



Report and Financial Statements

For the year ended 31 December 2020

**Cicely Saunders
International**



Cicely Saunders International

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Cicely Saunders International

Charity information

Registered company number	4120060
Registered charity number	1087195
Trustees	John McGrath (Chairman) Dr. Kathleen Foley MD Sir Richard Giordano KBE Sir Hugh Taylor Mrs Kate Kirk Professor Sir Cyril Chantler Howell James CBE Ms Pamela Garside Mr Gareth Williams Mrs Kay Glendinning (appointed November 2020)
Company secretary	John McGrath
Treasurer and Administrator	Sian Best
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Registered office	6 Sutton Plaza Sutton Court Road Sutton Surrey SM1 4FS
Independent auditor	Mazars LLP 6 Sutton Plaza Sutton Court Road Sutton Surrey SM1 4FS
Banker	HSBC Bank plc 60 Queen Victoria Street London EC4N 4TR
Solicitor	Bates, Wells & Braithwaite Cheapside House 138 Cheapside London EC2V 6BB

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List of Abbreviations

APCA	African Palliative Care Association
BETTER_B	BETter Treatments for Refractory Breathlessness
BSS	Breathlessness Support Service
BuildCARE	Building Capacity, Access, Rights and Empowerment
C-POS	Children's Palliative Care Outcome Scale
CBIS	Cambridge Breathlessness Intervention Service
COPD	Chronic Obstructive Pulmonary Disease
COVID-19	Coronavirus Disease 2019
CS	Cicely Saunders
DEE	Dissemination, Engagement and Empowerment
DRTB	Drug-Resistant Tuberculosis
EMBED-Care	Empowering Better End of Life Dementia Care
EoLC	End of Life Care
HEE	Health Education England
IARE	International Access, Rights and Empowerment
IPOS	International Palliative Care Outcome Scale
IPOS Dem	IPOS for Dementia
IPOS-Renal	IPOS for end-stage kidney disease
MORECare	Methods for evaluating service delivery models for end of life care (EoLC): development of best practice guidance
MyPOS	Myeloma Palliative Care Outcome Scale
NIHR	National Institute of Health Research
NPCRC	National Palliative Care Research Center (USA)
OPTBreathe	OPTimizing cost-effective support for older patients with refractory BREATHlessness and their carers: An economic modelling evaluation incorporating preferences through Discrete Choice Experiment (OPTBreathe)
OPTCare	Optimising Palliative Care
PACE	Palliative Care for Older People in Europe
POS-DemA	Palliative care Outcome Scale - Dementia
QoL	Quality of Life
QUALYCARE	Quality of Care in the Last Phase of Life
SIPSCare	Short-term Integrated Palliative and Supportive Care Services
SPACE	Symptom and Psychological Assessment and Communication Evaluation
WHO	World Health Organization

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Trustees' Report for the year ended 31 December 2020

The trustees, who are also the directors of Cicely Saunders International ("CS International"), present their report and the financial statements for the year ended 31 December 2020. The financial statements comply with the Charities Act 2011, the Companies Act 2006, the Memorandum and Articles of Association, and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

Structure and Governance

Governing documents

CS International is a company limited by guarantee governed by its Memorandum and Articles of Association dated 30 November 2000.

Guarantors

The liability of each of the members of CS International in the event of a winding-up is limited by guarantee to £1.

Organisation structure

The trustees are responsible for the direction of CS International. They are advised by the International Scientific Expert Panel, which comprises five recognised experts in palliative care research or related areas. Their role is to identify appropriate areas of research in collaboration with the Scientific Director, to review research proposals, to monitor progress and standards and to review findings, in terms of quality and rigour of any conclusions. ISEP accounts to CS International's Board of Trustees. The charity's Life President is Christopher Saunders, brother of Dame Cicely Saunders.

Professor Irene Higginson, Scientific Director of CS International, is a physician and Professor of Palliative Care, Policy and Rehabilitation at King's College London. She was appointed to the role following open competition and reports to the Board of Trustees. Professor Higginson is also a non-voting member of ISEP.

Methods for recruiting and appointment of new trustees

The election or appointment of trustees is set out in the Articles of Association of CS International. The minimum number is three and there is no maximum. The trustees are appointed by the members (who are also the directors) at the Annual General Meeting and re-appointed by rotation.

All new trustees meet with the Chairman and Scientific Director (in some instances, other trustees) before their appointment and early on in their activities. In addition, they are provided with aims, objectives and relevant reports. Training is then developed in a bespoke way, taking into account all trustees to date have considerable charitable and business acumen. In 2020 one new trustee was appointed.

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Trustees' responsibilities

Company law requires the trustees to prepare financial statements for each financial year, which give a true and fair view of the state of affairs of CS International as at the balance sheet date and of its income and expenditure for the financial year. In preparing those financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently.
- make judgements and estimates that are reasonable and prudent.
- state whether applicable accounting standards and Statements of Recommended Practice have been followed, subject to any material departures disclosed and explained in the financial statements.
- prepare the financial statements on the going concern basis unless it is inappropriate to assume that the charity will continue in operation.

The trustees are responsible for maintaining proper accounting records that disclose with reasonable accuracy at any time the financial position of CS International and enable them to ensure that the financial statements comply with the Companies Act. They are also responsible for safeguarding the assets of CS International and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Objectives and activities

CS International was established in 2002 in the name of Dame Cicely Saunders, a founder trustee and its President. Dame Cicely is widely acknowledged as the founder of the modern hospice movement and is credited with “mentoring some of the great world leaders in this field” (Professor Eduardo Bruera). Its mission is to promote research to improve the care and treatment of all patients with progressive illness and to make high-quality palliative care available to everyone who needs it – be it in hospice, hospital or home.

Despite the fact that as many people die each year as are born, research in palliative and end of life care is a relatively new and very neglected field. Improved research methods and capacity are urgently needed to discover better treatments and cost-effective care for all who are approaching the end of life. There is no other charity specifically concerned with carrying out work to identify and promote best practice in palliative care.

The Cicely Saunders Institute of Palliative Care

A key early objective of CS International was to fully fund and establish the world's first institute of palliative care, a centre of excellence housing research, education, information provision and clinical care. This was achieved in January 2010 with the official opening in May 2010 of the Institute on the Denmark Hill campus of King's College London, after 20 months of construction, at a cost of just under £10 million. Since opening it has become a major hub for palliative care and its impact is felt in both the UK and internationally. Situated adjacent to King's College Hospital, which provides high-quality palliative care for patients in South East London and the surrounding area, the Institute integrates this care with teaching and research, creating a multi-professional environment examining every aspect of palliative care. Bringing together academics, healthcare professionals, community organisations, patients and carers in one centre, the Institute also acts as the focal point for a network of international research. King's College London, our academic partner at the Institute, is the largest provider of healthcare education in Europe and has an international portfolio of research.

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CS International continues to pursue its mission by:

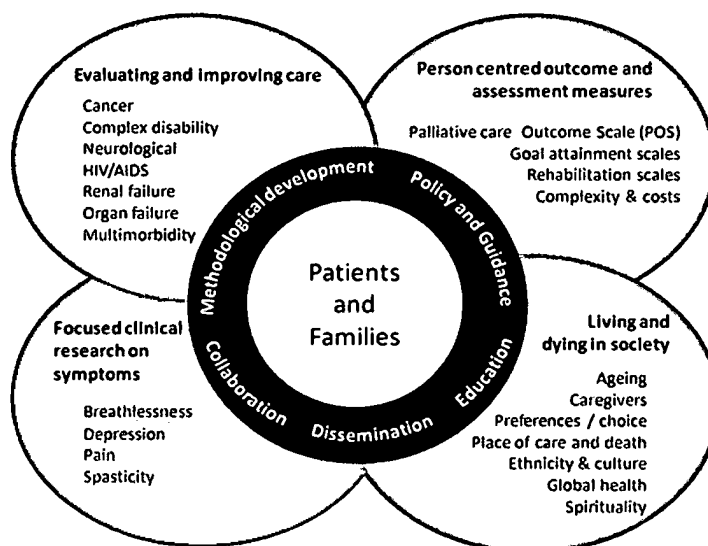
- Supporting world-class research in effective, person-centred and spiritually sympathetic forms of palliative care, and developing relevant and robust methods to set an international gold standard of palliative care.
- Supporting the investigation and promotion of high-quality care for patients with cancer and non-cancer progressive illnesses, and from sections of society that miss out on the best in palliative care.
- Supporting the finest postgraduate and undergraduate education for doctors, nurses and other professionals in the field.
- Constantly promoting public understanding of palliative care, the available treatments and services, and contributing to the development of policy, nationally and internationally, to improve care towards the end of life.

