

ICUsteps Annual Report: 1 February 2022 – 31 January 2023

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 2023. It also briefly sets out our agreed workstreams for the year to 31 January 2023. We welcome and invite your comments on our work at contact@icusteps.org.

Covid-19 pandemic

The pandemic has affected the population's physical and mental health, and hampered access to care, with continuing staff shortages and restrictions in funding. This brought further significant suffering to many as well as medical, wellbeing and resource challenges to hospitals generally and intensive care units (ICU) in particular, across the UK and beyond.

With infection rates and hospital admissions continuing to fluctuate into the second half of 2022, Covid-19 will have a significant and long-term impact on the physical and emotional wellbeing of former ICU patients, their relatives and healthcare professionals. The pandemic has demonstrated that many more people will need professional and peer support and information throughout their recovery pathway. As we noted both in last year's report and in our successful #RehabsCritical campaign, the ICU journey does not end with discharge to the ward or home: a life saved is not enough. Former patients should be enabled back to a life lived to its best potential through rehabilitation and psychological support. This is how ICUsteps can help.

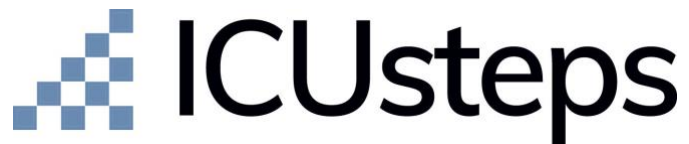
We do this through information, support groups, raising awareness, collaborations and research.

Information

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

In 2022, we:

- continued to have available for free on our website twelve 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).



- Catherine White ICUsteps Trustee and Information Manager is working on an End-of-Life Document alongside co-authors Dr Natalie Pattison, Dr Joe Cosgrove and Dr Kathryn Mannix. This information will cover 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. Once complete this will be available on the web site and as a PDF for Intensive Care Units to use.
- continued to have available on our website nineteen 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.
- our nutrition information (developed in collaboration with British Dietetic Association) was included on the NHS website for helping recovery from Covid <https://www.yourcovidrecovery.nhs.uk/>
- released videos on our YouTube channel about critical care delirium, the experiences of younger adults in ICU and employment and related benefits for former patients and their families.
- The website had over 100,000 page views, a decrease of nearly 10% on the previous year with users and sessions both falling by 12.5% to 30,682 and 40,177 respectively. Positive figures were seen on pages per session (up by 3%), average session duration (up by 11.7%) and bounce rate (down by 2.5%) indicating improved engagement with site visitors. All our information resources are available on our website at icusteps.org.

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 common 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 in 2022.

A list of the affiliate groups, and when they aim to meet, is available at:

<https://icusteps.org/support/supportgroups>

Information about forming an affiliate group is available at <https://icusteps.org/contactus>

In the year, we also:

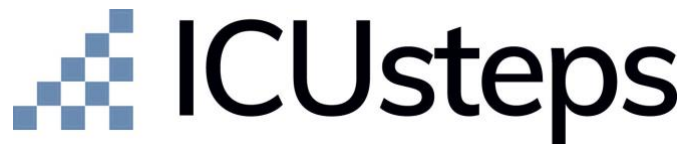
- Responded to email contacts from former patients and relatives by providing information and/or signposting to affiliate groups or other organisations.
- Provided online support, guidance and presentations to healthcare professionals.

We will continue to reach out and share knowledge and learn from the affiliate groups. We have online meetings arranged to share experiences with existing groups and to enable us to focus on strengthening the Network. There are scheduled dates for speaker events which will enable us to support the groups, these will be recorded and banked for support groups to use at their support group meetings.

Online community – HealthUnlocked

ICUsteps hosts an online moderated community for former patients, relatives and healthcare professionals at:

<https://icusteps.healthunlocked.com>



Community engagement decreased this year, most likely in light of the end of the pandemic, with page views down by 54%, sessions down by 46%, users down by 40% and active users down by around 25%. The all-time number of members increasing by almost 8 percent to 6,700. The all-time content increased by 7.5% to 22,048 posts offering peer support and advice about critical illness, recovery and rehabilitation.

We thank all those who contributed to the community in 2022.

Awareness and Collaborations

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

A particular success in 2021 was founding our #RehabsCritical campaign, which aimed to highlight the desperate need to commission services across the UK to support those recovering after critical illness:

- We established and celebrated the first #ICURehabDay by launching this campaign in April 2021. This was continued on 22nd July 2022 and proved very popular on Twitter with rehabilitation teams across the UK contributing information about their programmes.
- We authored a letter to the Secretary of State for Health and Social Care in England calling for rehab services to be commissioned across the UK.
- We were delighted to receive co-signature support in the campaign from nine organisations including The Chartered Society of Physiotherapy (CSP), The Royal College of Occupational Therapists and the British Association of Critical Care Nurses.
- The campaign also received support from former critical care patient, Michael Rosen, author and former Children's Laureate.
- Our Parliamentary petition secured over 6,000 signatures and coverage on BBC Radio 4 Today.
- We joined the Community Rehab Alliance, hosted by the CSP and the National Rehab Collaborative, established by the Intensive Care Society.

We thank all those who contributed to the campaign in 2022 and who provide the much-needed rehabilitative support to current and former ICU patients.

We will build on this work by way of the #ICURehabDay on 21 July 2023.

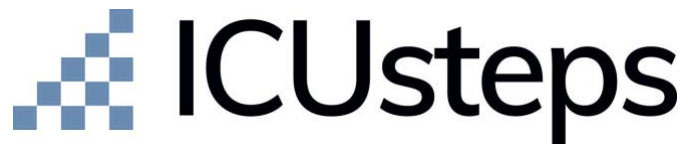
ICUsteps have been invited to contribute to the NCEPOD (National Confidential Enquiry into Patient Outcome and Death) study examining rehabilitation following critical illness. The inaugural meeting was held in December 2022. Full publication is scheduled for November 2024.

