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ICUsteps Annual Report: 1 February 2025 – 31 January 2026

Registered charity in England and Wales (1169162) and in Scotland (SC054221)

Registered address: ICUsteps, Kemp House, 152 City Road, London EC1V 2NX

Introduction

ICUsteps is the intensive care patient and relative support charity. Run by and for former patients and relatives, our goal is to improve the care and support available to patients recovering from critical illness during their long recovery.

As a charity, we aim to:

- support patients and relatives affected by critical illness,
- support and promote rehabilitation,
- promote recognition of the physical and psychological consequences of critical illness through education of the medical profession and the public,
- encourage research into treatment and the prevention of these issues.

We deliver on these aims through a small team of volunteers, led by a Board of Trustees that includes former intensive care patients, relatives, and healthcare professionals. We have no paid staff and rely entirely on donations and fundraising efforts.

This report sets out the work undertaken by ICUsteps and its volunteers to support and promote the interests of patients and relatives affected by critical illness. It begins by setting out our agreed workstreams for the year were, followed by a more detailed summary of what has been achieved in the year 01 February 2025 to 31 January 2026. We welcome and invite your comments on our work at contact@icusteps.org.

Workstreams for the year 01 February 2025 to 31 January 2026

The Board agreed in 2025 a budget for the year and a series of detailed workstreams to 31 January 2026. These covered:

- Governance and Administration.
- Support Group Network.
- Rehabilitation.
- Research.
- Communication and marketing.
- IT (including web development plan).
- Projects and Campaigns.
- Trustees and volunteers who have expertise in any one area and are willing to support are assigned to the workplan. Progress against the workstreams is reported to each Board

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meeting and will inform the next annual report. There are cases whereby plans change and priorities are moved around.

As a charity we work to the following values:

- Empathy.
- Integrity.
- Communication.
- Community.

These are values agreed by the Trustees as key aspects which we showcase in our work. We continue to integrate these values further into the charity's work for the year ahead.

Rehab Campaign – July 2025

Following on from our successful Rehab Campaign in July 2024 we celebrated another day in July 2025. It was a great celebration of the whole multidisciplinary team, showcasing why they are so important in helping people make their best recovery during and after critical illness.

A recent report by NCEPOD on Rehabilitation following Critical Illness highlights the challenges that people can face after critical illness, and one of the opportunities highlighted in the report was the value and importance of goal setting to help support recovery. This year we felt that anchoring the theme to the forthcoming NCEPOD report and specifically the recommendations around person centred goals and information for patients and families could be the achievable target.

So, to mark #ICURehabDay25, we launched the #MyRehabGoals campaign to coincide with the Women's EURO football tournament from the 2nd to 27th July 2025. The #MyRehabGoal Template was available to use and adapt in whichever way worked for patients, friends and families.

Information

ICUsteps is recognised in the critical care community for the quality and accessibility of its patient-centred information resources. In 2025, we:

- continued to provide guidance, freely available on our website including 13 information sheets, developed by former patients in collaboration with healthcare professionals.
- continued to provide printed copies to ICUs of:
    - '*Intensive Care: a guide for patients and relatives*' – receiving 62 orders and supplying 20,875 booklets.
    - '*Visiting Intensive Care Unit*' an activity book for children who are visiting a special person in an intensive care unit – receiving 40 orders and supplying 2,275 activity books.

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- continued to make freely available via our website translations of the 'Intensive Care: a guide for patients and relatives' booklet to ensure we reach as wide a community of former patients and relatives as possible.
- completed the latest revision of the Guide to Intensive Care https://icusteps.org/information/guide-to-intensive-care
- continued our collaborative working with a national working party to review further supplements that can be downloaded alongside our existing guides. The aim of this activity is to develop a central repository of information for people to access.

Support

ICUsteps has developed a strong reputation for patient, relative and healthcare professional support across the critical care community in the UK and beyond.

As part of this, we enable local intensive care support groups to benefit from the name recognition and reputation we have established by applying to become affiliates of ICUsteps. These groups benefit by sharing information and learning from being part of a network of likeminded former patient peers and healthcare professionals working towards widespread support and rehabilitation aims. They can also contribute to ICUsteps' role as a national intensive care patient organisation by helping us to speak with a louder, and wider representative, critical care patient voice.

There are 18 affiliated groups in England, Scotland, Wales, and the Republic of Ireland.

