



SEPSIS RESEARCH
FEAT



James
Lind
Alliance
Priority Setting Partnerships

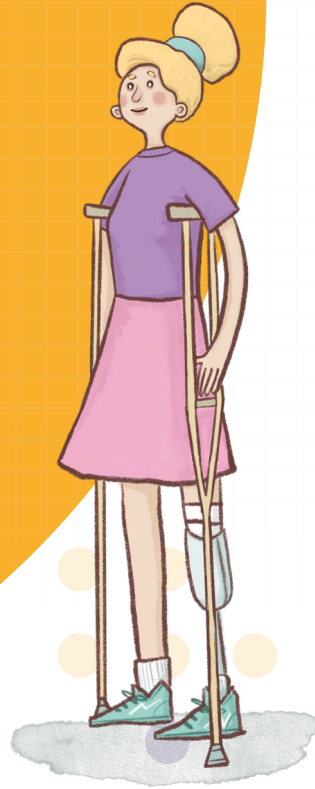
Shaping the future of sepsis research

The sepsis priority setting partnership:
results for future transformative research



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“I was diagnosed with sepsis when I was only 16. It’s very important to me that we carry out more research around sepsis to understand who gets sepsis and why. The top 10 list is a great way to focus research into the areas that are most important to the patients that have had sepsis, the carers that do an amazing job looking after family and loved ones suffering with the after effects of sepsis and also the healthcare professionals who do their best to minimise the impact of sepsis on their patients.”

Walter Hall, patient, Bristol

Foreword

In the UK, great strides have been made in sepsis awareness through government initiatives and NHS training. This has improved survival rates, yet treatments for sepsis largely remain unchanged. The complexity of sepsis, affecting individuals differently, stresses the urgent need for research in genetics, diagnostics and care to save lives and help survivors live better lives.

The sepsis priority setting partnership, funded by Sepsis Research FEAT with input from sepsis patients, carers, family members and healthcare experts, scrutinised 950 sepsis-related research questions, culminating in the identification of 10 unanswered sepsis research priorities.

This report advocates for increased investment in sepsis research from funders, healthcare decision-makers and researchers to fill critical knowledge gaps and mitigate the devastating effects of sepsis. We encourage those affected by sepsis and medical professionals to engage with and support these research priorities. The findings urge those who provide funding and make decisions within the healthcare system to allocate more resources to sepsis research, improving treatment and care while reducing its burden on healthcare systems and society. **This will ultimately save lives.**



Colin Graham
Chief Operating Officer



Professor Joanne McPeake
University of Cambridge

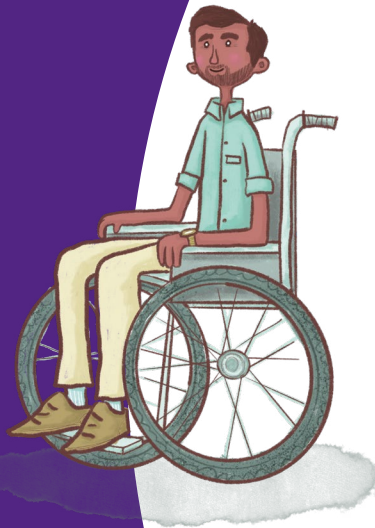
Why Sepsis Research FEAT led the Sepsis Priority Setting Partnership?

Sepsis is a serious problem that causes the deaths of 5 people every hour in the UK. Around half of the people who survive sepsis suffer from long-term physical and mental health issues.

Sepsis Research FEAT's decade-long commitment to funding exploratory studies set the stage for its leadership of this sepsis priority setting partnership.

By uniting patients, carers and healthcare professionals we have sought to understand where best to concentrate research efforts in the coming years.

Our ultimate aim is to stop people dying from sepsis and make life better for the people who are left with the consequences of sepsis.



