Building Palliative Care Globally: The Cicely Saunders Institute Journey

Olivia Dix and the Cicely Saunders Institute August 2017

Introduction

The importance of palliative care is increasingly acknowledged globally, as demonstrated by the World Health Organization's (WHO) resolution on palliative care in 2014 that recommended *"strengthening of palliative care as a component of integrated treatment within the continuum of care."* This resolution outlined a set of standards and guidelines for palliative care and signalled to national governments that palliative care must be part of their health policies, budgets, and healthcare education. However, there is still a very long way to go. A 2014 report by the WHO and the Worldwide Palliative Care Initiative estimated that only 14% of those in need of palliative care receive it.[1]

This case study looks at the impact of the establishment of the Cicely Saunders Institute (CSI) at Kings College London, U.K, on the field of palliative care. CSI was established in partnership with the charity Cicely Saunders International and BuildCARE, an Atlantic Philanthropies' (Atlantic) funded programme within the Institute. The case study focuses on the International Access Rights and Empowerment Study (IARE 1), which aimed to generate information to improve the access, rights, and empowerment of older people who need end-of-life and palliative care and human capital development at senior and junior levels. It identifies the societal and clinical issues that the Institute and the initiatives intended to solve, appraises their impact, both immediate and long-term, and highlights the learning points from the work.

The Cicely Saunders Institute of Palliative Care, Policy, & Rehabilitation

The Cicely Saunders Institute, for which Atlantic was the biggest single funder and whose support of matched funding made the Institute happen, opened in 2010. It is the world's only institute dedicated to palliative and end-of-life care and rehabilitation and is a designated WHO Collaborating Centre. It is a partnership between Cicely Saunders International, the only organisation in the world solely dedicated to research and the improvement of services in palliative care; King's College London, one of the world's leading teaching and research universities; and King's Health Partners, a pioneering academic health science centre with three leading London NHS Foundation Trusts: Kings College Hospital, Guy's and St Thomas', and the South London and Maudsley. Professor Irene Higginson, head of the department of palliative care and policy at Kings College London and a world leader in palliative care, heads the CSI.

The Institute building houses:

- The academic department of palliative care, King's College London
- The clinical teams of King's College Hospital, and other King's Health Partners

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[1] *Global Atlas of Palliative Care at End of Life.* Connor SR, MCS B editor. London 2016: World Health Organisation

(Guys and St Thomas's and Princess Royal University Hospital)
- Macmillan Patient and Information Support Centre.

Why Build an Institute?

Despite the growing need for palliative care, driven by an ageing population living longer with more complex needs, palliative care still lacks the status it deserves. It is vulnerable to losing funding in times of austerity, it has not been integrated into the care of all people with diseases who could benefit from it, it lacks some tools and measures, and does not yet provide a strong career track for medical professionals and researchers. While there are pockets of excellent end-of-life and palliative care globally, huge disparities exist in the care provided to patients and their families.

The Cicely Saunders Institute is a beacon centre, a combination of investment in physical, human, and research/intelligence capital. It pioneers the very best in palliative care and rehabilitation through the integration of cutting-edge research, skilled multi-professional care, and innovation in engagement and education. The creation of physical capital, in the form of a building, is a visible sign of the importance of palliative care and provides essential infrastructure for the staff.

The Institute brings together in one centre, in person and through its networks, the human capital - the academics, community organisations, patients, and carers - and acts as a hub for international research. It offers high quality palliative care solutions to patients as well as education, patient information, and support. Through the range of activities within the centre, its international collaborations, and the quality of its research outputs it has raised the awareness and status of palliative care globally.

The physical space plays an important role in supporting CSI’s work. It was carefully designed along hospice principles −with strong patient involvement − to be a calm and welcoming building, conducive to reflection, study, and collaboration. The central atrium, and the ability to see from one floor to another and from one side to another, emphasises the spirit of collaboration and a single shared coffee area/kitchen space allows ideas to flow between clinical and academic teams. The Institute has been awarded a BREEAM award, the world’s leading sustainability assessment method, for its environmental credentials, including ground source heat pumps and natural cooling.