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 2022, we:

- responded to 44 requests for help with research studies, including 16 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 18 patient information sheets and lay research summaries.
- co-applicant on two research projects: REGAIN, trialling virtual exercises for hospitalised COVID patients; and PIM-Covid, looking at Covid-19 ICU patients experience of recovery. REGAIN will finish recruitment in November 2022 and patients will be followed up for six months. PIM-Covid finished recruiting in September 2021. The patients in this study were followed up for a year to September 2022.



- In January 2022 Mo Peskett attended a gala dinner in Southport hosted by a gentleman who was an Intensive care patient following COVID-19. His hospital admission was over a six-month period and since his journey of recovery has wanted to give something back. **"I will forever be thankful to the NHS team who brought me back to life and to ICU Steps for supporting my wife and children when I could not, there are no words, deeds or donations that will ever express my gratitude.**
- Through an incredibly generous donation from this gentleman ICUsteps Active began its journey, the development of an online rehabilitation programme alongside two experienced ICU physiotherapists and a therapy assistant have been recruited. ICUsteps Active online classes with a support group following the exercise section will start in May 2023.
- Attended virtually: The Annual John Hopkins Critical Care Rehabilitation Conference in November, emphasising the work of ICUsteps.

If you would like to support our research work, as a volunteer or researcher, please visit www.icusteps.org/research.

Fundraising

ICUsteps received generous donations from individuals, small groups and corporate companies during 2021. As a charity run by and for former critical care patients and relatives, we are very grateful for this support.

Workstreams for the year to 31 January 2023

The Board agreed in 2022 a budget for the year and a series of detailed workstreams to 31 January 2023. these cover:

- information
- affiliate support groups
- research
- #RehabsCritical campaign
- communications
- charity governance.

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

As part of this work, the following values were agreed for ICUsteps:

- Empathy
- Integrity
- Communication
- Community.

These are values agreed by the Trustees as key aspects which we showcase in our work. We look forward to integrating 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 approved a revised safeguarding policy which incorporates a 'safer recruitment' approach.

The Board met, remotely, on four occasions in the year to 31 January 2023. 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 2023.

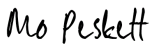


The trustees in the year to 31 January 2023 were:

Mo Peskett (Chair)
Peter Gibb (Chief Executive to October 2021)
Catherine White (Chief Executive from October 2021; Information Manager) resigned December 2022
Helen Ashley Taylor Fundraising Manager resigned March 2022
Andrew Davis (Secretary)
Dr Julie Highfield resigned September 2022
Bryan Hislop resigned December 2022
Dr Christina Jones (Research Manager)
Dr Pamela Page (Safeguarding lead)
Dr Kate Regan (Lead Clinician) resigned March 19th, 2022
Dr Monica Trivedi (Lead Clinician) appointed September 2022
Phil Smith (Treasurer)
Olivia Fulton (appointed September 2020)

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 26^h September 2023 and signed on their behalf by:

DocuSigned by:

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Mo Peskett, Chair

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Andrew Davis, Secretary

	Charity Name ICUSTEPS		No (if any) 1169162		CC16a
	Receipts and payments accounts				
	For the period from	Period start date 01/02/2022	To	Period end date 31/01/2023	
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	524.06			524.06	1340.86
Fund raising	628.80			628.80	924.91
Bequest				0.00	
Funding donation				0.00	3000.00
Presentation expenses				0.00	
Charities Aid foundation				0.00	1000.00
Website maintenance				0.00	
Covid donations (lottery/ Wasps)				0.00	
Booklet Orders	2068.00			2068.00	2080.00
				0.00	0.00
Sub total (Gross income for AR)	3220.86	0.00	0.00	3220.86	8345.77
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	3220.86	0.00	0.00	3220.86	8345.77
A3 Payments					
Stationery and postage	644.37			644.37	452.87
Website hosting & Software	1763.43			1763.43	1699.80
Re branding & advertising				0.00	
Other	206.29			206.29	25.89
Bank charges	60.00			60.00	10.00
Donation or development work				0.00	
IT Development	100.00			100.00	
Training	61.00			61.00	
Mail Management				0.00	
Payment for the Hall				0.00	
Ins/ Legal costs	1022.23			1022.23	413.20
Booklet orders/ design work	140.00			140.00	2921.76
Travel exps ICU Meetings				0.00	
Travel expenses on behalf of ICU				0.00	77.41
INACTIC Grant Funding (re imbursement)				0.00	
Start up fund for new Group				0.00	
Sub total	3997.32	0.00	0.00	3997.32	5600.93
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	3997.32	0.00	0.00	3997.32	5600.93
Net of receipts/(payments)	-776.46	0.00	0.00	-776.46	2744.84
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	-776.46	0.00	0.00	-776.46	2744.84
Section B Statement of assets and liabilities at the end of the period					
Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £	
B1 Cash funds	Bank Account	45101.48	0.00	0.00	
	ICU Reserve		6000.00	0.00	
		0.00		0.00	
CCXX R1 accounts (SS)	Total cash funds	1 45101.48	6000.00	0.00	

	(agree balances with receipts and payments account(s))	Agreement Error	Agreement Error	OK
		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
	DocuSigned by: <i>Phil Smith</i> C19964EA6F124B4...	Philip Smith		27-09-2023
	DocuSigned by: <i>Mo Peskett</i> 1213448AD41A474...	Mo Peskett		28-09-2023