“It’s been a pleasure to take part in this very important process for sepsis research. I saw how quickly my husband deteriorated with sepsis, so ensuring that the carer’s viewpoint was heard through the process was key for me. I found the process very inclusive of all of the different members of the steering group. Everyone was listened to and was instrumental in getting to our top 10. I really hope that the top 10 questions lead to research that will ultimately stop loved ones dying from sepsis.”

Jane Weaver, carer, Edinburgh

Voices of Impact: Testimonials from the Sepsis Community



“The work that Sepsis Research FEAT is doing in leading this JLA priority setting partnership for sepsis is invaluable and transformational. Findings from this PSP will change the landscape of research into sepsis over the course of the next decade and beyond, supporting delivery of evidence-based clinical practice, and ultimately improving the outcomes for patients and their families who experience this terrible illness.”

**Professor Bronwen Connolly
Queen’s University Belfast**



“As a surgeon dealing with episodes of sepsis on a day to day basis, I’m delighted to see the top 10 research priorities for sepsis. Sepsis is a life threatening condition that we still know little about. We don’t know why some people have a simple infection and recover and some people develop sepsis. The top 10 will give focus to research enabling us to answer these important questions and save more people from dying from sepsis, whilst also mitigating the effects of sepsis on those that survive.”

**Professor Susan J Moug
Royal Alexandra Hospital, Paisley
& Golden Jubilee University National Hospital**



“I’m excited to keep working with the sepsis community to focus on research and policies in these key areas, which will help improve how we treat and care for sepsis. Many people who have had sepsis don’t get enough support to get their lives back on track, and not enough research is part of the problem. I hope that by putting more money and effort into these important areas, we can help more people not just survive sepsis but also recover and live better lives afterwards.”

Mark Oakes, patient, Essex

Establishing Priorities Together

Through a structured process with the James Lind Alliance, Sepsis Research FEAT combined input from all sectors affected by sepsis including patients, carers and family members, to identify research priorities. This inclusive approach ensures that future research aligns with the needs of those most impacted by sepsis.

November 2022

Sepsis Research FEAT Board approved Sepsis PSP budget

June 2023

First steering group meeting consisted of clinicians, patients and carers

April 2023

Appointment of the Sepsis PSP leads – Professor Joanne McPeake, University of Cambridge, Professor Nazir Lone, University of Edinburgh and Dr Bronwen Connelly, Queen’s University, Belfast

September – December 2023

Unanswered questions about sepsis collected through a survey and shared with the steering group members

January – March 2024

Questions checked against the Sepsis PSP scope and existing evidence.

718 NUMBER OF RESPONSES

950 NUMBER OF QUESTIONS GATHERED

250 CLINICIANS OR CARE PROVIDERS RESPONDED

GEOGRAPHICAL AREA

England
Scotland
Wales
Northern Ireland

March – June 2024

950 questions condensed to 54 for launch of second online survey.

941 NUMBER OF RESPONSES

474 CLINICIANS OR CARE PROVIDERS RESPONDED

25 QUESTIONS RANKED & SELECTED FOR FINAL WORKSHOP

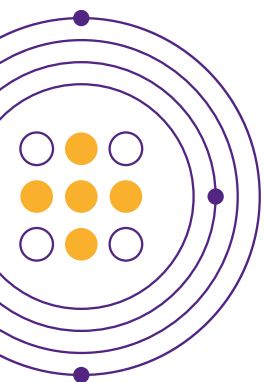
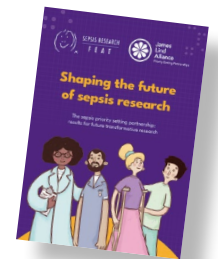
September 2024

Face to face workshop held in Cambridge to decide on the top 10 priorities.



13th September

World Sepsis Day – top 10 launched and publicly available



The Top 10 Research Priorities

We're excited to outline the top 10 research priorities identified, focusing on genetics, diagnostics, prevention, awareness, treatment, and long-term care. These areas represent the most urgent questions in sepsis research today, guiding our next steps towards impactful discoveries.



