



ICUsteps Annual Report: 1 February 2023 – 31 January 2024

Registered charity no: 1169162

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,
- 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 occasional fundraising efforts.

This report sets out some of the work by ICUsteps and its volunteers to support and promote the interests of patients and relatives affected by critical illness in the year to 31 January 2024. It also briefly sets out our agreed workstreams for the year to 31 January 2024. We welcome and invite your comments on our work at contact@icusteps.org.

Rehab Campaign July 2023

Following on from our successful Rehab Campaign in July 2022 we celebrated another day in July 2023 supported by our trustees and health care professionals Kate Tantam and Paul Twose. Our campaign highlighted the lack of support for patients once discharged from hospital and to encourage health care professionals to sign up to a pledge to improve the information they give to people once they are discharged from hospital.

It was a great celebration of the whole multidisciplinary team and showcasing why they are so important in helping people make their best recovery after critical illness. We are delighted with the stats (below). We had three times the number of tweets compared to last year and over double the number of people taking part, including a few units from across the world.

The Numbers

1.050M Impressions

3,152 Tweets

853 Participants

4 Avg Tweets/Hour

4 Avg Tweets/Participant

Tweet!

Twitter data from the #ICURehabDay23 hashtag from Sat, June 24th 2023, 12:45PM to Mon, July 24th 2023, 12:45PM (Europe/London) – Sympplr



Information

ICUsteps is recognised in the critical care community for the quality and accessibility of its patient-centred information resources. In 2023, we:

- continued to have available for free on our website thirteen 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' and 'Visiting the ICU' (for children).
- developed EOL (End of Life) information by Catherine White (ICUsteps Trustee and Information Manager) alongside co-authors Dr Natalie Pattison, Dr Joe Cosgrove, and Dr Kathryn Mannix. This information covers what happens when someone might be at the end of life in an ICU, what to expect and how relatives, family and friends can support the patient and themselves. This document is now available on our web site and as a PDF for Intensive Care Units to use via this link: <https://icusteps.org/information/information-sheets/end-of-life>
- continued to have available on our website translations of 'Intensive Care: a guide for patients and relatives' to ensure we reach as wide a community of former patients and relatives as possible.
- saw our nutrition information (developed in collaboration with British Dietetic Association) included.

Support

Since starting as a local group in Milton Keynes in 2005, 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, inform, and learn 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, more representative, critical care patient voice.

There are 20 affiliated groups in England, Scotland, Wales, and the Republic of Ireland. The pandemic brought significant challenges for these groups, with face-to-face meetings having to be postponed at a time when they were most in need. Thankfully, many of the groups were able to use remote 'meeting' solutions to continue their work by bringing together and supporting former patients, relatives, and healthcare professionals in the critical care community. We are pleased to see that groups are returning to face-to-face and/or hybrid meetings.

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:

- Began introductory 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 because the lack of support following discharge from hospital was highlighted by a trustee and volunteer with lived experience. ICUsteps have offered support and guidance to enable the collaboration of this working party with an aim to plan and facilitate a virtual support group meeting later in the year.
- responded to email contacts from former patients and relatives by providing information and/or signposting to affiliate groups or other organisations, and
- provided online support, guidance, and presentations to healthcare professionals.

We will continue to reach out and share knowledge and learn from the affiliate groups. We have facilitated online meetings to share experiences with existing groups and to enable us to focus on strengthening the Network. Three speaker events were organised in 2023/24 and more discussed for the future.



Through working on the insurance information for groups, the need for a local safeguarding policy was discussed. A small working group was established to scope the charity/voluntary sector to how this could be achieved and to look for transferable knowledge and skills.

Online community – HealthUnlocked

ICUsteps hosts an online moderated community for former patients, relatives, and healthcare professionals at: <https://healthunlocked.com/icusteps>.

Community membership increased this year by nearly 10% with total members rising from 6,859 to 7,534, with monthly active member remaining steady (337 in April 2023 compared with 324 in April 2024).

We thank all those who contributed to the community in 2023.