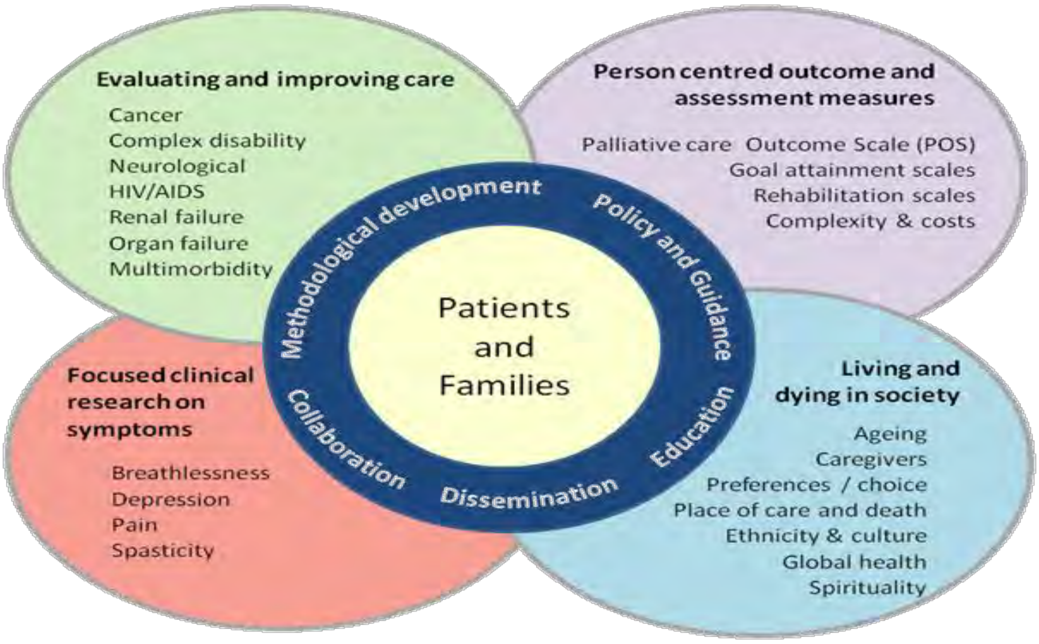
The Cicely Saunders Institute

"The impressions I had in my mind were about ebb and flow, not being sucked in or blown out, but being held long enough to make good decisions for oneself and/or for those other people we love. It goes without saying that quality speaks and conveys a positive message. It comes across in the skilful use of natural light and lighting, appropriate colours, textures, textiles and flooring. The use of natural growing plants is essential, not simply a standard part of the décor but as tangible signs of the cycle of life, sentinels along the pathways of hope and continuity."
Cynthia Benz: patient representative on the steering group for the CSI building

As well as a welcoming physical space in which to work, staff at the CSI are supported by inclusive personnel policies that reflect the collaborative and outward-looking nature of its work. The CSI it is proud to have an Athena Swan Silver award, which recognises advancement of gender equality, and a Bronze award under the Race Equality Charter, which provides a framework for institutions to improve the representation, progression, and success of minority ethnic staff and students.

The Institute provides a rare opportunity for clinical and academic pathways to exist in the same place, including clinicians from hospices, which operate outside the main healthcare system*.* Traditionally, there are tensions between the different perspectives of clinicians and academics, with the respective timeframes being a major issue. Clinicians deal with immediate patient problems daily and may not always see the value of research to their work whereas academics, with the longer, wider, view, can see clinicians as not concerned enough with the evidence base. The CSI community of academics and clinicians encourages a creative cross-fertilisation of ideas and peer-to-peer support and enables each to appreciate the other's contribution to the field.

Externally, patients and the public are involved in the design and execution of research programmes and staff and students are linked, through collaborative work, lectures, seminars, and education activities with many thousands of people globally.



Themes in the Cicely Saunders Institute: clinical, research and education integration; patient, family, public, and policy engagement.

Learning Points

- There are advantages and disadvantages to being part of another, larger institution. On the one hand it gives CSI access to the facilities, infrastructure, and expertise of Kings College, the hospital and Kings College Health Partners and the benefits of being associated with a world-renowned brand. It is also a model that has inspired other universities to engage in palliative care, and reaches medical student education. On the other hand, it is more difficult to ensure the CSI remains a distinctive and well-resourced entity when there are financial and political pressures on hospitals and academic institutions.