World-class research and high-quality care

The first two objectives for CS International are delivered through four complementary research programmes:

1. **Evaluating and improving care** for people with cancer, respiratory disease, heart failure, liver, kidney and neurological disorders and increasingly with multimorbidity.
2. **Focused clinical research on symptoms** - Discovering new ways of controlling common distressing symptoms, especially breathlessness, but also pain, fatigue, depression and spasticity, and undertaking clinical trials into new treatments.
3. **Person centred outcome and assessment measures** – Developing, refining and implementing robust patient-oriented measures of outcomes in palliative care and rehabilitation.
4. **Living and dying in society** - Investigating how we live and die is changing, including care for older people, support for caregivers, cultural issues.

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1. Evaluating and Improving Care

Improving Palliative Care for Older People

Scope and Objectives

The programme aims to improve palliative care for older people by capacity building and undertaking research work on priority areas. Capacity building is through lectureships/senior lectureships and PhD studentships. The research work focuses on intervention studies to develop and evaluate new interventions/services to improve older people's access to palliative care and outcomes from service/intervention receipt, and population-based studies to inform policy and service provision. Additional information concerning our work with older adults is covered in the BuildCARE section. Our plans for the establishment of a Professorship in Palliative Care to build capacity in this important and growing area were realised in 2020 with the appointment of a new Laing Galazka Professor in Palliative Care.

Progress in specific project areas

EMBED-Care

Empowering Better End of Life Dementia Care aims to deliver timely person-centred care, improving outcomes, including comfort and QoL, towards end of life for people with dementia and their families. The programme will develop new knowledge and pilot an innovative model of care to empower people with dementia of all ages, carers and staff, to identify and act upon changing physical, psychosocial and spiritual needs, addressing these across care settings and transitions. The intention is to leverage sustained improvement in care by working with the public, commissioners and policy makers and by creating a network for care, engagement and research capacity called *the Network for Excellence in Palliative Dementia Care (NEPDC)* with UK and international partners. The programme encompasses engagement in research by stimulating a public discourse on dying with dementia, integrate art and science to widen impact and engagement, and provide a platform for workforce development, capacity building in research and education, implementation and policy. There are currently 6 students undertaking PhDs on palliative care for older people and those with dementia.

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OPTCare Elderly

OPTCare Elderly: optimising palliative care for older people in community settings; development and evaluation of a new short term integrated palliative and supportive care service.

The OPTCare Elderly study is a phase II trial of early palliative care for frail older people. It is a joint project between King's College London and Sussex Community NHS Foundation Trust, and has been funded by:

- HEE/NIHR Clinical Lectureship (Dr Catherine Evans, March 2011-February 2015);
- NIHR Research for Patient Benefit (November 2013-May 2016); and
- CS International/The Atlantic Philanthropies (BuildCARE) (March 2015-April 2016).

OPTCare Elderly aimed to develop and evaluate the feasibility of short-term integrated palliative and supportive care service (SIPScare) for frail older people with non-malignant conditions, living at home or in a care home. The results found SIPScare is effective in reducing symptoms at lower costs versus usual care and is acceptable for patients, families and practitioners as a way to re-configure community palliative care and primary care services. The two main publications on developing SIPScare are published, and main trial publication is under-review for publication in a scientific nursing journal (*International Journal of Nursing Studies*). In 2020 dissemination of published results continues to impact service provision. For example, the SIPScare model is being replicated in a trial in Belgium and implemented in care homes in the South East London within a quality improvement programme.

SPACE

SPACE: Developing and evaluating a new tool, the Symptom and Psychological Assessment and Communication Evaluation (SPACE), to improve communication and palliative care for older people in community hospitals and during clinical uncertainty.

Community hospitals are important to deliver care for older people in transition between hospital and home. There are over 320 community hospitals in England providing care for 120,000 admissions per year. Most people admitted are aged 80 years or over, and around 40% have dementia/cognitive impairment. Admissions are often unplanned following marked decline from a stressor event, e.g. chest infection. Individuals are vulnerable to poor outcomes, and uncertainty often surrounds their recovery or continued decline leading eventually to end of life.

The study aims to develop and evaluate the feasibility of the new SPACE intervention to reduce anxiety and distress for patients and families, by improving communication and palliative care across the care continuum from admission to discharge, or end of life. The development phase of the study is complete. We conducted the first national cohort study on the characteristics and mortality of patients admitted to community hospitals over 1 year from admission, published in *BMC Medicine* <https://rdcu.be/cf00OA>. The study used linked national databases on hospital use and death registration data. The cohort included over 76, 000 patients admitted to 220 community hospitals in England. This is an ageing population with average age 81 years, living with multiple chronic conditions. Most admissions were unplanned. Over one in four were in the last year of life. The traditional focus on rehabilitation and recovery has changed with an ageing population and need for greater integration of palliative care to adjust care towards quality of life and anticipate and plan for end of life. We have two further publications under-review reporting a systematic review on evidence based tools to manage clinical uncertainty for people nearing the end of life (*BMC Palliative Care*); and consultation with staff and individual interviews with patients on priorities to used evidence based tools to manage clinical uncertainty, such as Integrated Palliative care Outcome Measure in routine care to enhance person-centred assessment (*BMC Geriatrics*).

The final feasibility study evaluating the implementation of the SPACE intervention using validated tools in routine care to manage clinical uncertainty has been disrupted by COVID-19. We plan to open for patient recruitment in April 2021. This programme of work is an important step forward to transform the care in community hospitals by integration of palliative care and implementation of

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evidence-based tools to improve care. It has delivered unique understanding of care for people in this neglected situation, and provides a solid foundation for a future study to test how the tools we develop may work nationally.

Two important projects are: telehealth implementation and evaluation to improve monitoring and timely access to primary and community services for people with multi-morbidities in community settings (at home and care homes); and implementation and evaluation of an End of Life Care Hub providing 24/7 telephone access to palliative and end of life care services for patients, families and health and social care practitioners.

These service innovations are providing opportunities to increase the impact of our research work in clinical practice, and use service evaluation as a means to pilot novel research methods to inform a full research study. For example, in the telehealth study the outcome measures (e.g. IPOS), and patient experience measures, are administered to the patient and carer via the telehealth CarePortal at set-time points. The study also uses a central database (Artemis) comprising GP electronic patient records for participants' demographic data, data on the comparator patient group (e.g. unplanned hospital admission rates) and economic data on service use.

Africa Programmes

The Cicely Saunders Institute's Centre for Global Health Palliative Care was launched in 2017. This initiative is:

- Developing and testing services that address the urgent challenge of rapid ageing and increasingly complex multimorbidity in lower and middle income countries.
- Creating models of palliative care and outcome measures that respond to locally prevalent illness and conditions such as HIV, TB and certain cancers.
- Identifying emerging leaders and building their potential for local clinical and academic leadership.
- Providing demonstrable evidence that can be translated into policy, education and practice by advocates, NGOs and governments.

