Building a Field:
The Atlantic Philanthropies' Investment in Palliative Care

Building capacity at field level requires a strategic and systemic approach that includes attention to the parts – organisations, structures, leaders, and resources – and to the whole – relationships, common concepts and language, and agreed principles.

Conducted for The Atlantic Philanthropies by

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Introduction

A core focus of the strategy adopted by The Atlantic Philanthropies (Atlantic) in achieving its vision, mission, and goals has been to build capacity in the sectors and fields in which it works. As Atlantic ends its grantmaking, this study aims to capture the legacy and the learning about building the field of palliative care over the more than 13 years of Atlantic's involvement. It prompts questions as to what is meant by a field, why field building is important, and the critical characteristics and dimensions of a field.

This study uses the lens of 'field' to examine the influence of Atlantic's investment in the field of palliative care, drawing on the Strong Field Framework,[1] which proposes the key elements that create a sustainable field. Examining the changes in the field of palliative care time using the framework emphasises the interconnecting importance of knowledge base, standards of practice, leadership, policy, and shared identity.

Atlantic's work and palliative care

Starting in the late 1980s, Atlantic began working closely with government and civil society in diverse areas including promoting higher education, funding research to create new knowledge, strengthening the voluntary sector, enriching the lives of children and older people, and promoting human rights. Emerging from its work in supporting research and evidence in relation to the lives of older people, Atlantic has been funding work related to end-of-life and palliative care since 2004.

Every grant made by Atlantic included the requirement to document and disseminate the resulting learning. In complex fields, Atlantic supported evaluation within and across individual initiatives, projects and programmes of investing. As its field-level work developed, it also focused on capturing learning at field level, across, and between fields. Atlantic has also undertaken reflection and distillation of its learning as a philanthropic enterprise, sharing its insights about its own operation and impact to benefit other philanthropic foundations and those concerned with achieving lasting social change.

The purpose of the study

The purpose of this study is to document and share the collective effects of Atlantic's investment in palliative care by conducting an independent review of the field. The focus is on the field, how it has changed, and how Atlantic's funding contributed to building the field.

While examining the work and impact of Atlantic's investment, this study is not an evaluation of individual projects or programmes. It sets out to capture the legacy and learning from investment in the palliative care field in terms of what it takes to establish and

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[1] The James Irvine Foundation. *The Strong Field Framework: A Guide and Toolkit for Funders and Non-profits Committed to Large-Scale Impact.* https://files.eric.ed.gov/fulltext/ED506586.pdf

develop a field and a community of organisations and individuals working towards a common goal. This should serve to assist field leaders in their efforts to integrate their practice into chronic illness care and to spur further innovation and wider application of the principles of palliative care. It also has value for related health fields and other domains in terms of recognising the long term and integrated work required to develop a healthy and sustainable field.

This study looks at investments by Atlantic between 2004 and 2017 in the palliative care field under the key themes that have emerged from the literature as the core elements of an effective field.

Data has been gathered through documentary analysis, site visits (in the Republic of Ireland and the Cecily Saunders Institute), attendance at seminars and conferences, and a series of in-depth interviews with a cross section of contributors including field leaders and Atlantic grantees, philanthropic and public funders, policymakers, service managers and senior clinicians and researchers.

Key advances in the field

This report is complemented by a set of case studies on major advances and accomplishments in the field of palliative care. These case studies were prepared by the principal investigator for each Atlantic grant in the field of palliative care who are also leaders in the field.

While there is a specific lens for each case study, the authors of this report worked with the field leaders to ensure the connection between the individual case studies and the field-level case study. The field leaders were responsible for completing the case studies. The case studies are:

Case Study Lead	**Focus of the case study**
Prof Irene Higginson, Cecily Saunders Institute Building Palliative Care Globally: The Cicely Saunders Institute Journey	The impact on the field of palliative care of the establishment of the Cicely Saunders Institute at Kings College London, U.K., in partnership with the charity Cicely Saunders International and of BuildCARE, an Atlantic-funded programme within the Institute. It focuses on the International Access Rights and Empowerment Study (IARE 1), an international research collaboration, 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.

Professor Max Watson The International Dimension of the Palliative Medicine Fellowship Programme: How Can Fellowships in Palliative Care Improve End of Life Care in Rural Communities?	Atlantic provided a unique opportunity to establish a palliative care fellowship for candidates from across the world. In addition, the programme, under the direction of the Cicely Saunders Institute at King's College in London, provided opportunities for fellows from developed countries to benefit from the rigor of academic study, research, and support from leading clinicians in England, the United States (U.S.), and Ireland. Such training has provided potential future leaders in palliative care with the chance to develop crucial skills and experience the mentoring of world class palliative care pioneers. The linkages created through the programme has been invaluable and have also led to the production of some excellent research projects.
Dr. Sean Morrison The Development of Palliative Care in the U.S.	An overview of the development of palliative care in the U.S. over the last 50 years, documenting an intertwined evolution of medical and academic leadership and advocacy, research-led strategic thinking supported by philanthropy, federal legislation, and policy and public awareness campaigns. These strands of development generated evolving models of palliative care, legislation, standards, funding models, systems of professional education, and professional networks as well as the infrastructure of hospice and hospital provision.
Prof Karen Ryan and Dr. Regina McQuillan Medical Leadership in Palliative Care	Report of a workshop for palliative care consultants that challenged participants to reflect on their vision for palliative care leadership and strategy for achieving it.
Prof Charles Normand Economics of Palliative Care: Evidence and Impact from Four Recent Studies	This report presents findings from four recent, innovative economic studies of palliative care. Three of the studies were funded by The Atlantic Philanthropies; the fourth was funded by the National Cancer Institute and National Institute for Nursing Research in the United States. The research team conducted its economic analyses through an Atlantic -supported research collaboration.

For clarity, this report will generally be referred to as ‘the study’, while individual case studies will be referred to as ‘the case study.’

The approach

Fields and field building

A field is a community of organisations and individuals working together towards a common goal and using a set of common approaches to achieving that goal.[2] As noted in the study of Atlantic's capacity building work in the children and young people's sector in Ireland[3], field building occupies a unique place in the work of philanthropic funders that want to bring about positive and lasting social change, and where the work of any one organisation cannot hope to achieve or sustain this level of systemic change. Commentators identify the need for sustainable change beyond the lifetime of a funding initiative as a rationale for philanthropic field building. While this is a way of making organisations more stable and going beyond a time-bound approach, field-building is seen as significantly more complex than supporting capacity development of a single grantee organisation:

> *"Field building inherently involves the consideration of an entire ecosystem of organisations, and often emphasises work at the intersection of organisations."* [4]

The Strong Field Framework[5] developed by the Bridgespan Group assesses the strengths and needs of a field. That framework highlights five key dimensions of a field:

- A **knowledge base** with a community of researchers and a body of evidence and ways of collecting and disseminating evidence
- **Standards of practice** with exemplary models, professional development, and resources for implementation
- **Leadership** and grassroots support (where influential leaders and organisations work across practice, research, and policy)
- **Supporting policy** (an enabling policy environment supportive of practice models, and organised funding streams from a range of sources)