Awareness and Collaborations

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

- As a member organisation of the CCLF (Critical Care Leadership Forum) ICUsteps endorsed the following document.
NHS England released its Long-Term Workforce Plan (LTWP) on 30 June 2023 (<https://www.england.nhs.uk/wp-content/uploads/2023/06/nhs-long-term-workforce-plan-v1.21.pdf>).
The LTWP models the NHS workforce and demand over a 15-year period but with a clear intention for this to be an iterative process with 2 yearly updates as circumstances change.
- ICUsteps have contributing to the NCEPOD (National Confidential Enquiry into Patient Outcome and Death) study examining rehabilitation following critical illness. The inaugural meeting was held in December 2022. An interim meeting was attended in May 2023 and the project is now live. We have also informed the patient questionnaire and the type and nature of the data being collected. Full publication is scheduled for November 2024: <https://www.ncepod.org.uk/ICURehab.html>.
- ICUsteps Volunteer section was able to assist the ICS (Intensive Care Society) by partnering with the Transformation Implementation team at NHS Elect to improve on existing Allied Health Professionals Capability Framework for Intensive Care, to incorporate all the learnings and change to practices over the past few years and ensure it future proofed. One of our volunteers with lived experience was able to share their experience both from a health care professional and patient perspective.
- ICUsteps has representation at both the CCLF and the ICS PRAG (Patient and Relative Advisory Group) this provides us with the opportunity to stay updated, share our knowledge and experience as well as network with partnering professional groups.
- ICUsteps has represented the Adult Critical Care Services PRG - evidence review and stakeholder engagement.

In summary, episodes of lower nurse-to-patient ratios and increased work intensity for the individual nurse at the bedside are associated with episodes of preventable harm. The evidence supports the critical role of adequate nurse staffing levels in adult critical care settings, not only in improving efficiency and reducing avoidable harm, but also in enhancing staff retention and job satisfaction.

- ICUsteps are contributing to the update (version 3) of the Guidelines for the Provision of Intensive Care Services (GPICS), produced by the 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. Review of the updated chapters is ongoing. No known date for publication yet.

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.



In 2023, we:

- responded to 41 requests for help with research studies, including 26 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 15 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. REGAIN is now finish recruitment and patient follow up finished in June 2023. The study showed that the virtual exercise classes were effective and were published in February 2024 in the BMJ.
- funded one place for the virtual 12th Annual Johns Hopkins Critical Care Rehabilitation Conference, Names were pulled out of a hat from those health care professionals who had registered interest. A nurse from ICUsteps Whitehaven was the lucky winner and was grateful to have the opportunity to share knowledge and network with others. If you would like to support our research work, as a volunteer or researcher, please visit: <https://www.icusteps.org/research>.

ICUsteps Active

Following some challenges to start 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 the exercise section supported by ICUsteps Trustee Christina Jones.

Several groups of former ICU patients have already participated in ICUsteps Active and following the success of these pilot cohorts we plan to work on a live version that can be accessed nationally.

"I feel like I can be myself as you have seen me at my worst...thank you for all of your help and getting me to where I am now, couldn't have done it without you..." (ICUsteps active participant)

Recruitment

Volunteer and trustee appointments

Five trustees were 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.

Eight 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.

Fundraising

ICUsteps received donations from individuals, small groups.

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.

Workstreams for the year to 31 January 2024

The Board agreed in 2023 a budget for the year and a series of detailed workstreams to 31 January 2024. These cover:

- information
- affiliate support groups
- research



- communications
- charity governance.

Progress against the workstreams is reported to each Board meeting and will inform the next annual report.

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.

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, on four occasions in the year to 31 January 2024. 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 2024.

The trustees in the year to 31 January 2024 were:

- Mo Peskett (Chair)
- Peter Gibb (Chief Executive to October 2021)
- Joanne Latham (Secretary) appointed September 2023
- Dave Young appointed September 2023
- Alexander Bastin appointed September 2023
- Dr Pam Ramsay appointed September 2023
- Sian Saha appointed September 2023
- Andrew Davis (Secretary) till September 2023
- Dr Christina Jones (Research Manager)
- Dr Pamela Page (Safeguarding lead)
- Dr Monica Trivedi (Lead Clinician) appointed September 2022
- Phil Smith (Treasurer)

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 Charity Commission's guidance on public benefit when exercising their powers or duties.