- Working with another charity, Cicely Saunders International has been vital. Its assessment of the research undertaken, through the International Scientific Expert Panel, helped ensure its quality and usefulness. The involvement of senior business leaders and the investment by Atlantic gives credibility to this area of science that is rarely seen as a priority for universities.

- Creating a community of clinicians and academics increases impact and understanding, but needs to challenge some deeply-held assumptions.

BuildCARE (2010 to 2014)

Atlantic invested substantially in both the physical and programmatic structure of the CSI through the programme BuildCARE. The investments were intended to kick start its core national and international work, leverage maximum benefit from the world-class facility and, overall, create a sea change in the way palliative and end-of-life care is regarded, implemented and prioritised internationally.

The key challenges addressed by the programmes in BuildCARE are:

- Palliative and end-of-life care have evolved in different ways across the world, leading to differential access and sometimes reduced empowerment of patients and families.

- The very oldest people often experience multiple chronic diseases, such as heart failure, respiratory failure, and cancer, and face a wide range of problems. Palliative care is only slowly moving into these areas.

- End-of-life and palliative care continue to be ‘Cinderella’ subjects in the medical field: the progress made in research and practice is not moving quickly enough from the centres of excellence into the day-to-day work of clinicians.

- There is a serious lack of expertise at every level globally.
    - Education in end-of-life and palliative care on undergraduate and pre-registration healthcare courses is patchy with many institutions lacking the expertise to teach up-to-date modules in this area.
    - Access to postgraduate courses is very limited and students often have pay for themselves, excluding a sizable number of people, particularly from developing countries. Very few courses are open to healthcare professionals other than doctors.
    - Researchers and clinicians working in end-of-life and palliative care often find a gap between qualification and obtaining senior level positions, discouraging them from pursuing this specialty so they switch instead to higher profile, better-resourced areas of healthcare.
    - The lack of mid-level staff and posts restricts the supply of experts of the calibre of current world leaders. This skills gap restricts the growth of the field and is a deterrent to investment in academic palliative care by healthcare institutions and grantmakers worldwide.
    - Public awareness is limited, and the scope of the discipline misunderstood. There must be broad public support for palliative care in order to build investment in this area from policymakers, grantmakers, and industry leaders.

In response to these challenges Project BuildCARE has three elements:

- Nurturing and building talent in the field by creating coherent career paths and plugging the skills gaps through the creation of Cicely Saunders International PhD Studentships and Cicely Saunders International Faculty Scholars.

- Improving access and empowerment and securing rights by conducting international comparison of end-of-life care for older people in three countries, where access and rights differ, to identify gaps and empower and improve care for those who are disadvantaged (the IARE study).

- Leveraging the strength of the Institute by creating a comprehensive international dissemination, public engagement, and empowerment programme.

Cicely Saunders International PhD studentships and Faculty Scholars programme

Faculty Scholars are exceptional individuals from around the world working in the field of end-of-life and palliative care. They are the future leaders and investigators, particularly in clinical areas. Each studies at the Institute for three to four years before moving on to take senior positions around the world.

This programme has demonstrated how it is possible to build palliative care capacity and career paths for academics and clinical staff. The first Faculty Scholar is now a professor of palliative medicine in Germany, the second and third have achieved prestigious posts at Cancer Australia and the University of Bristol respectively and two later Faculty Scholars have now won important further support and are on track to become future professors and leaders. One of these has won the first ever U.K Clinician Scientist in Palliative Care, the other the first ever National Institute for Health Research (NIHR) senior clinical lecturer in nursing in palliative care.

An important aspect of the research undertaken through this programme, BuildCARE in general and other CSI funding is its relevance to current and emerging health and societal needs. In relation to the economic climate and the need to show that services are cost-effective, the work on the economic costs and cost-effectiveness of palliative care has been crucial. With ageing populations, increased frailty, and multiple chronic conditions, palliative care needs to be available in more places and for more conditions. Research undertaken by the fellows, PhD students, and CSI staff has:

- Pioneered new approaches to hospital admissions for older people.
- Helped showcase how palliative care can be provided beyond cancer in Ireland
- Improved palliative care for people with dementia in nursing homes.