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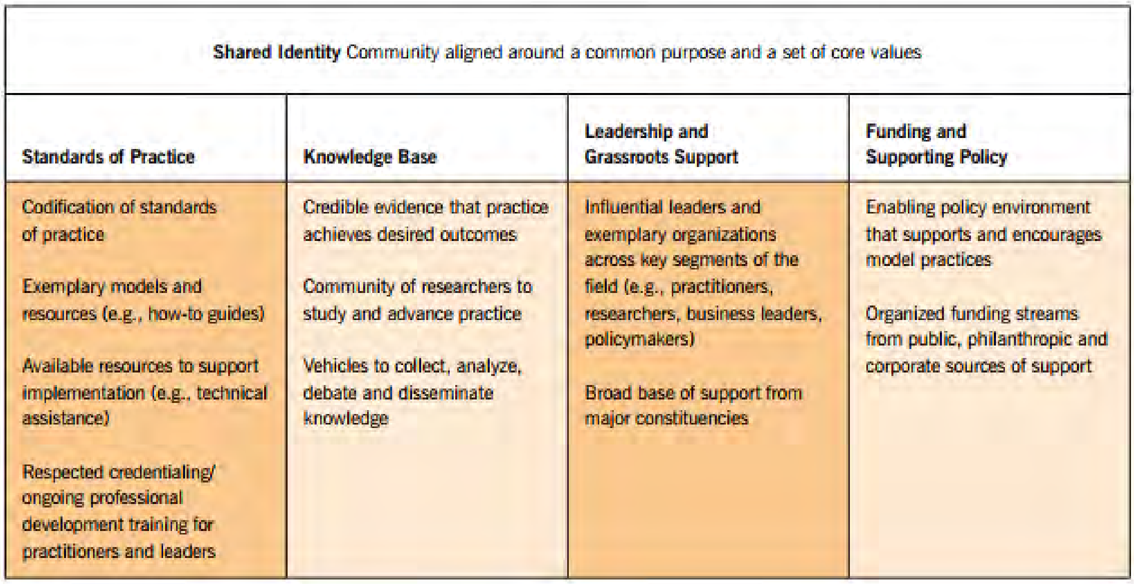
[2] The James Irvine Foundation. *The Strong Field Framework: A Guide and Toolkit for Funders and Non-profits Committed to Large-Scale Impact.* https://files.eric.ed.gov/fulltext/ED506586.pdf

[3] Rafferty, M., Colgan, A. (2016) *Capacity Building in the Children and Young People's Sector in Ireland: A Field-Level Study.*

[4] Bernholz, L., & Wang, T., 2010, *Building Fields for Policy Change*. Blueprint Research +Design.

[5] http://www.bridgespan.org/Publications-and-Tools/Advancing-Philanthropy/The-Strong-Field-Framework-A-Guide-and-Toolkit-for.aspx#.VqTnnLaLTRY

- **Shared identity** (a community aligned around a common purpose and a set of core values).



Shared Identity Community aligned around a common purpose and a set of core values			
Standards of Practice	**Knowledge Base**	**Leadership and Grassroots Support**	**Funding and Supporting Policy**
Codification of standards of practice Exemplary models and resources (e.g., how-to guides) Available resources to support implementation (e.g., technical assistance) Respected credentialing/ ongoing professional development training for practitioners and leaders	Credible evidence that practice achieves desired outcomes Community of researchers to study and advance practice Vehicles to collect, analyze, debate and disseminate knowledge	Influential leaders and exemplary organizations across key segments of the field (e.g., practitioners, researchers, business leaders, policymakers) Broad base of support from major constituencies	Enabling policy environment that supports and encourages model practices Organized funding streams from public, philanthropic and corporate sources of support

These dimensions offer useful lenses through which to view the work of Atlantic in the palliative care field. As required components of a field, it is appropriate to describe these features and how they have been influenced by Atlantic's investment. However, a thriving field is more than the sum of these building blocks. There are compelling forces that drive or inhibit the development of a field alongside the development of required infrastructure. A review of the work of the Robert Wood Johnson Foundation (RWJF) in the field of palliative care offers insights specific to the complexity of field building in palliative care.[6] Among the many dimensions of field building described, the authors refer to:

> *"…the interplay between listening to grantees and supporting their ideas, paying attention to the web of relationships that drive the system, supporting passionate people with visionary ideas, introducing incentives, marketing ideas and practices, and aggregating promising nodes of work."*

This interplay is strongly in evidence in Atlantic's investment in the field of palliative care. The authors also highlight the impact of infrastructural field building processes such as constructing viable places to practice palliative care and treat those who are dying, institutionalising palliative care in mainstream practice, focusing on quality standards and quality assurance system, and emerging professional networks for practitioners and researchers. RWJF emphasises the importance of the development of new knowledge through funded research that 'infiltrates' curricula, standards, service design and public policy, and the design of new models of service provision.

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[6] Patrizi, Patricia, Thompson, Elizabeth, Spector, Abbey (2011) *Improving Care at the End of Life: How the Robert Wood Johnson Foundation and Its Grantees Built the Field.* RWJF Retrospective Series.

This study will comment on these less tangible dynamics, relationships, synergies, and forces that have shaped the field, as well as the concrete focus of involvement and investment. In addition, it will interrogate the early field-building activities and conditions that enabled the establishment of an evidence base on which to promote palliative care as an approach to care and leverage government funding.

The Field of Palliative Care and Atlantic's Investment

The context

Improvements in public health and advances in clinical medicine have led to unprecedented gains in human longevity. These welcome advances have led to added years of life, but have increased the burden of illness, especially chronic, incurable illnesses that are associated with age. The bounty of longer life is allied to the burden of chronic disease, often characterised by increased dependence and frailty, added requirements for health resources and high family support needs. There is strong evidence that for many people, including those in countries with advanced health systems, chronic disease is associated with poorly managed physical symptoms, inadequate information, communication and planning, insufficient and fragmented care systems, and a significant dependence on family care.

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness through the prevention and relief of suffering by means of early identification and effective assessment and treatment of pain and other problems–physical, psychosocial and spiritual.[7] It is offered alongside curative and life-prolonging treatments. Given the changes of increased longevity, medical advances, and improved treatment outcomes, there is a steadily increasing demand for palliative care and end- of- life services for both children and adults. Historically, adult palliative care has been associated with patients diagnosed with cancer. In recent years, the value of palliative care has been recognised for patients with non-malignant and chronic illness such as neurodegenerative, cardiovascular and respiratory disease. The scope of palliative care has broadened so that palliative care is now provided earlier in the course of a patient's illness as appropriate.

Although palliative care in Ireland has its roots in the 1870s, where the Religious Sisters of Charity founded care centres for the dying poor at St. Patrick's hospital in Cork and Our Lady's Hospice in Harold's Cross in Dublin, improvements in medicine moved the focus away from care of the dying to curative care.

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[7] WHO Definition of Palliative Care. http://www.who.int/cancer/palliative/definition/en/

The systematic application of the principles of palliative care into an organised body of knowledge and approach to care is relatively new. Dr. Cecily Saunders, recognised as the founder of modern palliative and end-of-life care, first articulated her ideas about hospice care in the late 1950s based on the careful observation of dying patients. She advocated that only an interdisciplinary team could relieve the “total pain” of a dying person in the context of his or her family, and the team concept is still at the core of palliative care. She established St Christopher’s Hospice in London in 1967, including an interdisciplinary team focused on the control of pain and extending to home care by 1969.[8]

In the 1960s, a psychiatrist in the United States (U.S.), Elisabeth Kübler-Ross, confronted fierce resistance to treating people at the end of life with respect, openness and honest communication. Her groundbreaking 1969 book, *On Death and Dying*, revolutionized and humanised how dying patients were acknowledged and cared for.