The work of the Centre for Global Health Palliative Care addresses the increasing need for palliative care, and the development of affordable health systems to meet that need. We are building capacity through education and training and translating POS (Palliative care Outcome Scale) into other languages. We carried out an evaluation of Hospice Africa Uganda's innovative use of water bottles to introduce oral morphine into home care and are working with partners in South Africa on palliative care needs of drug-resistant TB patients. We worked with the African Palliative Care Association to produce the world's first outcome measure specifically for children and young people, the C-POS. It is the first tool for use within children's palliative care, a vulnerable patient group. Our current students are from India, Singapore, Mauritius, Ghana, China and Thailand.

Progress in specific project areas

The Institute's World Health Organization (WHO) Collaborating Centre status is continued and we are working increasingly with WHO Kobe, with a stronger focus on global policy, reflecting our research outputs and on the WHO Technical Working Group for Palliative Care. We are currently collaborating with WHO on a new mhealth app for palliative care caregivers in Africa. We have commenced our research in response to winning the World Health Organization's tender for research to underpin the World Health Assembly's resolution on Palliative Care.

Under BuildCARE Africa we mentor the following studies:

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- Zimbabwe - a feasibility cluster trial of lay community bereavement support. Protocol published, feasibility trial complete.
- Ghana - evidence-based guidelines on palliative care for severe burns. Systematic review complete, data collection and analysis has begun.
- Uganda - an RCT of palliative care for DRTB patients. Focus groups and Intervention development complete.
- Nigeria - a longitudinal observational study of symptoms and concerns among renal patients.
- Uganda and Zimbabwe - research on person-centred care.
- Ghana, Malawi and Zimbabwe – research on multimorbidity and care of older people.

2. Focused Clinical Research on Symptoms

Breathlessness Programme

Scope and Objectives

The Breathlessness programme forms a key part of our work of focused clinical research on symptoms. Breathlessness is a common, distressing symptom in advanced disease, causing disability, anxiety and social isolation for patients and their families and caregivers. Breathlessness increases as disease progresses, is associated with shortened life expectancy, is frightening for patients and families, and often results in emergency visits and hospitalisation as shown by our service use data. Despite an increase in the understanding of the mechanisms of breathlessness, this has not translated into effective and widely utilised treatment options. Thus, clinicians too experience distress when faced with this symptom due to the lack of effective interventions.

The initial work of the CS International 'Improving Breathlessness' programme, described types and trajectories of breathlessness, compared experiences across different diagnoses and led systematic reviews of drug and non-drug treatments for the symptom. We have since examined promising treatments in clinical trials, either alone, e.g. the hand-held fan or neuromuscular electrical stimulation, or in combination as part of breathlessness support services. In particular we have trialled a joint palliative care and respiratory medicine Breathlessness Support Service (BSS) in London and, with others, a Cambridge based Breathlessness Intervention Service (CBIS). A key feature of our work is the multi-professional approach to this symptom, which acknowledges the importance of features outside of the lungs, for example the skeletal muscles and the brain. We have also led the way in understanding appropriate treatment targets for people with chronic refractory breathlessness; to improve their mastery and functioning whilst living with the symptom.

Progress in specific project areas

BETTER-B

The BETter TreatmEnts for Refractory Breathlessness (BETTER-B) project aims to test the effectiveness and cost-effectiveness of mirtazapine for the reduction of patient-reported chronic or refractory breathlessness and quality of life in patients with COPD or ILD and at end of life, and on the caregiver burden, quality of life and experience of their lay caregivers and close family members. The trial is being conducted in the UK, Germany, Italy, Ireland, and Poland, and plans to recruit a total of 324 participants. The project also includes an online survey of physicians, production of Europe-wide guidance on breathlessness management in palliative and end-of-life care, and qualitative interviews with trial participants to understand their experiences. As part of the BETTER-B programme, a multinational online survey explored the practices of 450 respiratory medicine and palliative care physicians for managing breathlessness in chronic lung diseases. The survey found significant differences in choice of breathlessness management strategies by specialty and by diagnosis which were also influenced by physicians' knowledge of clinical guidelines. The trial is led by Professor Higginson, supported by the Leeds Clinical Trials Research Unit. The three UK sites are

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now open to recruitment, while other European sites are progressing towards opening.

Frailty in COPD

In our previous prospective cohort study we found that frailty affects one in every four patients with COPD entering pulmonary rehabilitation. Those completing pulmonary rehabilitation show favourable outcomes, but frailty is also a strong risk factor for non-completion. In response we are leading a project on developing 'frailty fit' pulmonary rehabilitation services for people with COPD. Our interview study with 19 people with COPD and frailty referred for pulmonary rehabilitation highlighted the multidimensional losses experienced by this group, and the unpredictable disruptions to their lives and health that could interfere with attending this service. Our realist review of exercise-based interventions for people with COPD and frailty then highlighted a potential role of integrating geriatric expertise to better support this group. As a result, we have developed an adapted approach integrating comprehensive geriatric assessment alongside pulmonary rehabilitation, which is now being tested in an ongoing mixed-method randomised controlled feasibility trial called 'Breathe Plus'.

OPTBreathe

OPTBreathe aims to determine the most cost-effective models of breathlessness support services that are valued and accepted by older patients affected by refractory breathlessness and their family or carers. In 2019 the study progressed to Phase 2 conducting economic modelling of the data.

E-Breathe

An online platform dedicated to innovations in breathlessness management aimed at clinicians, allied health professionals and management. The programme is based on findings from a randomised controlled trial into providing integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness. The platform enables users to develop new skills through self-paced eLearning and exchange knowledge through an interactive forum. It provides clear guidance on non-pharmacological and pharmacological interventions in breathlessness and explains to clinicians how to support patients.

The platform provides:

- Assessment information about the physical and psychological reasons for breathlessness and its associated symptoms.
- A guide to the effectiveness of different pharmacological interventions on patients with breathlessness;
- Practical guidance on a variety of techniques to teach patients to self-manage breathlessness (e.g. crisis and general management guidance, a hand-held fan or water spray, and a poem or short mantra to help breathing and relaxation during crises, home exercise/exercise DVD, positional techniques, distraction techniques and sleep hygiene).

Self-Breathe

Provision and access to breathlessness support services is limited. Delivering online breathlessness supportive services may be one way of improving access to non-pharmacological self-management interventions for people living with chronic breathlessness. Led by Dr Charles Reilly, Self-breathe is an internet based self-guided treatment of chronic breathlessness, and tests feasibility of a trial of SELF- BREATHE in addition to NHS health care vs NHS health care alone. A scoping survey of internet accessibility and willingness of patients with chronic respiratory disease and chronic breathlessness to use an online breathlessness supportive intervention is completed. In 2020 25 in-depth qualitative research interviews with patients with chronic breathlessness were completed to explore areas of uncertainty regarding the development of SELF-BREATHE and are being analysed. The SELF – BREATHE intervention has been developed, and the feasibility randomised controlled trial opens to recruitment in Jan 2021.

3. Person-centred Outcome and Assessment Measures

Scope and Objectives

The Palliative care Outcome Scale (POS) measures are a family of tools to measure patients' physical symptoms, psychological, emotional and spiritual, and information and support needs. They are validated instruments that can be used in clinical care, audit, research and training. Since it was launched, POS has been tested and improved by researchers around the world. A global network of researchers and clinicians continue to collaborate with researchers at the Institute to ensure that POS remains an outcome measure of choice.

Progress

Use of POS and IPOS continues to expand, both in clinical practice and in research studies. This expansion is occurring both nationally and internationally, and the POS development team continues to work with other teams to support uptake in the UK, and to encourage translation, cultural adaption, and validation of the different language versions across the world.

POS website

The POS website www.pos-pal.org is widely used for dissemination of the measures and related guidance and evidence. It provides free access to the complete family of POS and IPOS measures, although we ask users to register, so that we can better understand and support website use.

POS Development Team

The POS Development Team continues to support and monitor the use of POS and IPOS internationally. There are 13 different translations of POS freely available at www.pos-pal.org – Chinese (original), Chinese Simplified, Dutch, French, German, Italian, Japanese, Norwegian, Portuguese, Portuguese (Brazilian), Punjabi, Spanish and Urdu and two are in process. There are now 14,871 registered users and our measures have been downloaded 52,551 times (unique downloads).