Importantly to CSI's global vision, there are PhD and MSc students from many parts of the world, including Asia and Africa, for whom the CSI offers opportunities, unavailable in their own country, to pursue their academic and career interests and who, in turn, enrich the other work undertaken at the CSI.

As a PhD training research fellow, being part of the CSI has given me a wonderful opportunity for professional development, which I could not have achieved in Africa. I have benefited from the holistic approach to skill development – ideally, what any palliative care professional would ever need to deliver, with a touch of excellence, multi-tasking, and networking.
Eve Namisango, research manager, African Palliative Care Association

Learning points

- Flexibility and sustained effort were necessary to get this programme started. At first it was only possible to recruit to the junior posts. Palliative care is a speciality with shortages in personnel at all levels, which partly reflects that its status still needs to be increased. There are not enough people being trained or academic places available for researchers resulting in shortages in people coming through to senior posts. The CSI used its networks, increasing reputation, and its building to attract the Faculty Scholars, held out for talent and potential, and accepted that the programme would start late.

Recruiting internationally is fundamental to the CSI’s work but international travel and acquiring visa is difficult from many countries and exchanges can also be problematic, causing delays. The impact of Brexit is not yet known.

- When the programme started there were vacant chairs in palliative care across the world. The situation has improved, but an urgent need remains for more training programmes like the one at the CSI.

- It is essential to have end-of-life specialists to speak with authority equal to that of other specialties such as neurology, cardiology, or oncology.

- It is also important to develop capacity in the more junior level to help mid-career posts in the future.

- The model of identifying of individuals of talent, providing bridging funding, academic support and supervision to enable them to complete essential work, and/or win a more substantial research award appears effective.

- **In the U.K only 0.2% of funding goes to palliative care and even in cancer it is less than 1%.** This funding is split across a large number of small grants for short periods of time. Bridging funding helps to maintain people in the field while waiting for longer-term posts. It is usually for one year, but flexibility is critical, as these more sustained posts are difficult to win. This was not envisaged in the original application but flexibility from the funders allowed this model to emerge when the senior posts proved difficult to fill.

- A key remaining challenge is to ensure that the PhD alumni can access the next step to becoming major leaders in the field. This is a concern across CSI partners for doctors and allied health professionals working on dementia and in health economics where there are few or no clinical intermediate academic posts.

Staff and students of the Cicely Saunders Institute July 2017

International Access, Rights and Empowerment Programme
IARE I (2010 to 2014)

International collaboration is at the heart of CSI's work. IARE is a research collaboration between Ireland, the U.K, and the U.S. led respectively by Professor Charles Normand, Professor Irene Higginson, and Drs. Diane Meier and Sean Morrison. All three countries have ageing populations and the chronic disease burden this will bring will challenge their healthcare systems, despite palliative care being long established. However, access varies from country to country, by age, by social class, and by disease.

IARE1's aim was to generate information to improve the access, rights, and empowerment of older people who need end-of-life and palliative care. Because palliative care developed as an alternative to mainstream medical care for people with cancer near the end of their lives, the evidence base is focused on middle-aged white cancer patients. With a few notable exceptions, the leading palliative care research centres are located within cancer centres. It is therefore not surprising that symptom studies have focused predominantly on cancer patients and on pain and many studies have excluded older people and those with associated co-morbidities.

The study is a world first; with the exception of drug trials, which are usually focussed on a specific treatment rather than how care is provided, nobody has ever collected the same data prospectively or retrospectively across countries in palliative or end-of-life care. The study was based in the largest cities in Ireland, the U.K, and the US - Dublin, London, and New York City - to reflect their national demographic trends and where they have in common large Irish populations. It compared three models of care delivery provided by three academic centres in the respective cities: St James Hospital, King's College Hospital, and Mt Sinai Medical Centre. Their cities have:

- Different end-of-life and palliative care delivery systems that have evolved over time to meet their populations' changing needs. In New York services are focussed close to death, but care is for people with a range of diseases, whereas in Dublin services care almost exclusively for people with cancer. In London services care for people with cancer and non-cancer conditions, although cancer dominates, but care starts at an earlier stage and is shared with hospital and community services.

- A mix of tertiary hospitals, community services, and academic programmes, researching and providing end-of-life and palliative care to patients and families

- Policymakers and advocates who contribute to an active dialogue and help to disseminate knowledge rapidly, improving the quality of end of life and palliative care.