In 1974, a surgical oncologist at The Royal Victoria Hospital of McGill University in Montreal, Dr. Balfour Mount, coined the term *palliative care* to avoid the negative connotations of the word *hospice* in French culture, and introduced Dr. Saunders’ innovations into academic teaching hospitals. He first demonstrated what it meant to provide holistic care for people who were not dying but had chronic or life-limiting diseases and their families who were experiencing physical, psychological, social, or spiritual distress.

Hospice and palliative care did not exist in the American health system of the 1970s and early 1980s.[9] In 1997, the Institute of Medicine report, “*Approaching Death: Improving Care at the End of Life,*”[10] documented glaring deficiencies in end-of-life care in the United States.[11] Palliative care as a discipline in the US began in earnest in the early 1970s, effectively as a social movement led by medical professionals who had visited the U.K. and wanted to emulate the developments they had seen there, although the subspecialty of hospice and palliative medicine was not recognised by the American Board of Medical Specialties and the Accreditation Council for Graduate Medical Education until 2006.

With the support of the Robert Wood Johnson Foundation, which invested over €170 million to improve care at the end of life between 1996 and 2006 and the Open Society Institute, a major effort to bring palliative care into mainstream medicine and nursing was launched in the U.S.. *Clinical Practice Guidelines for Quality Palliative Care* were first released in 2004, expanding the focus of palliative care to include not just dying patients,

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[8] Baines, M (2011) *From pioneer days to implementation: lessons to be learnt.* European Journal of Palliative Care, 2011; 18(5): 223–227. http://www.stchristophers.org.uk/about/history/pioneeringdays

[9] Patrizi, Patricia, Thompson, Elizabeth, Spector, Abbey (2011) *Improving Care at the End of Life: How the Robert Wood Johnson Foundation and Its Grantees Built the Field.* RWJF Retrospective Series

[10] Field, M.I. and Cassel, C.K. (Eds) (1997) Approaching Death: Improving Care at the End of Life. Institute of Medicine, National Academy Press, Washington, D.C.

[11] American Society of Hematology, Loscalzo, M.J. (2018) Palliative Care: An Historical Perspective. http://asheducationbook.hematologylibrary.org/content/2008/1/465.full

but also patients diagnosed with life-limiting illnesses.[12] The case study on the development of palliative care in the United States describes the development of the field, over the decades since, including the legislation, policy and federal funding programmes which followed the early philanthropic investment.

Atlantic in the field of palliative care

Emerging from its work in supporting research and evidence in relation to the lives of older people, Atlantic began funding work related to end of life and palliative care in the Republic of Ireland and Northern Ireland in 2004.

In other fields (for example, children and young people), Atlantic adopted a blend of solution-focused approaches, using multiple entry points and mobilising strategic partners, and strongly focusing on impact and outcomes in order to achieve systemic impact and sustainability. In its end of life programme, working in a much less developed field, Atlantic used a different approach, identifying existing field leaders but also investing in establishing missing field structures and in supporting the collection of baseline data and the establishment of standards for settings and practice.

Atlantic invested some €58 million in palliative care in the Republic of Ireland, Northern Ireland, the United States, Viet Nam and the United Kingdom from 2004 to 2013 (see Appendix 1 for list of grants). This funding supported large national service-providing organisations, small-scale organisations, evidence-based programmes, primary research, technical supports for capacity development and supports for network-building across several domains of the field.

Having engaged with field leaders, Atlantic considered what added value could be contributed in a set of culminating investments from 2014 to 2017. It identified two key issues: addressing the issue of **global access** and **building field leadership for the future**. Six inter-connected totalling €7.6 million were awarded with these focuses (See Appendix 1 for details). These interconnected grants seek to enhance patient and family knowledge, develop human capital, and improve access to palliative care globally.

Palliative care in the Republic of Ireland and beyond

In his contribution to this study, Dr. Tony O'Brien of Marymount Hospice, Cork, records the strong history of caring in Ireland. He pays tribute to the role and work of the Sisters of Charity and notes the links they forged with the U.K. pioneer in palliative care, Dr. Cicely Saunders. The Sisters laid the foundations for the hospice movement by highlighted the need for dedicated wards for nursing and medical care for people who were dying.

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[12] National Hospice and Palliative Care Organization (2017) *History of Hospice Care*.

In terms of leadership in the field in Ireland, significant benefits were experienced from close links with the work of Cicely Saunders as well as from the leadership of Irish doctors who shared the values and philosophy of palliative care.

Documents setting out the service context for Atlantic grant-making in the field, note that since 1993 there was significant growth in delivery of palliative care along with significant regional variations in services. An Atlantic funded baseline study carried out in 2005 by the Irish Hospice Foundation (IHF) highlighted the wide regional variations in the provision of palliative care in all care environments. The study mapped the variations across the health boards in terms of specialist day care, beds in community hospitals, in patient units in acute hospitals, and bereavements services.

In Ireland, the first set of grants formed a programme to support palliative and hospice care in the Republic of Ireland. The objective of Atlantic's end-of-life programme was to ensure that:

> *By 2010 there will be evidence established of effective ways to care for older adults in the hospice and community settings and within the wider healthcare system towards the end of their lives. Applied research of an international standard on policy and practice will be completed and a cadre of multi-disciplinary care workers and clinicians will be trained in best practice in centres focusing on end-of-life care.*[13]

In 2004, Atlantic began a €25 million programme with the aim of turning Ireland into one of the best places in the world to experience end-of-life care. The programme's key components were:

- Improving services for hospice patients in hospitals, in-patient hospice settings and at home by both specialist palliative care professionals and generalists such as nurses and doctors.
- Supporting education and research activities including training workers and clinicians in best practices.
- Funding accreditation and advocacy efforts including supporting the establishment of standards and monitoring.

A detailed account of grantees and their work from 2004 to 2010 are presented in the *Evaluation of the Programme to Support Palliative and Hospice Care in the Republic of Ireland* (McCarron et al, 2012).[14]

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[13] Mc Carron, Mary; Higgins, Agnes; Larkin, Phil; Drennan, Jonathan; Mc Callion, Philip; Payne, Sheila; Hynes, Geralyn; May, Peter (2012) Evaluation of the programme to support palliative and hospice care in the Republic of Ireland: Final report. https://www.academia.edu/21335553/Evaluation_of_the_programme_to_support_palliative_and_hospice_care_in_the_Republic_of_Ireland_Final_report

[14] Ibid.

Later grants in the Republic of Ireland included support for a set of studies on the cost-effectiveness of palliative care services in Ireland. This work was the first economic analysis of palliative care and was innovative in its methodology and findings (see *Economics of Palliative Care: Evidence and Impact from Four Recent Studies* case study for details*)*.

Grants to both the Irish Hospital Foundation and the Northern Ireland Hospice addressed the needs of older people with dementia. This ground-breaking work supported the development, dissemination and implementation of best practice dementia palliative care in hospices and in the community.

Outside of Ireland, Atlantic made a grant in 2006 to leverage matched funding to build the Cecily Saunders Institute of Palliative Care, Policy & Rehabilitation. The Institute is the first one created with a focus on carrying out research into palliative care. The Institute also offer palliative care courses and other resources relevant for palliative care.