This annual report was approved by the Trustees on 24th September 2024 and signed on their behalf by:

Signed by:
Mo Peskett

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Mo Peskett, Chair

Signed by:
Jo Latham

5197B8BB19E446A...

Joanne Latham, Secretary

	Charity Name		No (if any)	CC16a	
	ICUSTEPS		1169162		
	Receipts and payments accounts				
	For the period from	Period start date	To		Period end date
		01/02/2023			31/01/2024

Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts					
Donations	2302.12			2302.12	524.06
Fund raising				0.00	628.80
Bequest				0.00	
Funding donation				0.00	
Presentation expenses				0.00	
Charities Aid foundation				0.00	
Website maintenance				0.00	
ICUsteps active (protected funds)		12309.80		12309.80	
Booklet Orders	3944.00			3944.00	2068.00
				0.00	
Sub total (Gross income for AR)	6246.12	12309.80	0.00	18555.92	3220.86
A2 Asset and investment sales, (see table).					
	0.00	0.00	0.00	0.00	
	0.00	0.00	0.00	0.00	0.00
Sub total	0.00	0.00	0.00	0.00	0.00
Total receipts	6246.12	12309.80	0.00	18555.92	3220.86
A3 Payments					
Stationery and postage	679.39			679.39	644.37
Website hosting & Software	1677.60			1677.60	1763.43
Re branding & advertising	576.00			576.00	
Other	761.33			761.33	206.29
Bank charges	60.00			60.00	60.00
Donation or development work				0.00	
IT Development				0.00	100.00
Training				0.00	61.00
Mail Management				0.00	
Payment for the Hall	85.00			85.00	
Ins/ Legal costs	656.60			656.60	1022.23
Booklet orders/ design work	1814.40			1814.40	140.00
Travel exps ICU Meetings	323.25			323.25	
Travel expenses on behalf of ICU	344.75			344.75	
INACTIC Grant Funding (re imbursement)				0.00	
ICUsteps active expenses		5953.80		5953.80	
Sub total	6978.32	5953.80	0.00	12932.12	3997.32
A4 Asset and investment purchases. (see table)					
	0.00	0.00	0.00	0.00	
	0.00	0.00	0.00	0.00	
Sub total	0.00	0.00	0.00	0.00	0.00
Total payments	6978.32	5953.80	0.00	12932.12	3997.32
Net of receipts/(payments)	-732.20	6356.00	0.00	5623.80	-776.46
A5 Transfers between funds	0.00	0.00	0.00	0.00	0.00
A6 Cash funds last year end			0.00	0.00	
Cash funds this year end	-732.20	6356.00	0.00	5623.80	-776.46

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds	Restricted funds	Endowment funds
		to nearest £	to nearest £	to nearest £
B1 Cash funds	Bank Account	44369.28	0.00	0.00
	ICU Reserve		6000.00	0.00
	Icusteps active		6356.00	
		0.00		0.00
CCXX R1 accounts (SS)	Total cash funds	1 44369.28	12356.00	0.00

	(agree balances with receipts and payments account(s))			
		Unrestricted funds	Restricted funds	Endowment funds
	Details	to nearest £	to nearest £	to nearest £
B2 Other monetary assets		0.00	0.00	0.00
		0.00	0.00	0.00
		0.00	0.00	0.00
		0.00	0.00	0.00
		0.00	0.00	0.00
		0.00	0.00	0.00
	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			0.00	0.00
			0.00	0.00
			0.00	0.00
			0.00	0.00
			0.00	0.00
	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			0.00	0.00
			0.00	0.00
			0.00	0.00
			0.00	0.00
			0.00	0.00
			0.00	0.00
			0.00	0.00
			0.00	0.00
			0.00	0.00
	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			0.00	
			0.00	
			0.00	
			0.00	
			0.00	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
	Signed by: <i>Phil Smith</i> C15064EA8F124B4...	Philip Smith	26/02/24	
	Signed by: <i>Mo Peskett</i> 1213448AD41A474...	Mo Peskett	26/02/24	