prior asbestos exposure can have mental health and wellbeing impacts before diagnosis. The legal and financial side of the illness may also mean effects occur after the patient has died. Mental health and wellbeing impacts can be different for carers and patients.

The complex and variable mesothelioma journey



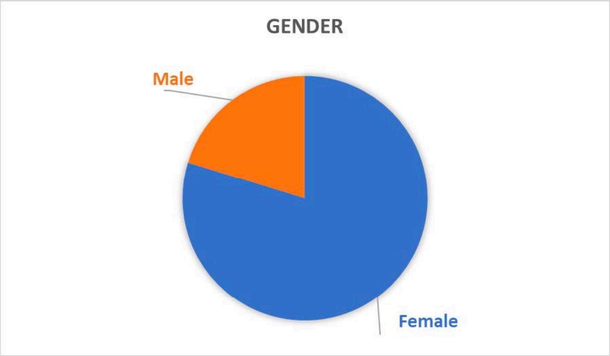
We discovered that people used many different helpful interventions, e.g., complementary remedies, exercise, special diets, creative activities and practical plans. People valued social support highly, which came from friends, relatives, asbestos support groups, spiritual communities and hospices. Psychologists and counsellors provided professional mental health support. Different types of people needed different support, e.g., patients and carers; men and women. None of the identified studies looked at how well interventions worked for those living with mesothelioma.

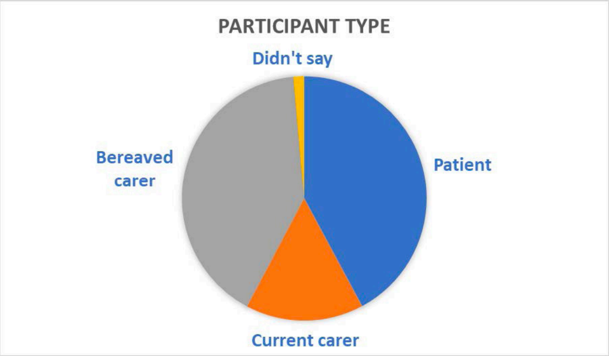
From the Google searches, we found the following:

- Some Asbestos Support Groups (ASGs) focused mainly on benefits and compensation. Others gave detailed MHWB information.
- UK law firms gave no specific MHWB information but signposted to Mesothelioma UK/ ASGs. Some provided patient stories, incorporating MHWB suggestions.
- Most major asbestos-related charities addressed emotional wellbeing, signposting to support, such as ASGs and singing groups.
- All the webinars/videos presented first-hand patient and carer experiences. Most talked about MHWB, describing negative impacts plus helpful interventions/coping strategies.
- When searching online, mainly US websites appeared. These acknowledged the psychological impact of mesothelioma, including on families/carers. They signposted to support in the US, listing types of MHWB professionals plus interventions.

Phase 2 findings

96 people responded to the survey with enough completed answers to be meaningful. Of these, 35 were patients, 47 were carers, and 14 did not say. 76 participants were female and 20 were male.

