

James Lind Alliance Top Research Priorities

The James Lind Alliance publishes lists of research priorities set in partnership with clinicians, patients and carers. This is in order to raise awareness of research questions that are of direct relevance and potential benefit to patients.

In the document the Top 10 Priorities for topics directly and closely related to respiratory medicine have been collated. There is further information about existing evidence and potential outcome measurements available on the JLA website (click the links for each title). This is intended to encourage trainees to develop and submit projects that address questions that are important to the patients we treat.

Title	Date
Asthma Top 10	2007
COPD Exacerbation Top 10	2021
Cystic Fibrosis Top 10	2017
Mesothelioma Top 10	2014
Palliative and end of life care Top 10	2015
Living With and Beyond Cancer Top 10	2018

Asthma Top 10

1. a) What are the adverse effects associated with long term use of short and long acting bronchodilators; inhaled and oral steroids; and combination and additive therapies in adults?

b) What are the adverse effects associated with long term use of short and long acting bronchodilators; inhaled and oral steroids; and combination and additive therapies in children?
2. What is the most effective way of managing asthma with other health problems?
3. What are the key components of successful "Self-Management" for a person with asthma?
4. What is the most effective strategy to educate people with asthma and health professionals about managing the adverse effects of drug therapies?
5. What is the most effective way of managing asthma triggers?
6. What is the role of complementary therapies in asthma management?
7. What are the benefits of breathing exercises as a form of physical therapy for asthma?
8. What type of patient (children and adults) and health professional education is most effective in gaining asthma control?
9. What is the most effective way to manage consultations and asthma control in adolescents and young people?
10. Psychological interventions for adults with asthma?

COPD Exacerbation Top 10

1. What can prevent exacerbations of COPD?
2. What is the best way to tell the start of an exacerbation from day-to day variation in symptoms?
3. What is the best way to tell the difference between an exacerbation and a different cause of changing symptoms in a person with COPD?
4. What is the optimal combination of treatments at COPD exacerbations and what is the best way to decide this for individual patients?
5. What are the associations between co-morbidity (other medical conditions) and risk of COPD exacerbations?
6. Which palliative care regimes should be used to treat an exacerbation, in which circumstances, and what are the potential benefits? ('Palliative care' is defined by the World Health Organisation as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering).
7. Why do some exacerbations recur (happen again) following treatment?
8. What are the risks and benefits of 'rescue packs' used to prevent COPD exacerbations, and how should they be best used?
9. How does the presence of anxiety and depression affect the prevention, diagnosis, and treatment of COPD exacerbations?
10. What are the risks and benefits of long-term antibiotics to prevent COPD exacerbations, and how should they be best used?

The following questions were also discussed and put in order of priority at the workshop:

11. What is the best way to treat breathlessness during a COPD exacerbation?
12. When should a COPD exacerbation be treated with steroids alone, antibiotics alone or both?
13. What is the value of integrated respiratory teams (health-care professionals working across organisations, and/or professions) in preventing COPD exacerbations and COPD admissions?
14. What is the role of nutrition in the prevention and treatment of exacerbations?
15. What factors determine whether someone with a COPD exacerbation can be managed at home or needs admission to hospital?
16. Does regular exercise reduce the risk of having an exacerbation (and to what level of exercise)?

Cystic Fibrosis Top 10

1. What are the effective ways of simplifying the treatment burden of people with Cystic Fibrosis?
2. How can we relieve gastro-intestinal (GI) symptoms, such as stomach pain, bloating and nausea in people with Cystic Fibrosis?

3. What is the best treatment for non-tuberculous mycobacterium (NTM) in people with Cystic Fibrosis (including when to start and what medication)?
4. Which therapies are effective in delaying or preventing progression of lung disease in early life in people with Cystic Fibrosis?
5. Is there a way of preventing Cystic Fibrosis related diabetes (CFRD) in people with Cystic Fibrosis?
6. What effective ways of motivation, support and technologies help people with Cystic Fibrosis improve and sustain adherence to treatment?
7. Can exercise replace chest physiotherapy for people with Cystic Fibrosis?
8. Which antibiotic combinations and dosing plans should be used for Cystic Fibrosis exacerbations and should antibiotic combinations be rotated?
9. Is there a way of reducing the negative effects of antibiotics eg, resistance risk and adverse symptoms in people with Cystic Fibrosis?
10. What is the best way of eradicating *Pseudomonas aeruginosa* in people with Cystic Fibrosis?