A list of the affiliate groups, and when they aim to meet, is available at: https://icusteps.org/support/support-groups. Information about forming an affiliate group is available at: https://icusteps.org/contactus.

This year we also continued:

- successful affiliation of ICUsteps Peterborough,
- continued meetings amongst trustees, volunteers and health care professionals who have expressed a keen interest to offer support to the London Community. The desire to help others came about due to lack of support following discharge from hospital. This was highlighted by a trustee and volunteer with lived experience.
- offering support and guidance to enable the collaboration of a working party leading to the London Community ICU Peer Support Group going live on the 06 July 2025. We successfully completed 6 months of the pilot up to November 2025 and agreed that the pilot would continue for a further 6 months to allow more time to network, build on social media and collate data.

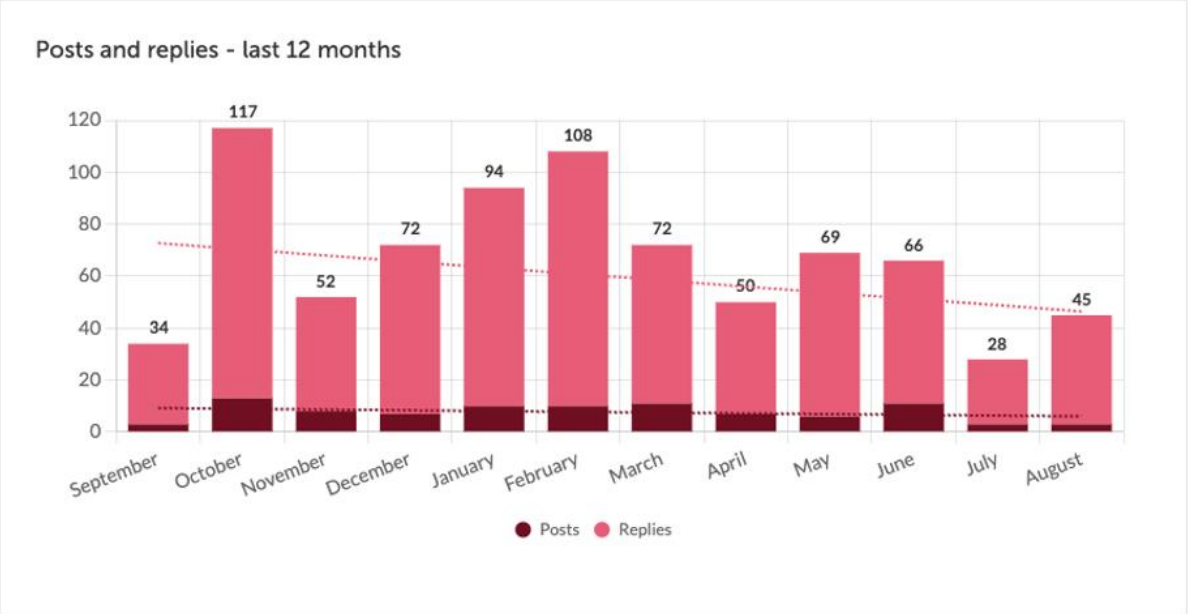
Online community – Health Unlocked

ICUsteps hosts an online moderated community for former patients, relatives, and healthcare professionals at: https://healthunlocked.com/icusteps. Some of our trustees share information and guidance based on their experiences of ICU to support other patients and families. We

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regularly signpost to ICUsteps information pages and share experience. It is important to recognise that everyone is an individual in their ICU experience and rehabilitation journey.

Community membership increased this year, with an additional 352 members between April 2025 and March 2026, with monthly active members remaining broadly steady (226 in April 2025 compared with 223 in March 2026). Notably, each post made generates on average 9x the replies.



All-time posts - by end of last month

2,645

All-time replies - by end of last month

23,550

Awareness and Collaborations

Raising awareness of the impact and consequences of critical illness continue to be a priority for ICUsteps.

- ICUsteps contributed to the NCEPOD (National Confidential Enquiry into Patient Outcome and Death) study examining rehabilitation following critical illness. The final report was published in June 2025 and can be found at: https://www.ncepod.org.uk/ICURehab.html. We have highlighted the report and associated recommendations on our website and via conference attendance. We are actively partnering with the Intensive Care Society (ICS) to support recommendations five and six.