From 2010, Atlantic made a series of grants including a Cross-National Study of Palliative Care Patterns and Costs which compared of patterns of palliative and hospice care, costs and experiences of older people in London, Dublin and New York. Led by the Cecily Saunders Institute, this work established the collaboration between field leaders in the U.K., U.S. and Ireland.

Under the leadership of CSI Project BuildCARE - - Building Capacity, Access, Rights and Empowerment – established of PhD Studentship and Faculty Scholarship Programmes and expanded a unique research study to build capacity in the field of palliative care (see *Building Palliative Care Globally: The Cicely Saunders Institute Journey* case study for details).

The palliative care final grants built on the capacity and leadership that Atlantic had already supported to improve global access to palliative care and build field leadership for the future.

Creating and Strengthening the Knowledge Base

The Strong Field Framework on which this study is based posits the development of a knowledge base as a core strand of field building.[15] Credible research that confirms or challenges the efficacy of core practices is needed to strengthen a field. A body of evidence is inextricably linked with having a cadre of experts who research the field, and who are engaged with ongoing improvement in the field. Alongside research activity is the need for

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[15] http://www.bridgespan.org/Publications-and-Tools/Advancing-Philanthropy/The-Strong-Field-Framework-A-Guide-and-Toolkit-for.aspx#.VqTnnLaLTRY

leaders to document and disseminate knowledge – leaders who are usually drawn from the community of expert researchers.

These facets of knowledge-driven field building are intrinsically part of all Atlantic grants in the palliative care field, whether these are explicitly focused on research, or an integral part of leadership development, or standards development. This systemic focus in the grant making work of Atlantic makes it difficult to separate out its knowledge creation work, intertwined as it is within the overall ethos of Atlantic grant making.

The wide-ranging research programme supported by Atlantic

Gathering data and learning for planning and model building

As noted, an early grant (2004) to the Irish Hospice Foundation provided for a baseline study of palliative care services across the country at that time. This project aimed to strengthen the regional needs assessment processes undertaken on foot of the findings of the 2001 National Advisory Committee on Palliative Care Report on Palliative Care. [16] which had highlighted the ad hoc and uneven nature of service provision across all areas including home care, day care, and specialist in-patient units. The baseline study set out to document current regional levels of palliative care service provision in all care settings, compared to the levels recommended in the National Advisory Committee on Palliative Care, to assess professional education needs, and, particularly importantly, to pilot the roll-out of a Minimum Data Set for Palliative Care in Ireland.

Around that time Atlantic also made grants to Marymount Hospice to enable research ton best practices in palliative care and hospice building design. A grant to Milford Care Centre enabled the Centre to test a model of Hospice at Home care, evaluate that model and make evidence informed recommendations for the continuing rollout of this service model. A 2010 grant to the Trinity Foundation enabled that body to carry out an evaluation of Atlantic's end of life programme in Ireland and capture the strategic learning. Thus, the very early focus of grantmaking on research and evidence came into play in the Republic of Ireland to provide robust support to palliative care planning and service design.

Improving hospice and palliative care for people with dementia

In 2013, Atlantic provided grants to the Irish Hospice Foundation and Northern Ireland Hospice that focused on hospice and palliative care for people with dementia, a neglected area in hospice care. The work supported by these grants was instrumental in changing the discourse about living and dying with dementia. It recognised the unique nature of dementia and prioritised the palliative care needs of people with dementia for the first time. This work extended and deepened Atlantic's and the hospice organisations' legacy through

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[16] Department of Health and Children, (2001) Report of the National Advisory Committee on Palliative Care. http://hospicefoundation.ie/wp-content/uploads/2012/07/Report-of-the-National-Advisory-Committee-on-Palliative-Care-2001.pdf

a more positive discourse and public support and innovative tools and education to promote advance planning. It also supported the creation of dementia practice development and tools and protocols to support coordination between services so that more people can die at home by preventing unnecessary hospital admissions.

In Northern Ireland, Atlantic's grant helped to build a new hospice which:

- Made explicit accommodation for people with dementia
- Developed a community dementia palliative care service, including increased supports for carers of people with dementia nearing the end of life
- Improved coordination of palliative care services for people with dementia.

The development of models of care planning and training of staff in dementia palliative care has shaped policy and service planning across Northern Ireland.

Providing an international evidence base for palliative care and equal access to care

In the U.K., the Cicely Saunders Institute (CSI) engaged in cutting edge research, with a unique focus on integrating research and professional education, acting as a hub for international research. Through the BuildCARE Programme (2010-2014) Atlantic invested substantially in CSI's research programme. For example, an international comparison of end-of-life care in three countries (United Kingdom, Republic of Ireland and the United States) helped to identify gaps and improve care for the most disadvantaged patients.

The CSI International PhD studentship and Faculty Scholars Programme enabled participants to pioneer new approaches to multiple aspects of palliative care, including hospital admissions for older people and improving palliative care for people with dementia in nursing homes.

The International Access, Rights and Empowerment (IARE) project, a key Atlantic investment, is an example of international research collaboration. A hallmark of CSI's research work, this study provided an evidence base from which to improve the access, rights, and empowerment of older people who need end of life care. A follow up study supported an international comparison of access barriers and key components of care. This research tracks patient outcomes internationally to provide a strong evidence base for investment in palliative care. The results intertwine with Project GlobalCARE, another CSI project to help embed palliative care into mainstream international healthcare.

Economic evaluation of palliative care

While Atlantic funded research was strongly focused on providing the evidence base for palliative care, one strand of that evidence was of particular importance from a policy perspective, namely the research that would test the palliative care from an economic perspective, and address the question as to whether it offers value for money relative to other demands on scarce health funding.

Policymakers are interested in how well an investment in one form of care compares with other kinds of interventions, and how and whether the relative benefits can be demonstrated. A grant to the Trinity Foundation laid important groundwork for this research and evaluation perspective. The Foundation was funded to undertake a phased set of studies on the cost effectiveness of palliative care services in the Republic of Ireland. This study, along with three others with a value for money dimension generated the inputs for a large-scale study of the economics of palliative care conducted by the Centre for Health Policy and Management in Trinity College, Dublin (see case study for more details).

Summing up

The influence of research conducted with Atlantic support and by Atlantic supported researchers on national and international policy is evident. Atlantic-supported researchers and clinicians have gone on to take on influential roles in research, policy and practice.

Atlantic insisted that all knowledge gained from research should be public and shared and all reports accessible. Atlantic grantees are particularly strong in dissemination and knowledge transfer.

In Summary: Knowledge Base

Atlantic support helped to establish a strong community of researchers working on dimensions of palliative and end-of-life care.

This work is helping to strengthen the evidence base and the wider impact of quality palliative care is more readily demonstrable.

The gaps in evidence are increasingly recognised by practitioners and policymakers.

The specific needs of particular groups are recognised and research into these needs is increasing (children, and people with dementia, intellectual disabilities, and chronic neurological diseases).

The requirement to measure the effectiveness of palliative care is recognised by practitioners, funders, and researchers and tools for doing this have been developed.

A range of tools for dissemination of knowledge and evidence have been developed and online and e-learning platforms are helping to improve global access to evidence and education. These will help to share knowledge and best practices at field level.

Knowledge from other relevant fields is being mobilised alongside research and knowledge specific to palliative care (i.e., improvement science and implementation science).