There are also 13 translations of IPOS now completed and available on www.pos-pal.org (Czech, Estonian, French, German, Greek, Hindi, Italian, Korean, Myanmar version, Polish, Portuguese, Swedish and Turkish), with links to IPOS-specific webpages in the home country as appropriate (to support use of www.pos-pal.org by non-English speakers). A further 14 translations and cultural adaptations of IPOS are in progress around the world, including work on adapting it in Te Reo Māori.

Disease-specific and other versions of POS and IPOS continue to be developed and validated.

- POS has been used in documenting the symptoms of COVID-19 positive patients admitted to palliative care services as part of the CovPall study which is a rapid evaluation of the COVID-19 pandemic response in palliative and end of life care. National delivery, workforce and symptom management research is being carried out to evaluate the palliative care response in COVID-19 to improve care now and in the future. This research is supported by Medical Research Council grant number MR/V012908/1.
- A version of IPOS for use in those with dementia, IPOS Dem, is now being used in Empowering Better End of Life Dementia Care (EMBED-Care) Programme, funded for five years by a £4.7m grant from the ESRC-NIHR Dementia Research Initiative
- IPOS Neuro has been developed for patients with Long Term Neurological Conditions (LTNC). Its full version contains 45 items. 37 items ask about symptom experience and the remaining

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items ask about information needs, practical concerns, anxieties of the patient and family, and their overall feeling of being at peace. Shorter versions S8 (8 items) and S24 (24 items) are also available. Shorter version IPOS Neuro S8 is currently being translated and culturally adapted to German.

- Translation, cultural adaptation and testing of African APCA IPOS currently being used in World Health Organisation evaluation of palliative care in six countries (Vietnam, Belorussia, Thailand, Oman, Jamaica and Zimbabwe), and has been translated and culturally adapted in these countries.
- We are organising expert consultations to improve the formatting and determining the next directions in patient reported outcome measurement
- We are supervising a number of undergraduate projects for medical students to exploring new avenues for expansion of our measures, for example in primary progressive multiple sclerosis, and lung conditions.
- We are also applying for funding to facilitate use of IPOS in economic evaluation to capture efficiency and cost effectiveness better and also to develop and calibrate a novel item bank to measure outcomes for people living with breathlessness, complexity and multimorbidity
- We are also developing a virtual learning platform of the POS family of measures. CS International/The Atlantic Philanthropies (Project GlobalCARE) is supporting this work, which will ultimately be a comprehensive and free resource for clinicians, researchers and service planners.
- We are also updating the translation, cultural adaptation, psychometric testing and scoring manual and developing user's guides for IPOS to assist its use in clinical assessment, research and quality improvement

4. Living and Dying in Society

Place of Death and Patients' Preferences

Scope and Objectives

This project aims to generate comprehensive and rigorous knowledge of place of death, taking into consideration individual, societal and healthcare implications. The project takes forward a coherent programme of studies on place of death, with a focus on home death.

In the longer term, our aims are to generate an optimised home palliative care model; one that responds to the challenges of caring in ageing populations and that improves further outcomes for patients and their families, without raising costs. Progress has been made in the last year towards the project goals and in ensuring the performance of high-quality research.

Progress in specific project areas

QUALYCARE

The QUALYCARE study aimed to examine variations in the care, costs, palliative outcomes and preferences associated with home death in cancer. Five papers have been published on comparison of death in hospital and at home: quality of the home care provided by general practitioners; factors associated with intensity of end of life care; factors associated with participation; active refusals and reasons for not taking part in the survey; and a secondary analysis on the relationship between caregiving intensity and adverse bereavement outcomes. The study has been replicated in Northern Ireland (QUALYCARE-NI).

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BuildCARE Programme

Scope and Objectives

BuildCARE (Building Capacity, Access, Rights and Empowerment) aims to create a 'sea change' in the way palliative and end-of-life care is regarded, implemented and prioritised internationally. The International Access, Rights and Empowerment (IARE) study was a foundation international research project in BuildCARE. IARE aimed to better understand the needs of patients aged 65 and over who have received palliative care for cancer and non-cancer conditions, and their families. This knowledge is being used to help improve access to these valuable services for this group. BuildCARE also included the Dissemination, Engagement and Empowerment (DEE) programme, the Faculty Scholar and PhD Fellowship programmes.

Progress

Overall, BuildCARE has supported five Faculty Scholars. We identified talented individuals and provided bridging funding, academic support and supervision, to enable them to complete essential work to win a more substantial award. All Faculty Scholars have successfully moved to senior posts, including a Professorship, an NIHR Clinician Scientist, an NIHR Clinical Senior Lectureship, and two leadership positions. The Faculty Scholars and other BuildCARE members are continuing to publish and disseminate high-quality evidence about the needs of older patients, and build on these findings in the IARE II study.

Palliative Care Clusters

Funded by The Atlantic Philanthropies, comprising:

- Project GlobalCARE
- The Fellowships Consortium
- International Access, Rights and Empowerment Study (IARE II)

The three programmes address the escalating need for palliative care both locally and globally as well as the issue of unequal and often poor access to palliative care services. Cicely Saunders Institute research estimates that although people are living longer, between now and 2040 there will be a 25% annual increase in number of deaths, and the future need for palliative care is estimated to be three or four times greater than that currently offered. This ageing is associated with increased complexity, multimorbidity and difficulty in predicting the course of illness. The World Health Organization passed a landmark resolution recommending integration and implementation of palliative care services at all levels of society into national health programmes.

Each programme complements the gains of the others in this cluster.

GlobalCARE

Project GlobalCARE addresses the issues of need and access by developing and providing screening tools, and new models of integrated working that can be embedded into mainstream care to improve patient and family care. The project will change the way chronic health conditions are managed in the future, with earlier identification of problems, appropriate action and care that is orientated around individual needs rather than systems. It will improve the quality of life for millions and have significant fiscal impact.

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PACE and SPACE

Supported by The Atlantic Philanthropies GlobalCARE grant, we are extending support for older patients in community settings through use of the SPACE toolkit (Symptom Psychological Assessment and Communication Evaluation toolkit, see above, **Improving Palliative Care for Older People**), and building on the Institute's programme of work on developing and evaluating the use of the Integrated Palliative care Outcome Scale (IPOS) and PACE in routine clinical practice to support comprehensive assessment, management of symptoms and concerns, and communication with patients and families. The Atlantic Philanthropies funding has supported the development and evaluation of a wider toolkit for older people in community hospitals during clinical uncertainty as to recovery or continued deterioration.

CS International/The Atlantic Philanthropies (Project GlobalCARE) is supporting the development of the **POS Virtual Learning Platform**, which will ultimately be a comprehensive and free resource for clinicians, researchers and service planners. POS eLearning modules are being developed. Following the successful launch of MORECare eLearning, the POS Virtual Learning Platform will host:

- 3 general introductory modules about outcome measures and the POS.
- 6 (or more) modules on specific diseases or population specific POS variations.
- 4 modules focused on clinical and research implementation and utilisation of measures.

Each of the modules will contain learning outcomes, an audio/visual presentation with 'talking heads' and slides, a reading list and a test. As the training will be hosted on the interactive Moodle platform, the modules will be accompanied by a user-forum, supporting a community of practice for clinicians, researchers and auditors. The training will be freely available and accredited for Continuing Professional Development (CPD) points from the Royal College of Physicians of the United Kingdom and other relevant bodies. Development of the POS Virtual Learning Platform responds to the oversubscription to our POS Workshops.

Fellowships Consortium

The Fellowships Consortium programme responds to the WHO resolution by investing in human capital to develop the palliative care field's future leaders. The programme establishes international leaders who will ensure the development of high-quality care for growing numbers of people with chronic illness. Through their international networks and collaboration, these leaders will inform policy and practice in the long term (15-20 years) delivering much needed advances and sustainable mechanisms.