The following questions were also discussed and put in order of priority at the workshop:

11. What is the best treatment plan for chronic suppression of *Pseudomonas aeruginosa* in people with Cystic Fibrosis?
12. What is the most effective way of reducing lung inflammation in people with Cystic Fibrosis?
13. What types of psychological and family support benefit people with Cystic Fibrosis to have regular treatment and good quality of life?
14. What is the most effective management of anxiety and depression in people with Cystic Fibrosis?
15. What types or combinations of exercise are most beneficial for people with Cystic Fibrosis at different levels of clinical status?
16. How do we manage an ageing population with Cystic Fibrosis?
17. What are the long term effects of medications for Cystic Fibrosis?
18. What is the best approach for end of life care in people with Cystic Fibrosis?
19. What are the long term effects of CFTR modulators, such as Ivacaftor (“Kalydeco”), (including adverse events, quality of life, Cystic Fibrosis related diabetes, reduction in medications and prevention of complications of Cystic Fibrosis)?
20. Are there differences in outcomes when IV antibiotics are delivered at home compared with in hospital?

Mesothelioma Top 10

1. Does boosting the immune system (using new agents such as PD-1 or PD-L1) improve response and survival rates for mesothelioma patients?
2. Can individualised chemotherapy be given to mesothelioma patients based on predictive factors (e.g. the subtype of mesothelioma (epithelioid, sarcomatoid, or mixed), or thymidine synthase inhibitor status (the protein that drugs like pemetrexed act against), etc)?
3. What is the best way to monitor patients with diffuse pleural thickening and a negative biopsy who are considered to have a high risk of developing mesothelioma (e.g. repeat biopsies, imaging, etc)?
4. In mesothelioma patients, what is the best second line treatment (i.e. what chemotherapy drugs should be used if a cancer has recurred following first line chemotherapy, usually with cisplatin and pemetrexed)?
5. Which is the most effective current treatment for ascites (excessive accumulation of fluid in the abdominal cavity) (e.g. denver shunt, pleurex catheter, etc) in patients with peritoneal mesothelioma?
6. What are the relative benefits of immediate standard chemotherapy compared to a watch and wait policy for mesothelioma patients?
7. For mesothelioma patients, what is the best follow-up strategy post-treatment, to identify and treat emerging side effects and other problems?
8. In mesothelioma, is there a role for intrapleural immunostimulants (a drug designed to stimulate an anti-cancer immune response, such as corynebacterium parvum extract) in addition to any other treatment?
9. Does an annual chest x-ray and/or CT scan and medical examination in high-risk occupations (e.g. carpenters, plumbers, electricians, shipyard workers) lead to earlier diagnosis of mesothelioma?
10. What, if any, are the benefits of pleurectomy (pleurectomy/decortication) compared to no surgery, and which mesothelioma patients might benefit?

In addition to the Top 10, the workshop participants requested that the following three questions also receive a special mention for their importance:

11. Can PET-CT scans (which produce 3D images of the inside of the body) help to diagnose mesothelioma (as well as aiding the assessment of response to treatment)?
12. How can the levels of mesothelin (a protein present in mesothelioma cells that can be measured in the blood) best be incorporated in the diagnosis, response and progression of mesothelioma?
13. What is the best current treatment for breathlessness in mesothelioma patients (e.g. exercise, handheld fans, etc)?

The following questions were also discussed and put in order of priority at the workshop:

14. Is giving a course of chemotherapy to mesothelioma patients before or after surgery beneficial?

15. What is the best current method of managing mesothelioma patients with chronic recurrent pleural effusions (e.g. tunnelled indwelling drain vs pleurodesis and repeated pleural tap)?
16. Should treatment for mesothelioma, if the patient has no symptoms, be given immediately or delayed?
17. Is giving a course of radiotherapy to mesothelioma patients (especially new techniques such as Intensity Modulated Radiotherapy) before or after surgery beneficial?
18. Is giving a course of radiotherapy to mesothelioma patients (especially new techniques such as Intensity Modulated Radiotherapy) before or after chemotherapy beneficial?
19. Would early referral to palliative care be beneficial for mesothelioma patients?
20. What is the value of weekly telephone support for mesothelioma patients during chemotherapy in reducing hospital admissions, side effects and anxiety?
21. What is the current best method (e.g. contrast enhanced MRI vs PET) to accurately assess disease progression in mesothelioma patients?
22. Can rehabilitation be used to improve long term chronic side effects in mesothelioma patients (especially following surgery) - e.g. the use of a comprehensive cancer rehabilitation team of health care professionals?
23. Is there an overall benefit for standard chemotherapy in terms of QALYS (Quality Adjusted Life Years, a measurement that combines survival and quality of life) compared to supportive care alone, for mesothelioma patients?
24. Should radiotherapy be given to mesothelioma patients at the incision site (as a result of surgery or thoracoscopy) to stop cancer cells spreading?
25. What, if any, are the benefits of palliative surgery (partial pleurectomy / surgical debulking) for mesothelioma patients?
26. Should interventions (e.g. cordotomy or radiotherapy) be used to control severe pain after surgical interventions for mesothelioma such as biopsy, VATS, pleurodesis, etc?
27. What is the best current treatment for fatigue in mesothelioma patients (e.g. drug interventions)?
28. What is the best way to monitor patients with pleural plaques (e.g. CT scan) for development of mesothelioma?
29. In mesothelioma patients, what is the best current treatment for sweating (e.g. Cox2 inhibitors)?
30. What is the best treatment to alleviate mucus in mesothelioma patients (e.g. steam inhalation, carbocysteine, physiotherapy, etc)?

Palliative and end of life care Top 10

1. What are the best ways of providing palliative care outside of working hours to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families.
2. How can access to palliative care services be improved for everyone regardless of where they are in the UK?

3. What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients' preferences? Who should implement this and when?
4. What information and training do carers and families need to provide the best care for their loved one who is dying, including training for giving medicines at home?
5. How can it be ensured that staff, including healthcare assistants, are adequately trained to deliver palliative care, no matter where the care is being delivered? Does increasing the number of staff increase the quality of care provided in all settings? To what extent does funding affect these issues?
6. What are the best ways to determine a person's palliative care needs, then initiate and deliver this care for patients with non-cancer diseases (such as chronic obstructive pulmonary disease (COPD), heart failure, motor neurone disease (MND), AIDS, multiple sclerosis, Crohn's disease, Parkinson's disease, dementia, and stroke)?
7. What are the core palliative care services that should be provided no matter what the patients' diagnoses are?
8. What are the benefits, and best ways, of providing care in the patient's home and how can home care be maintained as long as possible? Does good coordination of services affect this?
9. What are the best ways to make sure there is continuity for patients at the end of life, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case coordinator improve [this process?](#)
10. What are the best ways to assess and treat pain and discomfort in people at the end of life with communication and/or cognitive difficulties, perhaps due to motor neurone disease (MND), dementia, Parkinson's disease, brain tumour (including glioblastoma) or head and neck cancer, for example?

The following questions were also discussed and put in order of priority at the workshop:

11. How can people who live alone and do not have any friends or family nearby receive adequate palliative care, particularly if they wish to stay in their homes?
12. What are the best ways for healthcare professionals to tell patients, carers and families that a patient's illness is terminal and also explain the dying process compassionately and honestly? Can literature, including leaflets, be helpful? Who is the best person to provide this information and communication?
13. What are the best ways to facilitate communication across services and between healthcare professionals, including effective IT systems, team meetings and remote technology?
14. What is the best way to give palliative care to patients with dementia and their carers and families? This includes communicating about their diagnosis when they are being cared for at home or elsewhere?
15. How can distress that is not related to pain be best assessed and managed in palliative patients with dementia, Parkinson's disease and other diseases that affect communication?
16. What are the best modes of palliative care in an acute setting, such as a hospital?
17. What are the best ways to diagnose and treat delirium, agitation, distress, and restlessness in people at the end of life? Which sedative drugs (such as midazolam,

haloperidol and levomepromazine) are most beneficial and best in terms of side-effects? Do these drugs have an effect on other symptoms?