Standards of Practice

The literature on the development of social fields identifies the capacity to deliver high-quality, evidence-based services, and high practice standards as key elements of an effective social field.

The concept of standards ranges across multiple dimensions of palliative care provision, including buildings, people, and practice. In a developing field, the design, testing and promotion of models of provision is also a key feature of standards development, seeking to lay down an evidence-informed basis for the ongoing development.

Over an 11-year period, Atlantic invested in all these dimensions of standards building across several jurisdictions. In the Republic of Ireland, there was a strong focus on baseline studies and data collection to support planning; the design and use of audit and accreditation systems was a key facet of a standards infrastructure; there has been huge investment in the design of models of care, and the task of mainstreaming palliative care in the wider health system. The physical environment, in which palliative care is delivered, was recognised as a central part of effective care from the perspective of patients, families, and clinicians and was the subject of significant Atlantic investment.

Gathering data to underpin standards development

In the field of palliative care, as in any medical field, standards play a central and crucial role, along with all the other strands of the infrastructure of provision. A key element of a field-building initiative is the gathering of data that can be used to guide future planning, to track progress and outcomes, and to support the development of standards.

National Audit System for End of-Life Care

A significant project funded in 2009 set out to expand the development of a National Audit System for End-of-Life Care in hospitals across the Republic of Ireland. This grant was part of Atlantic's strategic intent to build the architecture to support further growth and development of the palliative care field, as it moved towards exiting the field.

A key role envisaged for the National Audit system was to provide underpinning support for a largescale *Hospice Friendly Hospitals Programme* (Hahn) (discussed more fully below) through provision of data on end-of-life care and end-of-life experiences in hospitals. It would make the crucial link between audit and quality improvement, deepen understanding of end-of-life care and enable hospitals to assess and evaluate their end-of-life care against objective standards to be developed by the Health Information and Quality Authority. In terms of field building and strategic development, the partnership with HSE and HIQA provided the capacity to ensure sustainability of the audit process and their translation of findings into practice, beyond the life of Atlantic funding.

Designing a model of accreditation for a local service

The first ever accreditation process for a palliative care unit in Ireland was undertaken at Milford Care Centre, Limerick with Atlantic funding. A key objective for this work was to implement a quality and safety framework in the Centre, leading to accreditation by the Irish Health Services Accreditation Board. The project also sought to create an education and training programme to support a quality framework in a palliative care setting, and to make an impact on the care provision nationally by contributing to a nationwide specialist palliative care quality and safety framework.

Mainstreaming the palliative care model: strengthening the national and regional service delivery infrastructure and models of service

Cicely Saunders Institute Palliative Care Cluster: Project GlobalCARE

As one of its final grants, Atlantic provided funding to support and increase the integration of palliative care into mainstream systems through the development and support of tools and integrated models of care. Project GlobalCARE at the Cicely Saunders Institute set out to improve how chronic conditions are managed for millions of people by developing 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 rationale for this international, multi-jurisdictional grant was that tools and better models of care are needed to ensure appropriate referrals to specialist and non-specialist levels of care, address the lack of knowledge and training among general practitioners, and increase clarity as to what modern medicine can feasibly accomplish. These tools are disseminated to non-specialists via e-learning, conferences, and training workshops.

Building models of care in the Republic of Ireland

As noted earlier, Atlantic's strategic approach to supporting the development of the field of palliative care in Ireland was to adopt a multi-strand focus; a key strategy was provision of support for palliative care in the hospice setting but also in acute hospital/community settings or other places where people actually die, and in so doing to extend the palliative care model and expertise to a much wider cohort of people and families. The rationale for this approach was clearly highlighted in research that showed the high proportion of people dying in hospital who wished to die at home.

Atlantic invested in strengthening and expanding quality service delivery geographically in these diverse settings through both national and regional programmes. A key focus at both levels was to address shortcomings in the quality and standard of care in the acute hospital setting, and to expand the concept and model of palliative care into a wide range of community settings such as nursing homes and community hospitals. In this way, the professional approach to palliative care could be extended to a far greater population of patients and families, while also respecting the core value of respecting people's choices about where they wish to die.

The National Hospice Friendly Hospital Programme

One of the most substantial Atlantic investments in Ireland addressed the major shortcomings and challenges found in the capacity of acute hospitals to provide care for people dying in hospital and their families. This €5 million grant provided support for a five-year programme the *Hospice Friendly*

Hospital Programme (HfH), to transform how older people die in Republic of Ireland hospitals. The initial design phase of the *HfH* programme was underpinned by an earlier separate grant that enabled data collection and research making the case for the programme.

Based on the model of the earlier work, the HfH Programme adopted a multi-faceted approach to bringing about culture change. The approach included a comprehensive framework of standards to address the needs of the dying, their families, and care staff in acute hospitals. Core elements of the programme addressed the central dimensions of quality care – integrated care, communications, patient autonomy, and design of patient rooms and family rooms. Key outcomes included a standards framework, communication training programmes, assessment tools, and increased awareness.

The HfH programme was the first of its kind in the European Union to develop standards for palliative care in acute hospitals and to underpin these with a comprehensive National Audit System.

The Milford Care Centre Hospice at Home project

Aligned with the objective of extending the models of effective care in settings where people die, grant funding was provided to a series of programmes run by Milford Care Centre in Limerick, whose long term aim was to provide a community-based specialist palliative care service for all, which could be delivered in a range of community settings including nursing homes, community hospitals and nursing units. A further objective of this programme was to influence government policy in order that this type of programme would be funded nationally.

The *Hospice at Home* pilot project would provide a service and evidence of the cost effectiveness and quality of the service. One of the innovative aspects of this programme was the decision to design a model of service that included a wide range of professions to provide personal nursing care, home help services, and therapeutic assessments. This approach reflects the theme of integrated care that is responsive to the individual and family needs.

Building a palliative care model of care in Vietnam

Atlantic also supported the development of hospice and palliative care in developing countries. In 2010, Atlantic funded Massachusetts General to integrate palliative care into Vietnam's healthcare system through the establishment of a palliative care home care model, a palliative care clinical training centre and a speciality training programme, and through the formation of a Vietnamese palliative care foundation.

Developing the physical infrastructure

The Cecily Saunders Institute

The work of creating the Cicely Saunders Institute (CSI), for which Atlantic was the biggest single funder, began in 2006, and the Institute opened in 2010. This Institute places huge emphasis on the significance of the physical space in which palliative care is provided as a foundational dimension of standards and quality care. Designed along hospice principles, with strong patient involvement, it sets out to be a calm and welcoming building for both patients and staff. Patients have welcomed the colours, textures, lighting, and the use of plants as ways of signalling a positive message of hope and continuity. In CSI, the physical infrastructure is interwoven through the Atlantic funded BuildCARE programme (2010-2014) with the nurturing and building of professional talent, international research on rights and empowerment (IARE) and the international Dissemination Engagement and Empowerment Programme (DEE)

Strengthening the physical palliative care infrastructure in the Republic of Ireland

The quality of the surroundings in which palliative care is delivered and the design of the space is a key element of quality care. As part of its strategic approach to the development of palliative care services in Ireland, Atlantic provided capital investment in high quality hospice and hospital buildings that were built to international best practice design standards. These facilities serve not only to provide quality care for patients and families in their catchment areas, but also as templates for planning and development of specialist palliative care units and services in the country.