The Fellowships Consortium is an international multifaceted programme, supporting the learning of tomorrow's leaders in the field of palliative care. The Institute is partnered with collaborating organisations in the USA (National Palliative Care Research Center or 'NPCRC') and Ireland (Trinity College Dublin) to deliver four strands:

- **Research Fellowships Programme:** CS International/The Atlantic Philanthropies grants directly fund MSc/PhD/Post-doctoral Fellowships across partner sites. As an incentive to attract additional funding for fellowships and scholarships, and to enhance the learning community, other components of the Fellowships Consortium programme are also offered to other fellows on an invitation basis.
- **Research Technical Assistance:** Early-stage palliative care researchers face unusual challenges around study design, instrument development and analytic techniques. This is due to the complexity of the statistical methods and study designs required to conduct high-quality research in people with serious illness. The Fellowships Consortium supports the development and delivery of technical resources and training to assist fellows with these challenges.
- **Community Building:** The Fellowships Consortium facilitates academic collaboration and

Cicely Saunders International

Trustees' Report for the year ended 31 December 2020

learning, peer-to-peer support and international exchange, creating an international research community of leaders dedicated to ensuring delivery of high-quality care for growing numbers of people with chronic illness.

- **International Engagement Action:** Fellows engage with patient and public involvement (PPI) representatives, clinicians and relevant policy makers to disseminate findings, influence public debate and raise the profile of palliative care. Innovative use of new and traditional media platforms, development of accessible web-based information, and participation in community events assist fellows to highlight the issues in palliative and end of life care, and to provide evidence-based solutions.

IARE II

IARE II follows phase one of the International Access, Rights and Empowerment (**IARE I**) study which provided evidence from London, Dublin, New York and San Francisco, of the preferences and experiences of older adult patients who access palliative care. **IARE II** examines the preferences and care experiences of patients and families with chronic disease, who are not afforded access to specialist palliative care. The study focuses on older people, so that results are directly relevant to the population of the future. Robust understanding of the inhibiting factors and the experiences of patients will provide vital evidence, drawn from a patient perspective. This will enable us to find ways to bring palliative and chronic care programmes together, to better support patients and families. The overall aim of the study is to improve equity of access to palliative care by understanding the trajectories of needs, experience and priorities over time of older adults in three countries living with frailty and advanced disease who have not yet received specialist palliative care.

Progress

We have progressed the project outcomes including:

- Recruitment for IARE II is complete and analyses are underway.
- Contributing to the information base on the care needs of those with chronic conditions – specifically dementia and heart failure.
- Fostering clinical-academic partnerships in projects, across various care settings, establishing new collaboration opportunities to raise awareness and increase capacity, as in the OPTCARE Elderly, POS- DemA and the Transforming End of Life Care project.
- Increasing awareness of the need to understand variation in global access to palliative care in the dissemination of IARE I findings, in parallel project work and in our PhD recruitment strategy.

Education and training

Our third objective is to support the best training for doctors, nurses and other professionals in the field of palliative care.

The Cicely Saunders Institute (“the Institute”) is an international centre for education in palliative care, developing strong programmes tailored for international visitors, doctors, nurses and others training in palliative care, as well as for undergraduate, postgraduate and research students. The Institute trains approximately 400 students per year, with postgraduates training a further 7,000 medics. We calculate that this training benefits around 70,000 patients a year as well as over 180,000 carers and families.

The Fellowships Consortium (described above) fulfils part of our remit under this objective. A number of other training fellowships also contribute to capacity building.

Cicely Saunders International

Trustees' Report for the year ended 31 December 2020

Kirby Laing MSc Scholarship in Palliative Care

We were awarded a grant for four scholarships from the Kirby Laing Foundation for students focusing their research project on stroke or dementia. The first scholar (dementia) completed the course and graduated in 2018. Three further scholars (2 stroke and 1 dementia) have completed their studies and graduated in July 2020.

Sebba MSc Scholarship in Advanced Care Planning

In 2018 we were awarded funds from The Sam and Bella Sebba Charitable Trust for an MSc scholarship to include a research project study on Advanced Care Planning. We are pleased to report that the MSc scholar commenced in January 2019.

Dissemination

Our fourth objective is to promote public understanding of palliative care, the available treatments and services, and contribute to the development of policy, nationally and internationally, to improve care towards the end of life.

Clinical Services and Information Support Centre

The Institute houses an Information and Support Centre on the ground floor, funded and managed by Macmillan Cancer Support, to provide accessible information for patients, families, professionals and the general public. The Centre holds information on clinical services, treatment choices and up-to-date research findings. Staffed by information officers, it also offers a drop-in service, outreach to local community organisations and cancer networks, and services specifically tailored to the different groups it serves.

During the COVID-19 pandemic, although not operating a drop-in service, information services have continued to support hospital activity (with materials collected and distributed), and offers patients and families bookable space when attending cancer treatment (as no waiting areas are currently available in the hospital). Psychological support and other support services have been provided to patients by phone.

The CS International Annual Lecture 2020

In November 2020 the Cicely Saunders International Annual Lecture was given online by Professors Stephen Pantilat, Irene Higginson and Dr Eve Namisango. Entitled ***Palliative Care in an Era of COVID-19: Perspectives from three continents*** the lecture was an examination of the global role and response of palliative care to COVID-19 in the UK, USA and Africa. The event was attended online by 978 people. The subjects covered included the use of telemedicine to support palliative care during the pandemic in the USA, the impact of COVID-19 on palliative care in Africa and the findings from the multinational COVPALL study into the global role and response of palliative care to COVID-19.

Cicely Saunders International

Trustees' Report for the year ended 31 December 2020

Open Seminar Series

7 seminars were held in 2020 attended by 966 people.

22 January - Using Human-Centred Design to Mitigate the Impact of Neoliberalism on Burdensome End of Life Care (Dr Liz Dzeng)
26 February - Interdisciplinary Research, my journey and insights (Professor Dame Jessica Corner)
24 June - Departure Lounge (Nick Hillier & Holly Rogers)
22 July - The ImproveCare study: Lessons from a feasibility cluster RCT of the AMBER care bundle for patients in hospital settings (Dr Jonathan Koffman)
30 September - Re-claiming the public understanding of dying (Dr Kathryn Mannix)
28 October - Palliative care and advance care planning in nursing homes: what will move the needle? (Prof. Dr. Lieve Van den Block)
25 November - Longitudinal qualitative research in people living with incurable cancer (Dr Lynn Calman and Dr Eloise Radcliffe)

Visitors Programme

Supported by CS International/The Atlantic Philanthropies (Project GlobalCARE), the Cicely Saunders Institute's Visitors Programme was temporarily suspended in 2020 due to the COVID-19 pandemic.

CS International Newsletter

Three newsletters have been produced in 2020 and distributed in hard copy and by email.

Public benefit

The Trustees have complied with their duty per the Charities Act 2011 to have due regard to Public Benefit guidance published by the Charity Commission.

Financial review

Review of transactions and financial position

During the year, income of £179,831 was recognised (2019 - £893,589). This income was applied to the objects of CS International.

The net movement in funds for the year, as shown in the Statement of Financial Activities, amounted to a deficit of £256,011 (2019 – surplus of £454,979).

CS International's net assets at 31 December 2020 were £3,810,028 (2019 - £4,066,039).

Cicely Saunders International

Trustees' Report for the year ended 31 December 2020

Reserves

CS International's policy is to maintain general reserves to give financial stability to the charity and to its activities. General reserves exclude restricted and designated funds and they allow CS International to manage the risks that it faces and to fund future work to achieve its aims. Trustees have considered the range and risk level of the charity's various income sources and expenditure levels, and consider the desirable level of general reserves should be a minimum of 18 months unrestricted expenditure. In 2020 general reserves equated to 26 months unrestricted expenditure.

At 31 December 2020, free reserves were £136,901 (2019 - £124,331). These funds will be used to finance CS International's charitable objectives and to meet the ongoing expenses of operating the organisation. CS International has succeeded in raising all funds necessary for the construction and completion of The Cicely Saunders Institute of Palliative Care.

