



ICUsteps Annual Report: 1 February 2021 – 31 January 2022

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 general 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 2022. 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

We start by recognising that the period covered by this report was the second full year of the Covid-19 pandemic. 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. Tragically, again, many ICU patients died without their families by their sides; and the many more who survived Covid-19 were sadly more likely to experience delirium and may now be recovering from 'long Covid'.

With infection rates and hospital admissions continuing to fluctuate into the second half of 2022, it is clear that 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 2021, 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).
- launched a new information sheet 'About the ICU' for children unable to visit relatives in ICU.



- continued to have available on our website eighteen 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
- secured over 111,000 views of our website, a slight decrease on 2020 figures but higher than pre-pandemic levels; and visitor numbers increased to almost 46,000.

All our information resources are available on our website at icusteps.org.

We look forward to building on the success above in 2022, with an information sheet about 'Worry after Critical Illness' in production, among other initiatives.

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, Northern Ireland 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/support-groups>

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.

In 2022, we will look to reach out and share knowledge and learn from the affiliate groups. We have two online meetings arranged to share experiences with existing groups and to enable us to focus on strengthening the Network.

Online community – HealthUnlocked

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

The community continued to grow in the year, most likely in light of the pandemic, with the all-time number of members increasing by almost 18 percent to 6,215. The all-time content increased by 26% to 20,513 posts offering peer support and advice about critical illness, recovery and rehabilitation.

We thank all those who contributed to the community in 2021.



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 #RehabCritical 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.
- 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 2021 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 22 July 2022.

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 2021, we:

- responded to 40 requests for help with research studies, including 15 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 17 patient information sheets and lay summaries
- launched a new 'ICUsteps: the Next Step' support group, developed in light of feedback from a former patient to enable participants to put their critical care experiences behind them and to use positive psychology to facilitate post-traumatic growth
- recorded two podcasts about patient involvement in research and long-term fitness that will launched on our website in 2022
- partnered in the INACTIC project that identified competencies for advanced nurses in critical care – the peer reviewed research was published in the Intensive and Critical Care Nursing journal
- co-applied on two research projects: REGAIN, trialling virtual exercises for hospitalised COVID patients; and PIM-Covid, looking at Covid-19 ICU patients experience of recovery - both studies will finish recruitment in 2022
- attended: the virtual UK National Critical Care Research Conference in June; a patient and relative event at London's Lewisham and Greenwich NHS Trust in September; and the Annual John Hopkins Critical Care Rehabilitation Conference in November, emphasising the work of ICUsteps and how it can help researchers.

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 2021 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 2022. 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. The Board also met for a strategy session in November 2021 to agree the above workstreams.

The trustees in the year to 31 January 2022 were:

Mo Peskett (Chair)
Peter Gibb (Chief Executive to October 2021)
Catherine White (Chief Executive from October 2021; Information Manager)
Helen Ashley-Taylor (Fundraising Manager) (retired March 2021)
Andrew Davis (Secretary)
Dr Julie Highfield
Bryan Hislop
Dr Christina Jones (Research Manager)
Dr Pamela Page
Dr Kate Regan (Lead Clinician)
Phil Smith (Treasurer)
Anthony Vollmer (retired October 2021)
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 17th September 2022 and signed on their behalf by:

Mo Peskett, Chair

Andrew Davis, Secretary



Charity Name
ICUSTEPS

Receipts and payments

For the period
from

Period start date
02/01/2021

To

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £
A1 Receipts			
Donations	1340.86		
Fund raising	924.91		
Bequest			
Funding donation	3000.00		
Presentation expenses			
Charities Aid foundation	1000.00		
Website maintenace			
Covid donations (lottery/ Wasps)			
Booklet Orders	2080.00		
Sub total (Gross income for AR)	8345.77	0.00	0.00
A2 Asset and investment sales, (see table).			
	0.00	0.00	0.00
	0.00	0.00	0.00
Sub total	0.00	0.00	0.00
Total receipts	8345.77	0.00	0.00
A3 Payments			
Stationery and postage	452.87		
Website hosting & Software	1699.80		
Re branding & advertising			
Other	25.89		
Bank charges	10.00		
Donation or development work			
IT Development			
Sponsorship for other Group			
Mail Management			
Payment for the Hall			
Ins/ Legal costs	413.20		
Booklet orders/ design work	2921.76		
Travel exps ICU Meetings			
Travel expenses on behalf of ICU	77.41		
INACTIC Grant Funding (re imbursement)			
Start up fund for new Group			
Sub total	5600.93	0.00	0.00
A4 Asset and investment purchases, (see table)			

	0.00	0.00	0.00
	0.00	0.00	0.00
<i>Sub total</i>	0.00	0.00	0.00
<i>Total payments</i>	5600.93	0.00	0.00
<i>Net of receipts/(payments)</i>	2744.84	0.00	0.00
A5 Transfers between funds	0.00	0.00	0.00
A6 Cash funds last year end			0.00
<i>Cash funds this year end</i>	2744.84	0.00	0.00

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

Categories	Details	Unrestricted funds to nearest £
B1 Cash funds	Bank Account	45879.14
	ICU Reserve	
		0.00
	<i>Total cash funds</i>	45879.14
	(agree balances with receipts and payments account(s))	Agreement Error
		Unrestricted funds
	Details	to nearest £
B2 Other monetary assets		0.00
		0.00
		0.00
		0.00
		0.00
		0.00

B3 Investment assets	Details	Fund to which asset belongs
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Details **Fund to which asset belongs**

B4 Assets retained for the charity’s own use

B5 Liabilities

Details	Fund to which liability relates
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Signed by one or two trustees on behalf of all the trustees

Signature

No (if any)
1169162

accounts

CC16a

Period end date
01/31/2022

Total funds	Last year
to the nearest £	to the nearest £

1340.86	9087.62
924.91	13287.39
0.00	
3000.00	0.00
0.00	0.00
1000.00	52.00
0.00	
0.00	12460.00
2080.00	4568.69
0.00	
8345.77	39455.70

0.00	
0.00	0.00
0.00	0.00

8345.77	39455.70
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452.87	376.17
1699.80	1804.17
0.00	
25.89	
10.00	
0.00	
0.00	
0.00	1530.65
0.00	
0.00	
413.20	380.78
2921.76	19042.72
0.00	47.44
77.41	549.56
0.00	1306.23
0.00	400.00
5600.93	25437.72

0.00	
0.00	
0.00	0.00
5600.93	25437.72
2744.84	14017.98
0.00	0.00
0.00	
2744.84	14017.98

ie period

Restricted funds to nearest £	Endowment funds to nearest £
0.00	0.00
6000.00	0.00
	0.00
6000.00	0.00
Agreement Error	OK
Restricted funds to nearest £	Endowment funds to nearest £
0.00	0.00
0.00	0.00
0.00	0.00
0.00	0.00
0.00	0.00
0.00	0.00
Cost (optional)	Current value (optional)
0.00	0.00
0.00	0.00
0.00	0.00
0.00	0.00
0.00	0.00
Cost (optional)	Current value (optional)

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

Amount due (optional)	When due (optional)
0.00	
0.00	
0.00	
0.00	
0.00	

Print Name	Date of approval
Philip Smith	
Mo Peskett	