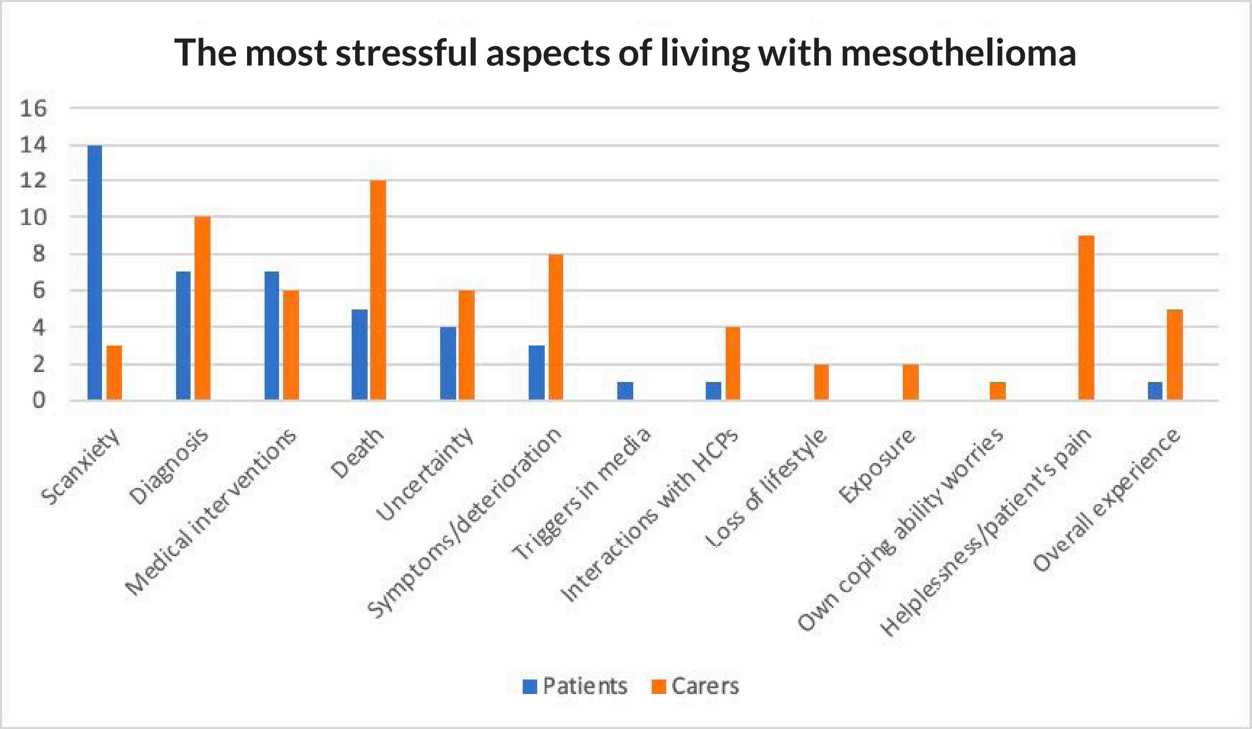




We found some clinically significant results. In the Anxiety and Depression section of the survey, 29 people (30.2%) showed a clinical level of depression, and half the participants had a clinical level of anxiety.

One third of participants scored 44 or more on the PTSD scale, indicating a clinical level of Posttraumatic Stress Disorder (PTSD).

In the Posttraumatic Stress section, participants were asked to identify which aspect of their experience of mesothelioma was the most stressful. The results are shown in the chart below.