The Marymount Hospice project in the Republic of Ireland

In the case of Marymount Hospice, Cork, a new prototype hospice was built in a greenfield site, [17] meeting national and international design specifications for hospice services. The model allows for development of a 'hub and spoke' model as proposed in the NAC report[18] of 2001. This model allows for integrated care through the sharing of practice of palliative care with all healthcare professionals at their different levels.

In keeping with Atlantic's emphasis on a strong evidence base for the work that it funds, the design and build was underpinned by an earlier grant that enabled an Advisory Group of international experts to undertake research into international best practice in palliative care services and hospice building design. Alongside design recommendations, the Advisory Group proposed a series of key service benchmarks, together with detailed implementation guidelines for each service element.

The Milford Day Centre project, Republic of Ireland

In Milford, Limerick, Atlantic funding augmented capital funding from the Health Service Executive to make possible the construction of a new day care centre. This day care centre had the capacity needed to provide for all the essential components of the *Hospice at Home* Service being rolled out with Atlantic funding support. The new facility also made possible a holistic approach to specialist care by creating the scope for education and training for general practitioners s, community nurses, care assistants, and home helps in the care of those dying at home and their families.

Summing up

Atlantic funding supported the development and dissemination of standards across several dimensions of palliative care. It also developed the capacities which continued the work of providing the evidence base and specifying standards. This ongoing work is not directly funded by Atlantic, but Atlantic's investment in leadership, knowledge and infrastructure helped to lay the foundations

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[17] A greenfield site is a site that has never been built on, is in an agricultural, forest land, or undeveloped site and typically have no significant amounts of toxic materials. They are also often on the outskirts of town, have less congestion, and provide pleasant environments.

[18] Department of Health and Children, (2001) Report of the National Advisory Committee on Palliative Care. http://hospicefoundation.ie/wp-content/uploads/2012/07/Report-of-the-National-Advisory-Committee-on-Palliative-Care-2001.pdf

through which this work is undertaken. The work of developing national clinical guidelines in palliative care in Ireland, for example, emerges from the international evidence and its application across all clinical programmes in Ireland. The leadership of the national clinical programme in palliative care has also been enhanced through opportunities created by Atlantic investments[19].

Standards relate not only to the design of buildings and practice and delivery in palliative care, but to the conduct of research too. The MORECare statement on good practice[20] [21], developed by researchers in the CSI has now been included in the EQUATOR[22] guidance as an international benchmark for research evaluating services & treatments in end of life care. The EQUATOR (Enhancing the QUAlity and Transparency Of health Research Network is an international initiative that seeks to improve the reliability and value of published health research literature by promoting transparent and accurate reporting and wider use of robust reporting guidelines.

Investments by Atlantic in palliative care are thus contributing to and shaping practice internationally, articulating and integrating the principles of palliative into the work of those who research, promote, design, fund and deliver palliative care and reaching into related and overlapping areas of policy and practice.

In Summary: Standards of Practice

Promising practices in the field, developed with Atlantic support, have been well documented and disseminated.

Evidence-based models have informed the development of regional and national standards of care and practice.

With Atlantic's support, the Irish Hospice Foundation developed "Quality Standards for End-of-Life Care in Hospitals". Ireland was the first country in the EU to produce national standards.

Frameworks of competencies have been published for the education and practice of relevant professionals.

Implementation of standards is now receiving more attention, but implementation and fidelity remains inconsistent and often undocumented.

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[19] Goal grant to Trinity Foundation to support the development of Academic Palliative Medicine in Ireland and the Fellowships Consortium of the Palliative Care Cluster.

[20] The MORECare statement sets clear standards on good research practice in evaluating services and treatments in end of life care. Higginson IJ, Evans CJ, Grande G, Preston N, Morgan M, McCrone P, Lewis P, Fayers P, Harding R, Hotopf M, Murray SA, Benalia H, Gysels M, Farquhar M, Todd C; MORECare. "Evaluating complex interventions in end of life care: the MORECare statement on good practice generated by a synthesis of transparent expert consultations and systematic reviews." *BMC Med*. 2013;24; 11:111.

[21] https://www.kcl.ac.uk/nursing/departments/cicelysaunders/research/studies/morecare.aspx

[22] Equator network: Enhancing the Quality and Transparency of health Research. http://www.equator-network.org/

Quality training and professional development opportunities for new and experienced practitioners are limited. There is a need to integrate education in palliative care into primary professional training as well as to provide increased opportunities for specialist training.

Palliative Care Leadership

The Atlantic investment in leadership and advocacy development

A key field-building strand of the Atlantic vision was to create leadership and advocacy capacity that would support growth and development in the field over the long term by strengthening individual organisational and system leadership.

Between the years 2004 and 2015, Atlantic made significant investments, creating an international cadre of palliative care leaders working across multiple jurisdictions. The strategic focus was to create collaborative networks of professional leaders who would build capacity within and between geographic settings. The collaborative networks built capacity, grew the influence of palliative care leaders on the wider health systems, and used their expertise to influence and shape policy. A key feature of this approach was to enable progress to be made in smaller and less affluent jurisdictions through sharing expertise and knowledge.

Investments were made in Ireland, Northern Ireland, the U.K. and the U.S. The work in Northern Ireland also supported the development of palliative care leadership in Nepal.

Building the Infrastructure in Ireland

While the island of Ireland (the Republic of Ireland and Northern Ireland) was acknowledged to have a strong tradition of hospice and palliative care and significant effort invested in education, training, and research, this activity was dispersed and fragmented and the field had developed sporadically. Between 2004 and 2010 Atlantic invested in a range of projects to address this deficit.

In 2005, the Irish Hospice Foundation laid the foundations for an All-Ireland Institute of Hospice and Palliative Care (AIIHPC) to address this problem. The Foundation sponsored the first part-time Visiting Professor of Hospice Studies jointly located at University College Dublin and Trinity College Dublin. The first holder of that post, Professor David Clarke, developed a vision for an all -Ireland multidisciplinary Institute for Hospice and Palliative Care, in consultation with key stakeholders. Professor Clarke's vision led to an investment by Atlantic that aimed to move beyond the vision to reality.

The role envisaged for the Institute was to serve as a key strategic influence in the palliative care field on the island of Ireland. The Institute would have an impact across all the key dimensions of field building, by becoming a leading international centre of expertise and information on education, research, policy, and practice in palliative and end of- life-care, by advancing the development of a sustainable and skilled workforce, strengthening the capacity for research and development and serving as a resource to service providers and policymakers, thus helping to shape practice and influence policy.

In the longer term, the expectation for the Institute was that it would support culture change by strengthening the public and organisational profile and positioning of palliative care in the wider healthcare system, provide education and research leadership to match evolving needs, and promote strong collaboration among service providers, educators, and researchers.

In addition to providing national and international leadership in the areas of education and research, the Institute would strengthen quality by devising standardised core professional curricula as well as public education programmes.

AIIHPC has delivered on these hopes, becoming a leading organisation with national and international influence driving excellence in palliative care. The development of the Palliative Hub[23] provides a portal to palliative care information to important stakeholder groups, including professionals and the public.

A professionally led leadership and advocacy body

Atlantic saw the need to complement the work of the Institute and underpin future expansion of work in the palliative care field by offering support to the Irish Association of Palliative Care (IAPC). IAPC is a multi-professional organisation of doctors, nurses, social workers, occupational therapists, physiotherapists, and a range of other clinical and managerial staff and volunteers involved in palliative care in Ireland. The organisation aspires to be the primary representative body for shaping improvements in palliative care provision in Ireland and the only body bringing together professionals in the field.