The programme:

- Examined how each system meets the needs of their patient population

- Compared the scope and delivery of end-of-life and palliative care services in these three settings with well-established care infrastructures to assess the extent to which each model meets the needs of the ageing, chronically ill population

- Highlighted common issues across the three different health systems

- Distilled learning points from the different approaches

- Developed an economic evaluation tool for end-of-life and palliative care

- Produced for each city costs of end-of-life and palliative care delivery and patients' care preferences.

Learning points

- The data showed that across all three countries people wanted similar things from palliative care; immediate, convenient access, individualised care, and expert services. Respondents showed a strong preference for a service that focused on improving quality of life, with or without extending life.

- There were equally strong preferences for home support and dying at home in all countries, although, interestingly, around 16% chose home as their least favourite option. Although older age did not make people less likely to want to be cared for and to die at home, they were less likely to do so, suggesting an imbalance between their wishes and their realisation.

- Inpatient hospices and palliative care units were an important second choice, suggesting that these are particularly important alternatives. In the U.S., the only setting where a palliative care ward in a hospital was offered, the preference for inpatient palliative care unit was highest, indicating that this alternative is preferred when available. People with non-cancer conditions were more likely to prefer inpatient hospice, and yet in the U.K and Ireland this group have the least access.

- The study concluded that:

    - The capacity to meet the needs of a patient and their family wherever the patient dies may be a better-quality indicator than simply achieved preferences.

    - In general, people were very satisfied with the palliative care services they received, but less so with other services.

    - There are common barriers to palliative care access in the U.K, U.S. and Ireland, yet variation in its affordability.

    - The data shows that overall care cost is highest in New York and lowest in London. Informal care costs – such as those provided by families and friends – are by far the largest components of costs, followed by hospital costs. Data also found major symptom and family burdens towards the end of life, underlining the importance of palliative care.

    - Patients’ and carers’ characteristics explain some variation, but society and country level factors need further exploration. Combined efforts to improve access may be effective, yet individual societal differences such as health care models, the labour market and benefit systems need to be taken into account.

The Dissemination Engagement and Empowerment Programme

Crucial to the work of CSI and the BuildCARE programme is ensuring that the profile of palliative care is raised, that the maximum number of people can engage with the work and that it influences public policy. The Dissemination Engagement and Empowerment (DEE) programme utilised the state-of-the-art facilities at the Institute to ensure all activities reached the widest possible audience and were recorded and available on the internet and other electronic platforms. This programme has been integrated into the general work of the CSI to ensure it is sustained.

The dissemination programme has two main elements:

Dissemination to healthcare professionals

- The centrepiece of this programme is the Dame Cicely Saunders Annual Lecture, given by an international leader in the field of palliative care. It also includes lectures and a week-long 'master-class' where end-of-life and palliative care professionals can access the expertise of the speaker.

- Healthcare professionals throughout the world, including developing countries in Africa, South America, and Asia, access the lectures and workshops. The Cicely Saunders International Scholars, PhD students, and staff working on the IARE programme are involved in these activities.

- There is open access for exchanges and visitors to the Institute to benefit from the expertise and to extend collaboration.

Public engagement and empowerment

A wide range of awareness raising activities take place to engage and empower the public in the issues of end-of-life and palliative care including:

- Using print, broadcast, and social media to enhance the profile of both the Institute and palliative care

- Open days for patients, their families, and user organisations

- Enhanced web-based access for members of the public with information on what constitutes the best in care and involvement with community events

- Participation in public debates and policy discussions.

The programme has reached over 30 million people by:

- Directly sharing knowledge with 240,000+ palliative care clinicians, service planners, service users, funders & policymakers

- Improving care for an estimated 12 million patients, benefiting 24 million families & carers

- Supporting 58 palliative care conferences and lectures in 4 years, with audiences exceeding 32,000 experts. The Institute's YouTube channel hosts 66 videos and has attracted over 14,000 views to date

- Engaging with more than 100,000 stakeholders via the online activity programme established under project BuildCARE

- The publication of 407+ outputs in high impact journals, read by an estimated 30,000 stakeholders.