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- ICUsteps has representation at the Community Rehabilitation Alliance, the CCLF Critical Care Leadership Forum and the ICS PRPAG (Patients, Relatives and the Public Advisory Group) this provides us with the opportunity to stay updated, share our knowledge and experience as well as network with partnering and professional groups.
- One of our trustees participated in Intensive Care Society, ICS workshops. They provided detailed comment to the ICS Initial Strategy Refresh 2025.The importance of patient dignity and respect were a key area, along with empathy as principles of care. For example, it is important to align with the individual's pace such as when a person can't speak without difficulty. Also, it is important not to assume there will not be further progress as everyone is different. Other aspects were around building trust, working in collaboration, and the need to set and maintain high standards when delivering patient centred care.
- ICUsteps contributed to the update (version 3) of the Guidelines for the Provision of Intensive Care Services (GPICS), produced by the Intensive Care Society in collaboration with the Faculty of Intensive Care Medicine (FICM). The previous chapter contributed by ICUsteps was about the patient voice. This has been expanded to two chapters including the family voice in ICU. GPICS 3 was published in January 2026 https://ics.ac.uk/guidance/gpics.html.
- ICUsteps is part of the National Rehabilitation Collaborative and the Community Rehabilitation Alliance, working together to implement change and improve the outcomes for all four nations.
- It has been a busy year with the ICUsteps stand as part of our plan to raise awareness, network and share our information and resources amongst health care professionals. Eight face to face study events and conferences were attended including London, Scotland, Blackpool, Birmingham and Cambridgeshire. There was also an invitation to give a presentation online to Barts Trust London.
- Attendance reaffirmed the need to network with health care professionals, they are at the point of care, and it is invaluable for them to know and understand the need for patient information and support.
- James Lind Alliance Delirium in the UK Priority Setting Partnership. The James Lind Alliance is a nonprofit making initiative established in 2004. The PSP brings together patients, carers and clinicians. One of our trustees has been participating in the UK PSP for delirium since August 2025. The PSP on delirium includes online and in person and online workshops and includes people with lived experience of delirium which is typically common in older patients. It is the commonest complication among hospitalised patients over 65. Delirium is a condition that can cause sudden confusion or drowsiness often due to illness or surgery. It can happen to young people.

Research

Research continues to be a key area of activity for ICUsteps, focused on research that potentially benefits current and former patients and their relatives. If you would like to support

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our research work, as a volunteer or researcher, please visit: https://www.icusteps.org/research. In 2025, we:

- responded to 40 requests for help with research studies, including 21 studies that sought input from our research volunteers,
- continued to support our information group of former patients and relatives who review and comment on 'Plain English' summaries of research, including 12 patient information sheets and lay research summaries,
- co-applicant on one research project: REGAIN, trialling virtual exercises for hospitalised COVID patients, looking at Covid-19 ICU patients experience of recovery. The study showed that the virtual exercise classes were effective and was published in February 2024 in the BMJ,
- Jo Latham an ICUsteps trustee is patient representative on the Trial Steering Committee (TSC) for The ROMEO Trial on Health Research Authority (Rest Or Moderate Mechanical Ventilation During ECMO Support) which investigates whether ultra-low frequency (near-apnoeic) ventilation accelerates lung recovery in patients with severe respiratory failure.

ICUsteps Active

ICUsteps Active began its journey in March 2023 with the recruitment of its first cohort of patients to take part in the development of an online rehabilitation programme alongside two experienced ICU physiotherapists and a therapy assistant. ICUsteps Active also has the benefit of an online support group following each exercise session. Two years on we are now at cohort 12, as expected the referral process has increased with demand for rehabilitation and due to proactive networking. The ICUsteps Active team has co-opted two additional therapists to help clear the assessment backlog.

The team continues to actively promote the programme as well as share their experience both online and face to face. Zoe van Willigen and Rachel Devlin presented in Edinburgh at the Association of Chartered Physiotherapists in Respiratory Care.

Rehabilitation remains our priority in supporting patients and families following critical illness, the NCEPOD report is high on the agenda, and we are working hard to support the implementation especially around goal setting and information.

We are grateful to our fundraiser Andrew Mikhail for his continued support. This has led to the opportunity for rehabilitation has helped so many people.

Social Media report and Just Giving

Over the past year, ICUsteps' social media presence has continued to strengthen our visibility within the critical care community, reaching healthcare professionals, survivors of critical illness, families and partner organisations across the UK and internationally. Our channels play an increasingly important role in raising awareness of post ICU-rehabilitation, promoting our resources and amplifying the messages centred on the work we do and the patients we support.