In order to strengthen the key leadership and advocacy role of IAPC, Atlantic provided support for the development and implementation of a five-year business plan. This investment envisaged key strategic outcomes at field level including strengthened alliances with important partners, networking among palliative care professionals, advocacy in support of essential policy and service development, empowerment of service providers through dissemination of research, and increased public awareness.

The IAPC continues to thrive and is active in a range of professional development activities. It organises a range of specialist subgroups, forums and working groups, runs regular local and national information and education events, and provides a useful and accessible repository of publications and videos. The directory of palliative care services and the

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[23] http://www.thepalliativehub.com/

database on education relevant to palliative care are important foundational resources. It will be important to maintain these resources and regular updating will require ongoing resources.

The palliative care cluster: developing academic palliative medicine in Ireland

One of Atlantic's final grants was in 2015 to the Trinity Foundation to address a significant gap in in the palliative care infrastructure in the Republic of Ireland – the absence of a medical academic infrastructure. The aim of this grant was to build on the earlier Atlantic investment in physical infrastructure, advocacy, and tailored palliative care programmes in order to develop a cadre of academic leaders quickly through fellowships. In keeping with the international and collaborative focus of all Atlantic's culminating grants, this grant sought to link academic centres, clinical facilities and physicians across jurisdictions and institutes, and to strengthen the expert academic research capacity across Ireland.

Not all the fellowships developed as planned. This work required alignment of agreement and action across and between academic institutions and health care service organisations. There were difficulties in achieving this alignment in relation to arrangements for some of the fellowships.

Planning for the future of leadership development in Ireland

In 2016, a workshop was convened as part of this field – level study to reflect on the vision for palliative care leadership and consider a strategy for developing that vision. The workshop, which was convened by the National Clinical Programme in Palliative Care identified strengths and needs in medical leadership. Potential threats to the future development of the field were also highlighted. Participants explored a range of initiatives to build and strengthen professional palliative care medical leadership.

Creating international leadership

The work of the Cicely Saunders Institute

In the U.K., The Cicely Saunders Institute, founded in 2010 with Atlantic as its biggest single funder, has become a world leader in leadership development in the field of palliative care. As part of its wider role in pioneering the best in palliative care and rehabilitation through the integration of cutting-edge research and innovation in the field, the development of a cadre of international palliative care leaders was and is a core focus of the Institute.

A key strand of the CSI leadership development work was the Cicely Saunders International PhD studentships and Faculty Scholars Programme. These scholars are future leaders and investigators who study at the Institute for four years before moving on to take senior positions around the world. Faculty Scholars now hold key roles in Germany, Australia, U.K., and other jurisdictions. Central to the CSI Global vision is the fact that this Programme has supported students who would not have had access to educational opportunities in their own countries.

A final grant to CSI in 2015 funded the establishment of a Fellowships Consortium, designed to build and bolster an international community of future leaders, as well as specific fellowships for the most promising clinical academic leaders in the Republic of Ireland, Northern Ireland, the United States, and Vietnam. The consortium develops a new generation of future leaders who would expand the evidence base for palliative care as well as enable policy and practice development. A key strength of this programme is its focus on community building within and across nations.

Atlantic provided a unique opportunity to establish a palliative care fellowship for candidates from across the world. Under the direction of the Cicely Saunders Institute the fellowship programme has provided opportunities for fellows from developing countries to benefit from the rigor of academic study, research, and support from leading clinicians in England, the United States, and Ireland. Such training has provided potential future leaders in palliative care with the chance to develop crucial skills and experience the mentoring of world class palliative care pioneers. The linkages created through the program has been invaluable and have also led to the production of some excellent research projects. Prof Max Watson's case study on *The International Dimension of the Palliative Medicine Fellowship* Programme describes the influence of this work on leadership capacity in Nepal.

The U.S. work of the Centre to Advance Palliative Care

A 2009 grant to the U.S. Centre to Advance Palliative Care (CAPC) funded support for development of 10-year plan for the leadership development work of the Institute.

Building on this initiative and expertise, one of Atlantic's culminating set of Investments in palliative care was to enable CAPC to enhance the knowledge and skills of providers of palliative care through e-learning and strengthen the dissemination of resources to palliative care programme leaders. Linking to the fellowships programme at the Cicely Saunders Institute the aim of the programme was to launch an international palliative care education pilot in collaboration with consortium partners.

Summing up

The development of strong, influential field leaders does not result in automatic consensus on priorities. There are ongoing differences and disagreements between individuals and organisations in the field. These are manifest in different ways and this is a sign of a healthy diversity in the field. There is general recognition of the value of ongoing communication and interrogation of different focuses and priorities. Risk arises where positions are polarised and willingness to communicate in the service of the field is diminished.

Where influential leaders and organisations work across practice, research and policy, the potential for synergies is created and the impact on the field is amplified beyond the influence of individuals. Leadership is recognised as the crucial ingredient for the achievement of access to and quality of palliative care at local, national, and international levels. Atlantic's investment is supporting the emergence of a new generation of leaders who will sustain the field into the future. Current leaders, who have also been supported by Atlantic investment, recognise and enact 'new power' which is based on networks, social movements, and communities.

However, they continue to work in policy and health service environments which are largely based on 'old power', based on positional authority and hierarchy.[24] It requires sophisticated application of skill and experience to navigate the mechanisms of 'old power' while modelling and promoting the inclusive and collaborative practices of 'new power'. Leaders in all jurisdictions who contributed to this study commented on the tension between the requirements and demands of institutions and service delivery structures and the compassionate and transformational leadership which are required for the complex and inter-related environment of health care and palliative care in particular.

Atlantic sought and invested in key leaders in the field of palliative care in Ireland, the U.K. and the U.S. Almost by definition, these individuals were intelligent, politically astute, agile, and successful. They had considerable status in their own institutions and were influencers at national and international levels in the field of palliative care. Atlantic designed big investments which required these individuals to collaborate. This presented ongoing challenges to individuals used to considerable authority and autonomy. The collaborative model certainly produced outcomes that were greater than those that could have been achieved by the collaborators individually, even with the same resources. The requirement also strengthened relationships between these field leaders, creating a shared purpose and commitments beyond individual reputations, professional or disciplinary backgrounds, institutions, or countries. The relationships established through this work are and will continue to be an important product of Atlantic's investment and will continue to shape the development of palliative care globally far into the future.

In Summary: Leadership Development

Atlantic support has helped to develop influential individual and organisational leaders in key segments of the field: researchers, intermediaries, advocates, and practitioners.

There are strong connections and linkages between field leaders and both individuals and organisations are connected in field-level networks and consortia.

There is increased and systematic attention to palliative care as a dimension of health care at local, national, international, and global health discourse.

There is an emerging national public awareness, understanding of and debate about death and dying and the role of palliative care.

Policy

In almost every context, experts, often experienced researchers and practitioners, have led policy development in the field of palliative care. It is notable that Atlantic sought out those

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[24] Wee, B. (2017) "End of Life care: how do we move forward?" *J R Coll Physicians* Edinb 2017; 47: 369–73 | doi: 10.4997/JRCPE.2017.415

who were recognised as leaders in the field and these were often already involved in policy and strategy development. In Ireland, the U.K. and U.S., Atlantic sought out those who already had significant clinical, academic, and policy expertise and who had already been active in shaping national policy. In other examples, grantees in whom Atlantic invested were recognised as key influencers in national health policy and delivery providers and this was in large measure because of the capacity that they were able to demonstrate as a result of Atlantic investment.