Risk management

The trustees have a risk management strategy which comprises:

- an annual review of the principal risks and uncertainties that the charity faces.
- the establishment of policies, systems and procedures to mitigate those risks identified in the annual review.
- the implementation of procedures designed to minimise or manage any potential impact on the charity should those risks materialise.

Financial sustainability is a financial risk for the Charity. A key element in the management of financial risk is a regular review of available liquid funds to settle debts as they fall due, regular liaison with the bank, and active management of trade debtors and creditors balances to ensure sufficient working capital by the Charity.

The operational risk from research and student grant awards that are ineffective in advancing knowledge and practice in palliative and end of life care is managed by retaining trustees of sufficient skill and expertise and recruiting International Scientific Expert Panel members to review research outputs annually. By retaining international experts active in the field we are assured that their knowledge is up to date and that they have the depth of insight to effectively review and evaluate research. The process of reporting and review assists us, and those we support, in keeping track of how research and knowledge is developing. This review process retains our focus on the public benefit derived from our funding of research.

King's College London is the sponsor for all research funded by Cicely Saunders International and therefore research processes, ethics approvals and contractual matters are covered by the standard or bespoke terms and conditions and sub-contract agreements for research undertaken by King's College London.

COVID-19

The trustees consider that the threat to potential funding by the economic consequences of COVID-19 is mitigated by the charity's direct relevance to the current crisis. Following the emergence of COVID-19 as a threat for the foreseeable future, there will be an acute increased need for palliative care. This new disease is leading to an urgent need for palliative care research, support for patients and families, and the development and management of services. The charity will therefore continue to focus on supporting activity at the Cicely Saunders Institute, working with other charities, funders and philanthropic donors. The charity is holding 26 months running costs for contingency. The level of unrestricted funds is sufficient to cover the charity's core costs for the foreseeable future.

Cicely Saunders International

Trustees' Report for the year ended 31 December 2020

Brexit

The trustees are continuing to assess the impact on the charity of the United Kingdom's decision to leave the EU. They are not expecting this to have a significant impact on the charity.

Investment policy

Any surplus funds expected to be required in the short to medium term to meet existing commitments are held on deposit with the Charity's bankers or invested in highly rated money market funds.

Principal funding sources

We are very grateful to our current and historic funders, The Atlantic Philanthropies, The Big Lottery Fund, The Department of Health, The Diana, Princess of Wales Memorial Fund, The Dinwoodie Settlement, the Dunhill Medical Trust, The Garfield Weston Foundation, Guy's & St Thomas' Charitable Trust, Hospice Education Institute, King's College Hospital Charity, The Kirby Laing Foundation, Mr S Khoury, Macmillan Cancer Support, PF Fleming Trust, The Rayne Foundation, The Samuel Sebba Charitable Trust, The Sir Halley Stewart Trust and The Wolfson Foundation, whose support has enabled CS International to undertake work in its key areas as set out in its mission statement.

Key management personnel

The key management personnel of the charity are considered to be the board of trustees. The charity does not employ any staff directly, and all key decisions are made by the board. Trustees do not receive any remuneration for their role as trustees.

Fundraising

The charity does not undertake significant activities to raise funds from the public, and has not used any professional fundraisers during the year. The charity has not received any complaints about its fundraising activities.

Plans for the future

Main objectives for the year

The aims of CS International for the coming year include developing a consistent funding stream for research projects in addition to covering operating costs; and maintaining administrative overheads at a target level not exceeding five per cent.

CS International continues to secure funding for the gold standard research being undertaken at the Cicely Saunders Institute and for capacity to build the specialty of palliative care. Plans for the establishment of a permanent endowed Professorship in Palliative Care have progressed in 2020 with the appointment of a new permanent professor in palliative care funded by a permanent endowment. Plans also include accessing support for our Centre for Global Health to advance our aim of ensuring that everyone has access to the best palliative care, wherever they live and wherever they are cared for. An Action Plan for Better Palliative Care was launched in January 2021.

Cicely Saunders International

Trustees' Report for the year ended 31 December 2020

Aims and objectives for the future

The need for palliative care has never been greater and is growing rapidly. As the population lives longer due to reductions in acute disease, the prevalence of other health problems increases. Patterns of dying are changing as chronic and progressive diseases coexist, and the boundaries between being ill and dying become obscured and prolonged. The very oldest people often experience multiple chronic diseases such as heart failure, respiratory failure and cancer. The dramatic increase in the older population and the multiple health and other problems of ageing will put great pressure on healthcare providers and many more people will need palliative care and support to help them live as well as possible until they die.

The creation of the new professorship in palliative care will greatly expand research, clinical and teaching capacity at the Cicely Saunders Institute enabling us to:

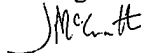
- Develop and trial new evidence-based models of care;
- Develop and trial scientifically robust new therapies for an older population with multiple co-morbidities;
- Better understand patient choice in order to ensure adequate resources are in place for a rapidly ageing population.;
- Increase clinical, research and teaching capacity within the field to develop the palliative care leaders of the future.

Statement of disclosure to the auditors

- a) So far as the trustees are aware, there is no relevant audit information of which the charity's auditors are unaware; and
- b) They have taken all the steps they ought to have taken as trustees in order to make themselves aware of any relevant audit information and to establish that the charity's auditors are aware of that information.

In preparing this report, the trustees have taken advantage of the small companies exemptions provided by section 415A of the Companies Act 2006.

Approved by the Board on 27 July 2021
and signed on its behalf by



John McGrath
Company Secretary

Independent auditor's report to the Trustees of Cicely Saunders International

Opinion

We have audited the financial statements of Cicely Saunders International (the 'charity') for the year ended 31 December 2020 which comprise the Statement of Financial Activities, the Balance Sheet, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 December 2020 and of its income and expenditure for the year then ended.
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice.
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the annual report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Independent auditor's report to the Trustees of Cicely Saunders International

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' Report for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Trustees' Report has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In light of the knowledge and understanding of the charity and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specific by law are not made; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of Trustees

As explained more fully in the statement of trustees' responsibilities set out on page 4, the trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of the financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. Based on our understanding of the charity and its activities, we identified that the principal risks of non-compliance with laws and regulations related to the Charities Act 2011, UK tax legislation, health and safety regulation, anti-bribery, corruption and fraud, money laundering, and we considered the extent to which non-compliance might have a material effect on the financial statements. We also considered those laws and regulations that have a direct impact on the preparation of the financial statements, such as the Companies Act 2006 and the Charities Statement of Recommended Practice.

Independent auditor's report to the Trustees of Cicely Saunders International

We evaluated the trustees' and management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls) and determined that the principal risks were related to posting manual journal entries to manipulate financial performance, management bias through judgements and assumptions in significant accounting estimates, in particular in relation to use of restricted and endowment funds, and significant one-off or unusual transactions.

Our audit procedures were designed to respond to those identified risks, including non-compliance with laws and regulations (irregularities) and fraud that are material to the financial statements. Our audit procedures included but were not limited to:

- Discussing with the trustees and management their policies and procedures regarding compliance with laws and regulations;
- Communicating identified laws and regulations throughout our engagement team and remaining alert to any indications of non-compliance throughout our audit; and
- Considering the risk of acts by the charity which were contrary to applicable laws and regulations, including fraud.

Our audit procedures in relation to fraud included but were not limited to:


- Making enquiries of the trustees and management on whether they had knowledge of any actual, suspected or alleged fraud;
- Gaining an understanding of the internal controls established to mitigate risks related to fraud;
- Discussing amongst the engagement team the risks of fraud; and
- Addressing the risks of fraud through management override of controls by performing journal entry testing.