1 How can the diagnosis of sepsis become faster, more accurate and reliable?

2 What are the long-term effects on the body from sepsis (sometimes called post-sepsis syndrome)? How are these long-term effects best treated and managed?

3 What is the role of treatments other than antibiotics in the care and management of sepsis?

4 Can diagnostic tests be developed for sepsis that can be used wherever the person is receiving care (e.g. in a GP surgery, hospital, ambulance or at home)?

5 Why and how do some people with sepsis become seriously ill very quickly?

6 Would specialist sepsis services improve outcomes for people with sepsis during hospital treatment and for follow-up care?

7 Are there ways to tailor treatment of sepsis to the individual (e.g. based on blood markers or other indicators)?

8 How does an infection lead to sepsis?

9 Would treatment before admission to hospital (e.g. provided by GPs or ambulance crews) improve outcomes for people with sepsis?

10 What are the safest and most effective ways to treat sepsis using antibiotics?

Additional Research Priorities

These responses didn't make the top 10 – but are still important

- 11 Are there ways to prevent long-term effects on the body (sometimes called post-sepsis syndrome) through treatment while the person has sepsis?
- 12 What are the barriers to people with sepsis receiving rapid treatment once diagnosed, and how can these be overcome?
- 13 What factors (e.g. genetics, age or ethnic background) influence whether a person recovers or dies from sepsis, and how well a person recovers?
- 14 What happens during sepsis to cause long-term effects on the body (sometimes called post-sepsis syndrome)?
- 15 How often is sepsis genuinely missed? Why does this happen? What would help health professionals to recognise sepsis (e.g. additional training)?
- 16 How can communication and care co-ordination be improved across the teams of health professionals caring for people with sepsis?
- 17 Are there any aspects of intensive care/hospital treatments that increase the risk of becoming seriously ill with sepsis?
- 18 What impact is Sepsis Six (a set of six steps to be taken within an hour of sepsis diagnosis) having on the recognition and treatment of sepsis?
- 19 Does sepsis affect the immune system in the long term, increasing the risk of infections and/or autoimmune conditions? If yes, how is this best treated and managed?
- 20 Can a test be developed to predict the outcome of sepsis, to identify which people are likely to recover, or become seriously ill or die?
- 21 Does living in poverty increase the risk of developing sepsis and/or lead to worse outcomes? If yes, how and why does this happen?
- 22 What are the best ways to monitor people after sepsis and to provide follow-up care?
- 23 How likely are people to experience repeat episodes of sepsis? Are repeat episodes different to the first experience?
- 24 Does sepsis increase the risk of developing long-term conditions (e.g. heart disease and chronic kidney disease)? How are these conditions best treated?
- 25 Are some people at greater risk of developing sepsis because of their genetic make-up? Does this mean their family members are also at risk?



“Having been diagnosed with sepsis just after I had my second child, ensuring there is more research into sepsis is very important to me and I hope that this will lead to better outcomes for patients of my children’s generation. I really enjoyed being part of the PSP process, particularly being part of the group that went through all of the individual questions we gathered to make sure our summary questions were truly reflective of the sepsis community’s input from the first survey. We want to ensure that future research will prioritise answering the questions that really matter to sepsis patients, their carers and families.”

Emily Perry, patient, Maidenhead



“Today has been incredibly valuable, as I’ve had the opportunity to collaborate with not only healthcare professionals but also sepsis survivors and the families of patients affected by sepsis. Hearing their perspectives has been insightful, helping us understand their priorities. The most important takeaway is that by working together, we can develop solutions that impact us all and advance future treatments and diagnoses.”

Reena Mehta, final workshop participant, London

Our Commitment to Sepsis Research

Identifying these priorities is just the beginning. We are now calling on the research community, funders and policymakers to support these priority areas. Sepsis Research FEAT is committed to leading this charge, ensuring that the sepsis research agenda addresses the most pressing needs and leads to tangible understanding in the genetics of sepsis, its diagnosis, treatment, prevention, treatment, and support.