The most stressful aspects of living with mesothelioma

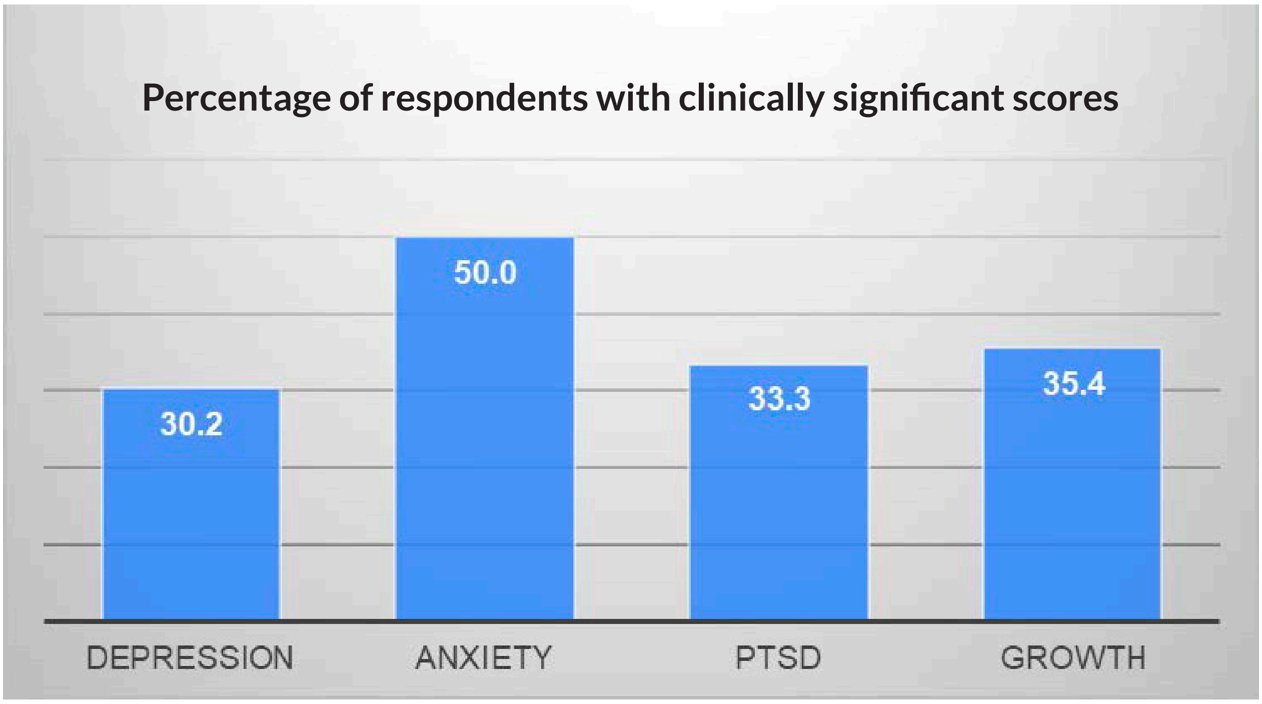
Notes to chart:

- The category ‘Diagnosis’ includes the shocking news, lack of information and support after diagnosis, and the difficulty of getting a diagnosis.
- The category ‘Death’ includes, for carers, their loved one’s death/fears about it, and for patients, fears about dying and news of others dying.
- Some people specified more than one aspect as ‘most stressful’. We added all of these choices into our totals.

> “The feeling of being helpless, having to watch dad lose his positivity and not being able to give him hope or change anything.”

The survey section dealing with Posttraumatic Growth revealed that 34 participants (35.4%) had experienced personal growth in one or more of these areas:

- Relating to others
- New possibilities
- Personal strength
- Spiritual change
- Appreciation of life



When we compared the scores in each section for carers (current and bereaved) and for patients, we found that carers were more likely to report worse depression and PTSD symptoms than patients. Carers also scored lower for wellbeing than the patients they cared for.

Phase 3 findings

In this section, we explain what we found from the interviews. We have arranged our findings under five headings:

1. Carers are important too
2. Self-management strategies
3. Support from services
4. Prognosis
5. Social connections and communication

1. Carers are important, too

Both patients and carers wanted us to understand the importance of carers' mental health and wellbeing needs being met.

- Carers' MHWB needs are different to patients'. Sometimes carers take all their cues from the patient, and go with their way of coping.
- The main focus is on the patient, from professionals and from the carers themselves. Carers may be too busy to notice the mental health and physical effects on themselves. For example, they may do less exercise or eat less well. Carers feel all the focus should be on the patient, none on them. They can be judgemental about their own needs, using terms like 'self-pitying' or 'selfish'.
- Younger carers may be caring for an elderly patient plus the patient's elderly partner, as well as younger family members. Sometimes the patient is already a carer for someone else, which adds complexity to the situation.
- Hospices do a good job in looking after carers' mental health and wellbeing. Carers who had previous experience of living with cancer knew this.
- Carers recommended there should be advice and encouragement early on about looking after themselves. This would include advice about how to handle the issue of receiving money from compensation.

> "[My mental health] didn't seem to be a thing that I needed to consider because I was just there to help dad. It wasn't my condition, it was his, and so mental health-wise, it was not something that either my mum or I really thought about."

2. Self-management strategies

Patients and carers shared with us the many different ways they met their own mental health and wellbeing needs. The following ways were typical.