Government thinking and policy

Influencing policymakers requires both robust evidence and engagement. Integrating a dissemination element into the overall BuildCARE research programme ensures that the evidence being presented to policymakers and others is robust, believable, and defensible. Policy change is long-term, and often slow, and the solutions to the problems posed for health and social care in the future are complex, but **CSI and BuildCARE have had notable impact. One international example is The World Health Assembly Resolution on palliative care in 2014. The needs assessment underpinning the evidence of global need for palliative care and its effectiveness used research from the CSI and the BuildCARE programme and several team members acted as advisors.**

In the U.K, during the BuildCARE programme, achieving home care and death at home, if preferred, became a key part of National Health Service (NHS) strategy.

Evidence from the Institute, including findings on the needs of older people in palliative care, has been cited in policy documents helping to plan and shape services. The U. K's National Institute for Health Research (NIHR) chose to focus on palliative and end-of-life care as its first Themed Review on the Impact of NIHR supported research, published as *Better Endings*, in December 2015.[2] It drew substantially on research undertaken at the Institute and highlighted existing evidence to help those delivering, planning, or using end-of-life services.

Evidence needs to be combined with advocacy and the CSI helped to establish the End-of-Life Care Campaign in the U.K with six other charities in 2015. This was successful in getting government and media attention but, as with all collaborations, it had some difficulties. Largely these were because some of the charities were focused on advocacy and had set agendas that were not always founded on good evidence. This caused tensions, although the subsequent discussions led to the Campaign choosing more evidence-based priorities.

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[2] National Institute for Health Research. *Better Endings: Right Care, Right Place, Right Time.* NHS London December 2015

END OF LIFE CARE COALITION

We are calling for high quality, personalised care for people approaching the end of their life, wherever and whenever they need it. Our priorities are:

Delivery of the National Commitment on end of life care

Embedding the Government's new National Commitment across all health and care programmes – including local Sustainability and Transformation Plans – backed up by adequate resource, robust and evidence-based evaluation and an annual progress review

1. Coordination of care between services

Enabling patient and family priorities to be consistently addressed, whoever is providing care

- Access to an assigned contact point for people to liaise with about their care and preferences
- Ensure all health and care partners have access to appropriate information

2. Provision of a range of high quality community care options

Ensuring dying people, their families and carers, have access to the best community support, advice and care

- Prompt access to community nursing, pharmacy, and occupational therapy services to support people to stay at home
- Provision of 24/7 specialist palliative care team advice and support in the community

3. Improvement in the quality of end of life care in hospital

Providing excellent care to the fifty percent of people who currently die in hospital, and their families and carers

- Access to face to face, specialist palliative care services seven days a week
- Training in end of life care for all health care professionals caring for dying people