There are inherent limitations in the audit procedures described above and the primary responsibility for the prevention and detection of irregularities including fraud rests with management. As with any audit, there remained a risk of non-detection of irregularities, as these may involve collusion, forgery, intentional omissions, misrepresentations or the override of internal controls.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Use of the audit report

This report is made solely to the charity's members as a body in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charity's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's members as a body for our audit work, for this report, or for the opinions we have formed.


Nicola Wakefield (Sep 27, 2021 18:34 GMT+1)

Nicola Wakefield (Senior Statutory Auditor)
For and on behalf of Mazars LLP,
Chartered Accountants and Statutory Auditor
6 Sutton Plaza, Sutton Court Road, Sutton, Surrey, SM1 4FS

Date: 27 September 2021

Cicely Saunders International

Statement of financial activities for the year ended 31 December 2020

	Notes	Unrestricted funds £	Restricted funds £	Total funds 2020 £	Total funds 2019 £
Income and expenditure					
Income from:					
Donations and legacies		100,906	49,282	150,188	859,113
Investments		29,643	-	29,643	34,476
Total income		<u>130,549</u>	<u>49,282</u>	<u>179,831</u>	<u>893,589</u>
Expenditure on:					
Raising funds	2	7,391	6,441	13,832	14,593
Charitable activities	3	54,788	367,222	422,010	424,017
Total expenditure		<u>62,179</u>	<u>373,663</u>	<u>435,842</u>	<u>438,610</u>
Net income/ (expenditure) before transfer		68,370	(324,381)	(256,011)	454,979
Transfer between funds		-	-	-	-
Net income/(expenditure)		<u>68,370</u>	<u>(324,381)</u>	<u>(256,011)</u>	<u>454,979</u>
Reconciliation of funds					
Balance at 1 January 2019		<u>1,855,198</u>	<u>2,210,841</u>	<u>4,066,039</u>	<u>3,611,060</u>
Balance at 31 December 2020		<u><u>1,923,568</u></u>	<u><u>1,886,460</u></u>	<u><u>3,810,028</u></u>	<u><u>4,066,039</u></u>

All of the charity's activities are derived from continuing operations.

A comparative statement of financial activities is provided in note 13.

Cicely Saunders International

Balance sheet at 31 December 2020

	Notes	2020 £	2019 £
Fixed assets			
Tangible fixed assets	7	-	-
		<hr/>	<hr/>
		-	-
Current assets			
Debtors	8	3,148	20,991
Cash at bank and in hand		4,004,426	4,349,213
		<hr/>	<hr/>
		4,007,574	4,370,204
Creditors: Amounts falling due within one year	9	(197,546)	(304,165)
		<hr/>	<hr/>
Net current assets		3,810,028	4,066,039
		<hr/>	<hr/>
Net assets		3,810,028	4,066,039
		<hr/>	<hr/>
Funds	10		
General funds		136,901	124,331
Designated funds		1,786,667	1,730,867
Restricted funds		1,886,460	2,210,841
		<hr/>	<hr/>
		3,810,028	4,066,039
		<hr/>	<hr/>

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime.

Approved by the Board on 27 July 2021
and signed on its behalf by



John McGrath
Trustee

Cicely Saunders International

Statement of cash flows for the year ended 31 December 2020

	Notes	2020 £	2019 £
Net cash (used in)/provided by operating activities	11	(374,430)	358,667
Cash flows from investing activities:			
Interest received		29,643	34,476
Net cash provided by investing activities		29,643	34,476
Change in cash and cash equivalents in the year		(344,787)	393,143
Cash and equivalents bought forward		4,349,213	3,956,070
Cash and equivalents carried forward		4,004,426	4,349,213

Cicely Saunders International

Notes to the financial statements for the year ended 31 December 2020

1 Accounting policies

1.1 Basis of accounting

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

The charity meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

1.2 Going concern

These financial statements have been prepared on the going concern basis. The charity has significant net current assets, and the trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern. As stated on Page 18, COVID-19 is generating an increased need for palliative care, and for research reflecting the complexity of the management of symptoms in the acute stages, in the rehabilitation phase, in bereavement impact on society, and the delivery of integrated services, for example in care homes. It is anticipated that research activity will increase and has the potential to generate further funding from donors.

1.3 Income

All income is included in the Statement of Financial Activities when the charity is legally entitled to the income, receipt is probable, and the amount can be quantified with reasonable accuracy. For legacies, entitlement is the earlier of the charity being notified of an impending distribution or the legacy being received. Interest earned on fixed term deposits is accrued at the year end and included in debtors.

1.4 Expenditure

Costs of raising funds include costs incurred in encouraging others to make contributions to the charity.

Charitable expenditure comprises costs incurred in furtherance of the charity's objects, and includes research costs, and support costs.

1.5 Tangible fixed assets

Tangible fixed assets with a value exceeding £1,000 are recognised in the balance sheet at cost less depreciation. Depreciation is calculated at rates intended to write off the excess of the cost over the anticipated residual value of the assets on a straight line basis over their estimated useful economic lives. The rate used is as follows:

Computer equipment – 25% per annum

Cicely Saunders International

Notes to the financial statements for the year ended 31 December 2020

1.6 Fund accounting

Unrestricted funds comprise those monies which may be used towards meeting the charitable objects of the charity at the discretion of the trustees.

Designated funds relate to monies set aside by the trustees for a particular purpose or project from unrestricted funds.

Restricted funds comprise monies given for particular restricted purposes or projects.

1.7 Critical accounting judgements and key sources of estimation uncertainty

In the application of the Charity's accounting policies, the Trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and underlying assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

There were no specific judgements, estimates and assumptions that were critical to the preparation of these financial statements.

Cicely Saunders International

Notes to the financial statements for the year ended 31 December 2020

2 Raising funds

	Unrestricted funds £	Restricted funds £	Total funds 2020 £	Total funds 2019 £
Materials	1,303	-	1,303	4,731
Support costs (see note 4)	6,088	6,441	12,529	9,862
	<u>7,391</u>	<u>6,441</u>	<u>13,832</u>	<u>14,593</u>

3 Charitable activities

	Unrestricted funds £	Restricted funds £	Total funds 2020 £	Total funds 2019 £
Direct programme costs	-	309,256	309,256	335,272
Support costs (see note 4)	54,788	57,966	112,754	88,745
	<u>54,788</u>	<u>367,222</u>	<u>422,010</u>	<u>424,017</u>

4 Support costs

	Raising funds £	Charitable activities £	Total 2020 £	Total 2019 £
Administrator costs	6,440	57,966	64,406	61,860
Travel & subsistence	41	367	408	4,906
Printing, postage & stationery	320	2,878	3,198	1,011
Audit fee	776	6,981	7,757	6,218
Accountancy	270	2,430	2,700	2,700
Company Secretarial	174	1,566	1,740	1,416
Professional & consultancy	4,489	40,402	44,891	19,657
Other expenses	18	164	182	839
	<u>12,529</u>	<u>112,754</u>	<u>125,282</u>	<u>98,607</u>

Support costs are allocated based on the staff time spent on each activity. Governance costs consisted of professional fees of £57,088 (2019: £29,991).

Cicely Saunders International

Notes to the financial statements for the year ended 31 December 2020

5 Net movement in funds

	Unrestricted funds 2020 £	Unrestricted funds 2019 £
Net (expenditure)/ income is stated after:		
Depreciation	-	-
Auditors' remuneration		
- Audit	7,757	6,218
- Accounting services	2,700	2,700
- Company secretarial	1,740	1,416
	<u> </u>	<u> </u>

6 Staff costs and trustees' remuneration

The charity does not directly employ any members of staff. Costs relating to the Scientific Director and Administrator are shown in notes 3 and 4. These costs are recharged from King's College London.

The trustees received no remuneration in respect of their services to CS International during either year. No trustees were reimbursed expenses during the year (2019: one trustee received £224).