- *Making social connections* was very important. This included meeting up with friends; having days out; marking celebrations; enjoying alcohol and humour.
- *Taking exercise* was highly valued by many participants, both patients and carers. Dog-walking and cycling were often mentioned.
- *Interacting with nature* was seen as helpful for maintaining mental health and wellbeing. Examples included walking outdoors, and having a view of the natural world through a window.
- *Finding distraction* helped many participants. Typical ways of finding distraction were becoming more productive at work; consciously not thinking about the illness; and volunteering for charities.
- *Gaining a sense of control* was beneficial for several participants. This could mean making a plan; actioning practical adaptations; and getting involved in clinical decisions, such as whether to join a trial. Being able to ensure that their family would be taken care of often helped patients' mental health.

These different strategies often overlapped. For example, arranging to go out cycling with friends in the countryside could involve them all.

3. Support from services

Our participants told us how professional services from healthcare workers, lawyers and asbestos support workers could support patients' and carers' mental health and wellbeing.

- *Effective signposting* to support was vital. This could be done by professionals such as the clinical nurse specialists.
- Professionals *checking in throughout the journey* really helped. This meant carers and patients did not feel abandoned or left in limbo. They felt 'held in mind' and listened to. This could also be important for bereaved carers after the patient had died.
- *Helping people find the right service at the right time* mattered. Transitions in the illness journey can be unsettling and have unexpected effects, e.g., feeling more anxious after surgery than before. Not everyone wants to have counselling, but when it is needed, it should be the right kind of counselling at the right time. One of the benefits of counselling can be learning self-compassion: two of our carer participants said, "Be kind to yourself!"

4. Receiving a prognosis

Being given a prognosis (the length of time someone is likely to live) was revealed as having major impacts on both patients and carers.

- *The language used* by professionals is crucially important. Patients often wanted to have control over this information.
- *Living beyond the prognosis* that someone had originally been given could bring new challenges, as it introduced more uncertainty around being a long-term survivor.

5. Social connections and communication

Having social connections and communicating with other people who have had similar experiences can be very helpful for mental health and wellbeing.

- *The role of support groups* is very important for many patients and carers. They find peer support encouraging and value sharing information and experiences. However, our participants highlighted some issues with accessing support groups. Some people didn't think groups were open to them, e.g., bereaved carers. Others had difficulty attending, such as those with jobs. Some people may not find the format of a support group comfortable, e.g., older men, and those who cope by not thinking about the illness.
- *Other groups provided support* at different times. For example, some bereaved carers benefited by joining in with campaigning groups or groups involved in mesothelioma research.
- *Having a 'meso buddy'* was suggested as helpful. This would be someone with shared experience who could be contacted when needed during the illness journey.
- *Patients and carers have different support needs* was a key message from our participants. One size does not fit all.

Phase 4 Outcomes

From the discussions in the first co-production workshop, we developed a list of ideas for actionable tools.