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LinkedIn remains our strongest platform for engagement, generating 14,420 organic impressions in the last year, 605 reactions, 21 comments and 7 reposts. Three major periods of high activity are evident:

- September 2025 – ICU Week and rehabilitation content.
- October 2025 – National Critical Care Conferences and ICUSteps representation.
- January 2026 – rehabilitation messages, NCEPOD recommendations.

Content featuring trustees, volunteers, clinicians and ICUsteps involvement at events across the country consistently achieved high engagement. Posts linked to rehabilitation, recovery and NCEPOD recommendations also performed well on LinkedIn.

Instagram is our second most relevant channel, with a predominantly UK based audience of ICU nurses, health professional and ICU survivors engaging with us. On this channel we have a high number of non-followers engaging with our content, indicating a strong potential for further growth.

Key insights for social media:

- Rehabilitation content is our strongest performer across all platforms.
- Event based posts consistently drive spikes in impressions and engagement.
- LinkedIn is a high value channel for us and leads our communication strategy currently.
- Instagram has potential but needs more content in other formats to succeed (video, reels).
- Our audience is predominantly women, 35-64 with 95% UK based.

Recruitment – Volunteer and Trustee appointments

One trustee was recruited and appointed via a safer recruitment process over the last reporting year. All trustees are interviewed, online disclosure checks are completed, and two references taken up. All trustees undertake safeguarding training as part of their induction.

Volunteers were recruited to support the work of the Charity over the last reporting year. Volunteers are supported via a 'buddy' system and quarterly touch points are scheduled. A volunteer guide has been produced as an introduction to ICUsteps.

There are 14 active volunteers (not including trustees) who also have undergone a virtual interview with a panel of two trustees, and then two references are obtained as part of the recruitment and selection process. Regular volunteer support meetings take place monthly, as an opportunity to update volunteers on ICUsteps news, meet trustees and then have a private space with each other and the buddies to focus on self-care and wellbeing as a volunteer.

Fundraising

ICUsteps received donations from individuals & small groups, plus support from our corporate partner Hamilton Medical.

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We had several fundraisers support our work by setting challenges and fundraisers through our JustGiving page. There were 7 new challenges that encouraged 337 donations to various challenges, such as sponsored walks and marathons.

One of these pages was a Charity of The Year partnership with Maurice Turnor Gardner who raised £5,229 (www.mauriceturnorgardner.com).

The ICUsteps Active project remains funded by our fundraiser Andrew Mikhail.

As a charity run by and for former critical care patients and relatives, we are incredibly grateful for this support.

Thank you to all our brilliant fundraisers.

Governance

ICUsteps is a charity run by and for former critical care patients and relatives. We deliver on our aims through a small team of volunteers, led by a Board of Trustees including former intensive care patients, relatives, and healthcare professionals.

The Board have in place a safeguarding policy which incorporates a 'safer recruitment' approach.

The Board met, remotely and face to face on four occasions in the year to 31 January 2026. At each meeting, the Board receives and considers a report from each office holder (see below), including the Treasurer, and, since October 2021, a risk register. A workplan meeting is scheduled for the new year 2026.

At the AGM in September 2025 a Vice Chair was appointed with the aim of becoming Chair in September 2026. To support this transition, Mo Peskett, the current chair will mentor for a period of 1 year.

The trustees in the year to 31 January 2026 were:

- Mo Peskett (Chair)
- Jeanette Kaye (Vice Chair appointed Sept 2025)
- Joanne Latham (Secretary)
- Dr Christina Jones (retired September 2025)
- Alexander Bastin
- Dr Pam Ramsay
- Sian Saha
- Andrew Davis (Treasurer)
- Dr Pamela Page (Safeguarding Lead)
- Dr Monica Trivedi (Lead Clinician)
- Dr Colette Grundy

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- Sarah Park
- Stella Amor

The trustees are conscious of, and have regard to, their legal responsibilities in relation to ICUsteps. This includes complying with their duty to have due regard to the England and Wales Charity Commission's guidance along with the Scottish Charity Regulator (OSCR) on public benefit when exercising their powers or duties.

This annual report was approved by the Trustees on 22 September 2026 and signed on their behalf by:

Signed by:
Mo Peskett
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Mo Peskett, Chair

Signed by:
Jo Latham
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Joanne Latham, Secretary