7 Tangible fixed assets

	Computer equipment £
Cost	
At 1 January 2020	3,822
Additions	-
	<u> </u>
At 31 December 2020	3,822
	<u> </u>
Depreciation	
At 1 January 2020	3,822
Charge for the year	-
	<u> </u>
At 31 December 2020	3,822
	<u> </u>
Net book value	
At 31 December 2020	-
	<u> </u>
At 31 December 2019	-
	<u> </u>

Cicely Saunders International

Notes to the financial statements for the year ended 31 December 2020

8	Debtors		
		2020	2019
		£	£
	Prepayments and accrued income	3,148	20,991
		<u> </u>	<u> </u>
9	Creditors: Amounts falling due within one year		
		2020	2019
		£	£
	Accruals	197,546	304,165
		<u> </u>	<u> </u>

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Notes to the financial statements for the year ended 31 December 2020

10 Funds

	At 1 January 2020 £	Income £	Expenditure £	Transfers £	At 31 December 2020 £
General funds	124,331	30,549	(17,979)	-	136,901
Designated funds					
Cicely Saunders Institute Research	319,118	-	-	-	319,118
Other designated funds	30,178	-	-	-	30,178
Research implementation	625,000	-	(33,400)	-	591,600
International Palliative Care Research and International Development	756,571	-	(10,800)	-	745,771
Dementia Health Economics	-	100,000	-	-	100,000
Total designated funds	1,730,867	100,000	(44,200)	-	1,786,667
Total unrestricted funds	1,855,198	130,549	(62,179)	-	1,923,568
Restricted funds					
Breathlessness Programme	132,708	-	(13,057)	-	119,651
BuildCARE	443,560	-	2,896	-	446,456
Palliative Care Clusters	1,108,929	-	(173,989)	-	934,940
Support for MSc scholarships	1,007	-	(600)	-	407
Gulbenkian Foundation	1,227	-	-	-	1,227
Garfield Weston	252,214	-	(168,913)	-	83,301
Professorship grant	264,770	49,282	(20,000)	-	294,052
The Sir Halley Stewart Trust	6,426	-	-	-	6,426
Total restricted funds	2,210,841	49,282	(373,663)	-	1,886,460
Total funds	4,066,039	179,831	(435,842)	-	3,810,028

Cicely Saunders Institute Research: Funding for the construction of the Cicely Saunders Institute was not fully used after matched funding so it was agreed with Atlantic Philanthropies that the excess would be put to research at the Institute. The timescale for the use of these funds is under review pending the outcome of the current fundraising initiative for capacity building via the permanent establishment of a professorship.

Research implementation: Unrestricted funds received in 2019 were designated by the trustees for a programme to put research into practice through training fellowships and outreach initiatives.

Cicely Saunders International

Notes to the financial statements for the year ended 31 December 2020

10 Funds (continued)

Other designated funds: Other designated funds include £3,615 for administration costs, £15,000 for Scientific Director costs, and £11,067 for IT and other costs.

International Palliative Care Research and International Development:

Hospice Education Institute has provided funds for palliative care research and international development. The programme of one-day international study days in 2017 and 2018 was followed in October 2019 by a study day on the use of big data in palliative care. The funds received were unrestricted. The board took the decision to transfer the funds to a designated fund to focus on international research and development. In 2019 the board decided to use some of the funds to match-fund the permanent professorship.

Dementia Health Economics:

In aging societies, more people with dementia will need palliative care. Building on the work of the BuildCARE and Palliative Care Clusters programmes this programme of research is investigating health economic costs of models of care for people with dementia.

Breathlessness Programme: Breathlessness and breathing difficulties are among the most common and distressing symptoms for several progressive illnesses, especially towards the end of life. CS International is working with the Department of Palliative Care, Policy and Rehabilitation at King's College London to establish a multi-centre research collaboration on breathlessness.

BuildCARE: This programme (commencing May 2011) is funded by The Atlantic Philanthropies to build capacity, and improve access, rights and empowerment. The project has four components: The Cicely Saunders International PhD Studentship Programme; Cicely Saunders International Faculty Scholars; the International Access, Rights and Empowerment Study (IARE); and the Dissemination, Engagement and Empowerment Programme (DEE). Via these four streams of activity we aim to identify, recruit and develop future academic and clinical stars in the field of palliative care; disseminate expertise and research developed by staff at the Institute across the globe; compare palliative care experiences in London, Dublin and New York City; engage our communities in our work; empower patients and improve their access to care.

Palliative Care Clusters: There are three elements to this programme which was awarded to CS International by The Atlantic Philanthropies in October 2014.

- **Project GlobalCARE :** the purpose of this grant is to improve how chronic conditions are managed for millions of people by supporting the development of palliative care tools, resources and training programmes that support health care professionals to identify problems earlier, assess patients' and families' needs, and respond with more appropriate and cost effective models of care.
- **Fellowships Consortium:** the purpose of this grant is to improve global access for the growing numbers of people in need of palliative care, and to embed palliative care into international policy and practice, by developing a global Fellowship Programme that supports international collaboration, community building and leadership development. Collaborators in this programme are based in London, Dublin, New York, Northern Ireland and Vietnam.
- **International Access Rights and Empowerment Study (IARE II):** building on the IARE component of the BuildCARE programme (see above), the purpose of this grant is to influence

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Notes to the financial statements for the year ended 31 December 2020

policy, funding and practice and to integrate palliative care into chronic care settings by supporting Phase II of an international comparative study (London, Dublin and New York).

10 Funds (continued)

Support for MSc scholarships: Funding has been provided in memory of Professor Rob Buckman for two scholarships and by Grunenthal Limited to support MSc scholarships in palliative care at King's College London.

Gulbenkian Foundation: Gulbenkian Foundation has funded the setting up of the Clinical Academic Forum of Palliative Care of the north region of Portugal.

Garfield Weston Foundation: The Garfield Weston Foundation has provided funds for new infrastructure and facilities at the Cicely Saunders Institute to enable the Cicely Saunders Institute's outreach programme to reach more than one million people each year across the country, capitalizing on our position as one of the leading providers of palliative care development, education and clinical research in the UK.

Professorship Grant: The Atlantic Philanthropies has provided funds for an endowed Professorship in Palliative Care.

The Sir Halley Stewart Trust: The Sir Halley Stewart Trust has provided funds for a scholarship programme to improve capacity for care for the dying in Africa through the vision of Dame Cicely Saunders.

All fund balances at 31 December 2020 were held within net current assets.

11 Reconciliation of net (expenditure)/ income to net cash provided by operating activities

	2020	2019
	£	£
Net (expenditure)/income for the year	(256,011)	454,979
Adjustments for:		
Interest receivable	(29,643)	(34,476)
Increase/(decrease) in debtors	17,843	(16,065)
(Increase) in creditors	(106,619)	(45,771)
Net cash (used in) / provided by operating activities	<u>(374,430)</u>	<u>358,667</u>

Cicely Saunders International

Notes to the financial statements for the year ended 31 December 2020

12 Financial instruments

	2020 £	2019 £
Financial assets measured at amortised cost	3,148	20,991
Financial liabilities measured at amortised cost	197,546	304,165

13 Comparative Statement of Financial Activities

	Unrestricted funds £	Restricted funds £	Total funds 2019 £
Income and expenditure			
Income from:			
Donations and legacies	626,498	232,615	859,113
Investments	34,476	-	34,476
Total income	660,974	232,615	893,589
Expenditure on:			
Raising funds	8,407	6,186	14,593
Charitable activities	33,071	390,946	424,017
Total expenditure	41,478	397,132	438,610
Net income / (expenditure) before transfers	619,496	(164,517)	454,979
Transfer between funds	(1,855)	1,855	-
Net income / (expenditure)	617,641	(162,662)	454,979
Reconciliation of funds			
Balance at 31 December 2018	1,237,557	2,373,503	3,611,060

Cicely Saunders International

Notes to the financial statements for the year ended 31 December 2020

Balance at 31 December 2019	1,855,198	2,210,841	4,066,039
	<u> </u>	<u> </u>	<u> </u>

14 Related party transactions

No donations were received from trustees during 2020 (2019: £500,000). The donations were made without conditions.