18. What are the benefits of, and best approaches to, providing palliative care in care homes, including symptom relief, emotional and spiritual support for patients, carers and families?
19. What are the best ways to make sure that palliative care patients receive adequate pain and symptom relief and which drugs for pain management are best in terms of side-effects, such as drowsiness? What are the best approaches to giving medicines such as morphine, for example using different cannulas, such as BD-saf-T-intima?
20. What are the best ways to manage acute and/or chronic breathlessness in patients with cancer and non-cancer terminal illnesses?
21. What are the signs that a person will die in the next few days and how can detection of these signs be improved? How can families be made aware?
22. Is there an appropriate time to withdraw artificial hydration and nutrition (for example, a drip) and how can this be done sensitively and consensually? What is the best way to communicate with the carers and family about this process?
23. What are the best ways to recognise and treat depression, anxiety and low mood in people who are dying? What are the pros and cons of different psychotherapeutic interventions, including drug therapies, and when is the best time to provide them?
24. What are the best care packages for patients, carers, family and staff which combine health care and social care and take individual prognosis into consideration?
25. Are outcomes (for example, symptom control and incidental prolonging of life) better for terminally ill patients the sooner palliative care is introduced and services are accessed?
26. What are the best ways to support children and young people when someone close to them is dying or has died? This includes communicating with them about the diagnosis and dying process, enabling them to talk about their experience and providing bereavement support.
27. What are the best treatments for nausea and vomiting (including for people with bowel obstruction and those having palliative chemotherapy)?
28. What are the best ways to manage the problems associated with difficulty in swallowing, including drooling and excessive salivation, for patients with Parkinson's disease, motor neurone disease (MND) and dementia who are at the end of their life?

Living With and Beyond Cancer Top 10

1. What are the best models for delivering long-term cancer care including screening, diagnosing and managing long-term side effects and late-effects of cancer and its treatment (e.g. primary and secondary care, voluntary organisations, self-management, carer involvement, use of digital technology, etc)?
2. How can patients and carers be appropriately informed of cancer diagnosis, treatment, prognosis, long-term side-effects and late effects of treatments, and how does this affect their treatment choices?
3. How can care be better co-ordinated for people living with and beyond cancer who have complex needs (with more than one health problem or receiving care from more than one specialty)?

4. What causes fatigue in people living with and beyond cancer and what are the best ways to manage it?
5. What are the short-term and long-term psychological impacts of cancer and its treatment and what are the most effective ways of supporting the psychological wellbeing of all people living with and beyond cancer, their carers and families?
6. How can the short-term, long-term and late effects of cancer treatments be (a) prevented, and/or (b) best treated/ managed?
7. What are the biological bases of side-effects of cancer treatment and how can a better understanding lead to improved ways to manage side-effects?
8. What are the best ways to manage persistent pain caused by cancer or cancer treatments?
9. What specific lifestyle changes (e.g. diet, exercise and stress reduction) help with recovery from treatment, restore health and improve quality of life?
10. How can we predict which people living with and beyond cancer will experience long-term side-effects (side-effects which last for years after treatment) and which people will experience late effects (side-effects which do not appear until years after treatment)?

The following questions were also discussed and put in order of priority at the workshop:

11. What are the most effective ways to stop cancer coming back (combining treatments and life-style changes)?
12. What are the social, financial and economic impacts of living with and beyond cancer – how does it affect families, relationships, finances, work and use of NHS services?
13. What are the best ways to cope with the fear and anxiety about cancer returning (combining self-management approaches, treatments and psychological support)?
14. How can we predict who is at risk of developing mental health conditions in people living with and beyond cancer (e.g. depression) and what are the best ways of supporting those with mental health conditions?
15. What are the best ways to support people living with and beyond cancer to make lifestyle changes to improve their health?
16. If people with cancer are involved in their own healthcare decisions (including participating in multi-disciplinary team meetings with health professionals), does this lead to better outcomes?
17. What are the psychological and social impacts on children who have a parent (or parents) with cancer, and what are the best ways to support those children?
18. What is the best form of rehabilitation and other support to help people living with and beyond cancer return to or maintain their usual activities (e.g. work)?
19. What are the best ways to manage the consequences of nerve damage caused by cancer treatments?
20. How do the support needs of people with rare and less common cancers differ from people with more common cancers, and how are those needs best met?

21. What can be done to reduce and manage the impact of cancer treatments on people's sex lives?
22. What are the best ways to support people living with and beyond cancer who live alone?
23. How is cancer perceived across multiple black and minority ethnic groups – what are the similarities and differences?
24. Can lymphoedema be prevented? If not, how is it best treated/ managed?
25. What is the optimal follow-up approach to detect whether a cancer has come back?
26. What are the spiritual care needs of people living with and beyond cancer?