Greater societal understanding and recognition of dying, death and bereavement

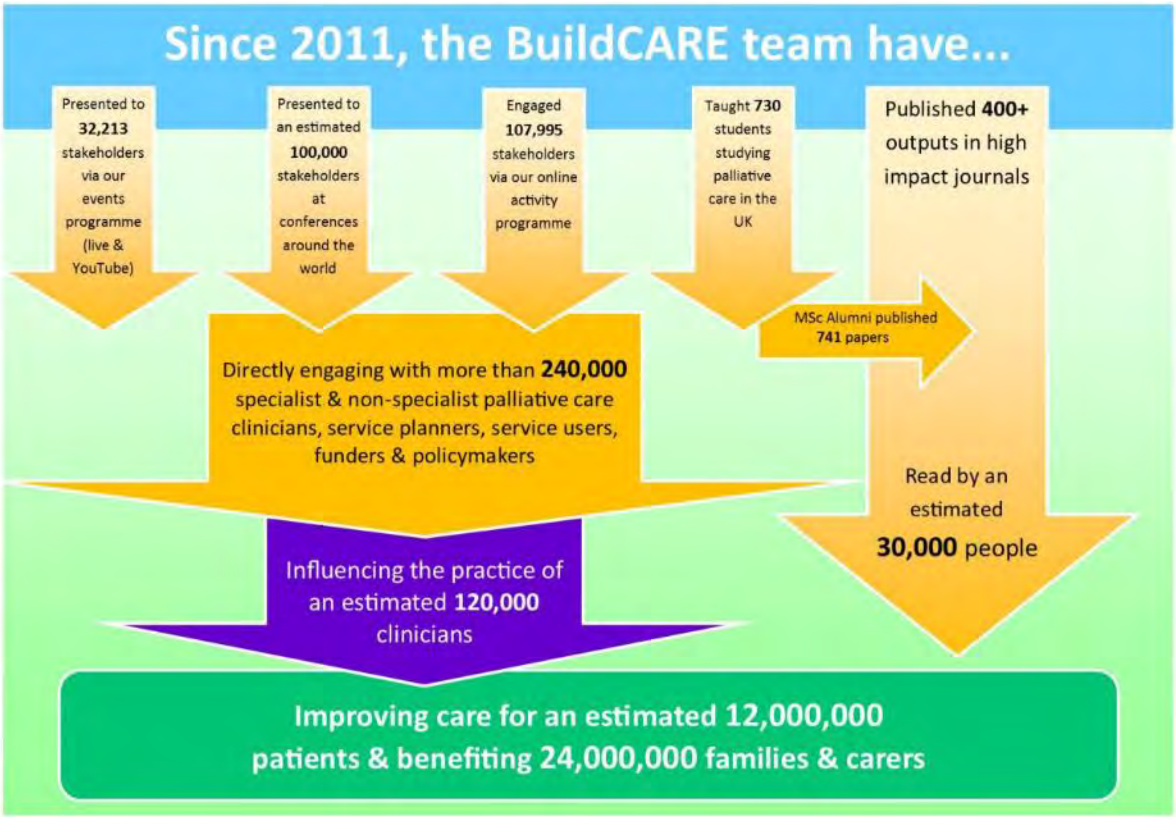
Find out more at:
endoflifecampaign.org

Media coverage

Media attention on palliative care increases public awareness and can strike a chord at a particular time. For example, an article published *BMC Medicine* in 2017 looking at needs for palliative care in the future entitled "How many people will need palliative care in 2040? Past trends, future projections and implications for services attracted considerable publicity," received 70 media hits with articles in most of the main newspapers in the U.K and two of them using the research in their analysis of the Conservative Party manifesto.

The *BMC Medicine* article projected an increase of up to 25% in annual deaths in England and Wales by 2040 with cancer and dementia being the main drivers for increased need for palliative care. The majority of the media reporting focused on the number of predicted dementia deaths, reflecting current public concern about dementia and one aspect of the Conservative Party election manifesto.

A summary of the overall impact can be seen in the diagram below.



Since 2011, the BuildCARE team have...

Presented to **32,213** stakeholders via our events programme (live & YouTube)

Presented to an estimated **100,000** stakeholders at conferences around the world

Engaged **107,995** stakeholders via our online activity programme

Taught **730** students studying palliative care in the UK

Published **400+** outputs in high impact journals

MSc Alumni published **741** papers

Directly engaging with more than **240,000** specialist & non-specialist palliative care clinicians, service planners, service users, funders & policymakers

Read by an estimated **30,000** people

Influencing the practice of an estimated **120,000** clinicians

Improving care for an estimated 12,000,000 patients & benefiting 24,000,000 families & carers

Learning Points

- Linking public engagement and advocacy to research in the way the DEE programme has done is transformational, as it gives substance to the advocacy work and ensures that important research moves from academia into the policy arena.

- Working with other organisations that share the same goals, but may have different approaches, increases impact but can lead to tensions that need to be resolved. This takes time.

- Funding for this type of work adds immense impact to research but is difficult to obtain.

- Consistent engagement with government and policymakers is essential to gain traction but progress can be slow.

- It is important to use as many ways of reaching and informing people as possible.

- Media coverage is important, but it can be difficult to control its direction.

- Patient and public involvement is essential in ensuring that research and solutions are grounded in their needs. This area of work continues to grow with the newest development being an online forum for patient and public involvement.

Funding

The programme has exceeded expectations, not only because of what BuildCARE and IARE have achieved but also because of the multiplier effect of Atlantic's funding. The capital grant for the CSI, an Atlantic Founder's grant, was the largest single donation and enabled the Institute to be built while the grant of £2.79m to Project BuildCARE allowed access to matched and other funding of £15 million, significantly increasing and prolonging the number of fellowships, research produced and overall impact.