Ideas for Actionable Tools

1. Support and signposting at diagnosis

2. Buddy system

3. 'What sort of communicator are you?' quiz

4. Wellbeing toolkit

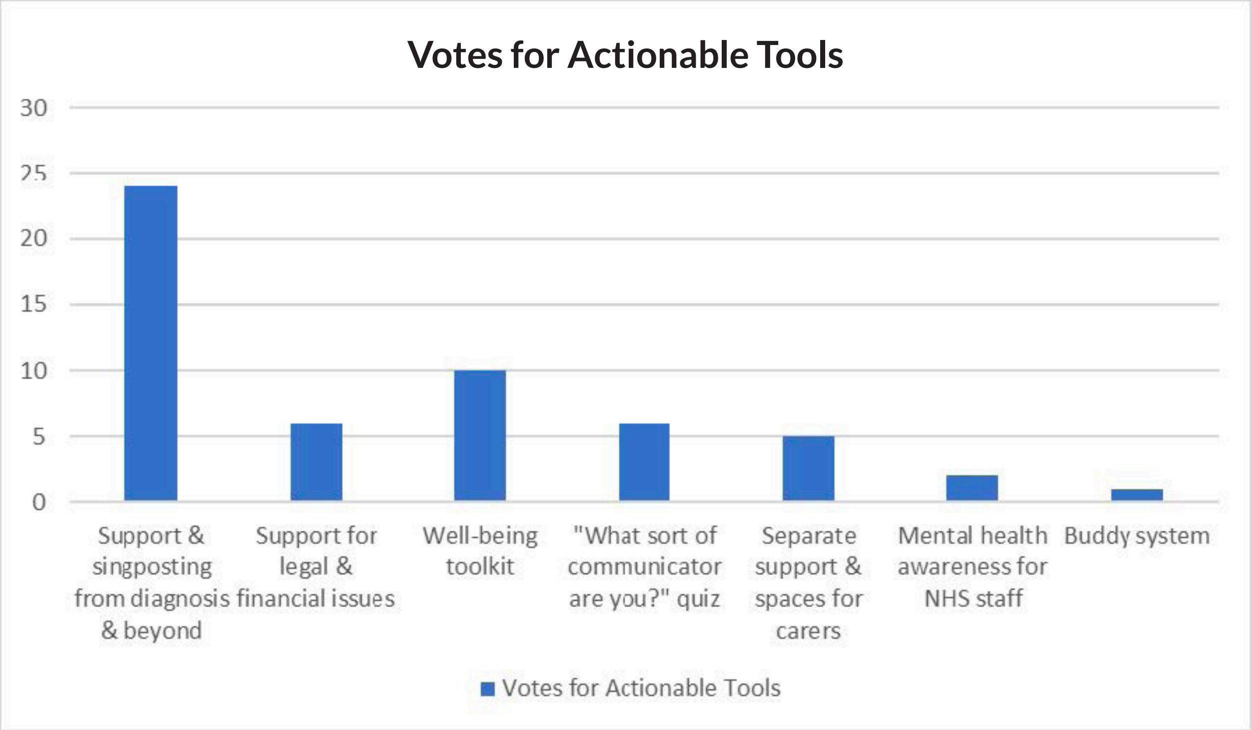
5. Mental health awareness for NHS staff

6. Support for legal and financial issues (including holiday insurance)

7. Separate spaces and support for carers

8. 'Superwebsite'

During the second co-production workshop, after discussion, a vote was taken to find out which actionable tools the group thought were most important. Each participant voted for their first, second and third most important choices. The scores were compiled, with weighting to show people's order of preference. The results were:



The actionable tools with the most votes are shown in the table below.

Actionable Tools	Number of votes
Support and signposting from diagnosis and beyond	24
Wellbeing toolkit	10
Support for legal and financial issues	6
'What sort of communicator are you?' quiz	6

4. Recommendations

Actionable tools for development

The actionable tools provide an evidence-based platform for researchers, charities and other organisations to take forward in the future. We are planning to produce a leaflet for Mesothelioma UK about mental health and wellbeing, to address the actionable tool ‘support and signposting from diagnosis and beyond’.

Recommendations for future research

From the MINNOW study, we have identified the following ideas which researchers could take forward in the future:

- Mental health and wellbeing interventions for patients and carers living with mesothelioma need to be evaluated, so that we can understand what works for whom and when.
- Better understanding is needed as to how people living with mesothelioma can get better access to mental health and wellbeing interventions.
- We found that scanxiety (anxiety about having scans and getting the results) is a significant issue for mesothelioma patients. Research is needed to better understand this experience and its effects.
- Our results showed that psychological trauma was affecting patients and carers living with mesothelioma. Trauma effects were both negative (traumatic stress) and positive (posttraumatic growth). More research into these would inform the provision of helpful interventions.

5. Conclusion

The MINNOW study used a mixture of research methods to gain a rounded picture of how mesothelioma impacts on the mental health and wellbeing of patients and their informal carers, and of the scale of this impact. We were able to identify the different ways that patients and carers were managing their mental health and wellbeing, and which strategies they found most helpful.

By hosting two co-production workshops, we identified four important actionable tools which could be taken forward for development by researchers, charities and other organisations. We also highlighted four gaps in the existing evidence where future research could benefit patients and their informal carers who are living with mesothelioma.

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