Sepsis Research FEAT pledges to:

- Work with the sepsis community and healthcare providers to boost funding and advancements in these key priority areas
- Guide research investment to address the issues that matter most to people affected by sepsis
- Make it easier for people who have been affected by sepsis to participate in research

We look forward to engaging with researchers and funders to implement and support the research prioritised in this exercise.



“It has been a privilege for me to support this James Lind Alliance priority setting partnership for sepsis as one of the clinical leads. We were really pleased with all of the interest that the process gathered. We had amazing engagement from both patients and carers, as well as healthcare professionals who work in the field of sepsis. This has allowed us to formulate our “top 10” list of sepsis research priorities. We are hopeful that this will highlight the issues around this potentially fatal condition and encourage more research, now that we have a clear direction for sepsis research. We look forward to seeing the future projects that will address the questions from our top 10.”

**Professor Nazir Lone,
University of Edinburgh**



“Sepsis can be such a devastating condition. I was delighted to join the steering group of the PSP and contribute to the process. There has already been significant research into sepsis, but the top 10 will give us the focus to really get to the bottom of the key questions we need to answer about sepsis. Current research has made excellent progress in specific areas of sepsis research, but we still have a lot to do to stop people dying from sepsis. Minimising the impact of sepsis on those that survive is also very important. The after-effects of sepsis can mean lifelong challenges that severely impact quality of life for sufferers. The project was very well supported by the JLA and Sepsis Research FEAT. I’m excited about seeing the research projects that look to answer these important questions.”

**Professor Paul Dark,
University of Manchester**

A heartfelt thank you...

...to everyone who contributed to the sepsis priority setting partnership. Your dedication and input have been invaluable. Now, at this pivotal point for the project, we invite researchers, survivors, healthcare professionals, and potential funders to join us in this vital work. Together, we can make a difference in the fight against sepsis and help to **#stopsepsisnow**.



Special thanks go to the following people:

Our clinical leads:

Professor Joanne McPeake – University of Cambridge

Professor Nazir Lone – University of Edinburgh

Professor Bronwen Connolly – Queen's University Belfast

Our steering group:

Kimberley Bradley – Edinburgh

Dr Andrew Conway Morris – Cambridge

Professor Paul Dark – Manchester

Walter Hall – Bristol

Mike & Clare Mahoney – Rochdale

Professor Susan Moug – Renfrewshire

Mark Oakes – Essex

Emily Perry – Berkshire

Dr Simon Stockley – County Durham

Jane Weaver – Edinburgh

Yvonne Wiggan – East Sussex

Our workshop participants:

Professor Kenneth Ballie, Caroline Coster, Dr Keith Couper, Professor Paul Dark, Jeremy Dearling, Walter Hall, Lynne Hinchliffe, Clare Hird, James Jackson, Dr Lamprini Kirkineska, Reena Mehta, Angie & Sophy Norman, Mark Oakes, Helen Pocock, Natalie Rushdie, Dr Kordo Saeed, Fraya Searle, Craig Stobo, Dr Simon Stockley, Brian Stoddart, Al Sylvester, Sarah Vaughan, Dr Dorothy Wade, Professor Sarah Wallace OBE, Zoey Warnock, Dr Huw Woodbridge

James Lind Alliance Advisors:

Dr Nahid Ahmad, Dr Louise Dunford and Dr Jo Watson

Special thanks also to

Professor Mahendra Patel – University of Oxford

And to the 1744 people who supported this project from beginning to end, from those that answered surveys to the charity's trustees and beyond.



“Working together is how we managed to set these important unanswered research priorities. I’m really grateful to all the patients, carers, family members and healthcare professionals who gave their time to help make this project a reality.”

**Lynsay Bischoff,
PSP Project Manager,
Sepsis Research FEAT**



For information on participating in future public patient involvement (PPI) or financially supporting Sepsis Research FEAT, please contact info@sepsisresearch.org.uk

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