Research Funding

One projected outcome of BuildCARE was greater funding for research in the future. Although change is slow, an increased proportion of research spending on palliative and end-of-life care can be seen in Ireland, the U.K, the US, Australia, and many other countries, despite the economic downturn.

This increase in support for palliative care research was boosted by CSI's work in highlighting the low levels of funding it received, which was published in *The Lancet*. Further work demonstrated the low levels of funding in non-cancer conditions and how research can be improved. The CSI also published a series of guidance on research methods in palliative and end of life care.

Why fund palliative care?

- Palliative care improves the quality of life for patients and their families at no additional cost. In the future an ageing population means there will be more people dying and living longer with more complex symptoms and frailties. For example, in the U.K, by 2040 there will be a 25% increase in annual deaths, mostly in people over 85 years old, with a concomitant increase of 42% in the need for palliative care.

- There is an urgent need to ensure there are enough trained palliative care clinicians and nurses to support this population. Where there is a general shortage of clinicians in resource-poor countries, innovative low-cost solutions need to be found to support the populations' palliative care needs.

- Research should be funded to ensure that there is a firm evidence base of the best way to provide palliative care in the future.

A tribute to the early successes of BuildCARE was Atlantic's decision to fund three strands of work 'The Palliative Care Cluster' separately from 2014 to 2017. The overall aim of these strands of work 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.

The strands are:

- The Fellowships Consortium encompassing:
    - The creation of thirteen fellowship positions - three each in the Republic of Ireland, New York and the CSI, two in Vietnam, and one each in Northern Ireland and India
    - Community building to bring together early-stage investigators and provide peer-to–peer support for research workshops, courses and web-based resources, and public and patient involvement.
    - Dissemination of findings from CSI and its partners, the Campaign for the Advancement of Palliative Care (New York), and Ireland.
- Project GlobalCARE, aiming to improve how chronic conditions are managed for millions of people by developing palliative care tools, resources and training programmes to support health professionals. Already, building on previously funded work by Atlantic, the CSI has launched a Global Centre for Health, Palliative Care.
- IARE II, building on the work of IARE I. This study is examining the preferences and care experiences of patients and families with chronic disease who are not afforded access to specialist palliative care. The team includes four patient and public involvement members. 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. (*See the case study *Economics of Palliative Care: Evidence and Impact from Four Recent Studies* by Bridget Johnston, Charles Normand and Peter May for details of IARE II).

Challenges for the Future
With an ageing population world-wide, there is an urgent need to identify better models of care and treatment that are cost-effective. To do this there needs to be a considerable growth of capacity in research and training and this can only happen if more substantial long-term funding is available. Convincing governments and the public of the importance of palliative care will remain a challenge.

Conclusion

The CSI has shown it is possible to have impact globally by adopting a rigorous, outward-facing, and collaborative approach. Thanks to the far-sighted funding by The Atlantic Philanthropies its work has demonstrated that access to programmatic, long-term funding with a combination of investment in infrastructure and human resources, builds the strong foundations that produce the future leaders in palliative care. Key to its success is that the Institute's work reflects the principles of palliative care. Putting the needs of the patient and their families at the centre of all clinical interventions and research ensures that the research produced has practical application in the health systems.

"I cannot praise too highly CSI's inclusivity and support. The first time I was invited to a Patient Family and Public involvement meeting was shortly after the recent death of my son, which had given me a commitment to improving communication between health care professionals and the public. I had spoken to professionals before, but never been faced with a room full of academics. I found that experience, and all subsequent ones, heartening and empowering. They were accepting of the value of the lay voice, and very keen to ensure that research always had a public/patient focus and a clear route to genuine improvement. I have been delighted to be involved in a variety of research projects with CSI. "
Tony Bonser

Resources

The Cicely Saunders Institute website https://cicelysaundersinternational.org/cicely-saunders-institute/

The Palliative Care Outcome Scale (POS) is a resource for palliative care practice, teaching and research https://pos-pal.org/

You Tube channel has lectures, seminars and discussions
https://www.youtube.com/user/CSIKCL

Patient, family and public involvement
https://www.kcl.ac.uk/cicelysaunders/patient-family-and-public-involvement/ppi

Information on BuildCARE and IARE
https://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/research/studies/buildcare/index.aspx

Cicely Saunders
International
Better care at the end of life