Grants were targeted at addressing gaps in knowledge and practice and at developing field leadership. The effect of these investments, taken together, provided compelling evidence for policy change and leaders who could mobilise this evidence in strategic ways. The strategic effect was to amplify the impact of individual projects and programmes of work and led to knowledge about influence and influencing that have had important policy consequences. In particular, the strong connections and linkages supported by, and in some cases required by Atlantic, aligned with the enhanced quality of knowledge and evidence, helped to build an understanding of how to mobilise the stakeholders in the field in support of an effective process of policy development.

Using the learning from its work in other fields, Atlantic set out to use its investments strategically to leverage recognition and investment from government and other actors. Specifically, it recognised the value in producing evidence of the difference that palliative care could make to the quality of life of those experiencing life-limiting illnesses. Its investment in economic analysis and comparative studies helped to show how palliative care can reduce the cost of other health services, as a way of motivating public and private investment in palliative care.

The Republic of Ireland

As in other countries, palliative care in Ireland was developed largely by service providers, in the absence of any overarching national policy or strategy. The Irish Association for Palliative Care (an all-island representative group for professionals in the field) was set up in 1993, and a key milestone was the recognition of palliative medicine as a medical speciality by the Irish Medical Council in 1995, followed by the creation of the first consultant post in palliative medicine.

In 1999, the National Advisory Committee (NAC) was established to prepare a report on palliative care services in Ireland. This report was published in 2001 and accepted as the official government policy for the development of palliative care in Ireland. The report led to a government commitment to spend an additional €56 million over a five-year period on implementing the staffing recommendations[25] although that level of funding did not

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[25] Department of Health and Children, (2001) *Report of the National Advisory Committee on Palliative Care.* http://hospicefoundation.ie/wp-content/uploads/2012/07/Report-of-the-National-Advisory-Committee-on-Palliative-Care-2001.pdf

materialise. The 2001 Health Strategy, *Shaping a Healthier Future,* included the first official recognition of palliative care by an Irish Government and committed to the continued structured development of palliative care and end of life services. From 2001 to 2015, several policy documents dealing with specific aspects of palliative care, including palliative care for children (2010), a national clinical programme (2010), primary palliative care in Ireland (2011) a palliative care competence framework for health and social care disciplines (2014),[26] the establishment of a national clinical programme for palliative care in 2010 and, more recently, a palliative care operational plan 2015.[27] In January 2018, a draft model of care for palliative care in Ireland was published for consultation. This is a significant advance for palliative care. This process has been led by a clinician who has been actively involved in several Atlantic grants and is a current Atlantic Fellow.

As the national organisation with responsibility for health service delivery, the role of the Health Service Executive (HSE) is central for palliative care development. In 2009, HSE developed an implementation strategy as part of its 5 -year Development Framework for palliative care services. In 2012, the HSE's palliative care programme set out 4 objectives dealing with planning, access, quality of care, and the improvement of partnerships to provide continuity of care. Since 2011, there is national co-ordination of services by the palliative care programme. This is one of several national clinical programmes initiated by the HSE to improve quality, facilitate equitable access, and promote efficient use of services.

The U.K.

Atlantic investment has enabled the Cecily Saunders Institute to develop critical capacities for influencing policy makers using both robust evidence and engagement. As part of the overall BuildCARE research programme,[28] the Dissemination Engagement and Empowerment Programme ensures that the evidence being presented to policymakers and others is robust, credible, and defensible. CSI recognises that policy change requires long term, careful, and skilled influence, especially in the context of complex and increasing demands for health and social care. The Institute points to several examples of direct influence on policy 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 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.

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[26] *Palliative Care Competence Framework* (2014) http://aiihpc.org/wp-content/uploads/2015/02/Palliative-Care-Competence-Framework.pdf

[27] Health Service Executive. *Palliative Care Operational Plan 2015*. https://www.hse.ie/eng/services/publications/corporate/pallcareopplan15.pdf

[28] BuildCARE was created to build capacity in the field of palliative care by supporting the creation of PhD Studentship and Faculty Scholarship Programmes and the expansion of a unique Research study.

- 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.[29] It drew substantially on research undertaken at the Institute and highlighted existing evidence to help those delivering, planning, or using end-of-life services.

The case study from the CSI, *Building Palliative Care Globally: The Cicely Saunders Institute journey,* notes that evidence needs to be combined with advocacy to influence government thinking and policy. 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 and in influencing partner charities to adopt more evidence-based priorities.

The U.S.

In the very different health and social care environment of the U.S., policy development often follows public opinion. Philanthropists and field leaders saw public awareness and public education as a critical factor in shaping the acceptance of palliative care, and there was huge philanthropic investment in this aspect of field building. The critical change which led to the firm establishment of palliative care in the U.S. was a shift away from a focus on death and dying.

In 2007, the Alliance for Care at the End of Life organization was created to provide the hospice community with a more comprehensive, strategic voice on national policy.

The goal of mainstreaming has been more or less achieved, and now it is a matter of sustaining the hospitals; the business case has been made and there are mechanisms to develop palliative care delivery in the community, and to evaluate programmes and disseminate them as with hospital programmes. Supported by an Atlantic grant, Centre to Advance Palliative Care has a critical role in enhancing the knowledge and skills of providers of palliative care through e-learning and the dissemination of operational resources to palliative care programme leaders to increase specialist access and educate non-specialists in basic principles and clinical skills.

Global

In 2007, the Worldwide Hospice and Palliative Care Alliance was formed to address global care needs at the end of life. CSI points to an important example of international impact when palliative care was formally recognised by the World Health Organisation in the World Health Assembly Resolution on palliative care in 2014 which calls on member states to strengthen the integration of palliative care services into national health services. The needs assessment undertaken in preparation for the resolution which demonstrated the

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

evidence of the global need for palliative care and its effectiveness used research from the CSI and the BuildCARE programme and several team members acted as advisors.

To maximise the opportunity provided by the WHO resolution, Atlantic crafted a large grant to the United States Cancer Pain Relief Committee to implement the World Health Organization's resolution to strengthen palliative care as a component of comprehensive care throughout the life course, calling on all national member states to integrate palliative care and pain relief into their health systems. Many Atlantic grantees and field leaders supported by Atlantic investment are represented in this work.

Over the term of its grant, CAPC has expanded its U.S.-based constituency and undertaken an international palliative care education pilot in collaboration with consortium partners through the Atlantic Fellows programme.[30]l. This will enable evaluation of global mechanisms for disseminating scalable online palliative care resources and skills training.

Atlantic support has supported the development and demonstration of models of palliative care in different settings and in the service of different needs. This model building and testing has led to knowledge which informs policy making. Effective communication and dissemination increase the opportunity and requirement for policy makers and funders to attend to the evidence.

In Summary – Supporting Policy

Policy and strategy for palliative care increasingly reflects research knowledge and standards of practice. This is true at local, national, international, and global policy levels.

Policy still reflects the ambition for palliative care. Implementation of policy remains fragmented within and across health care systems.

The significance of the World Health Organization resolution and its commitment to access to palliative care can only be realised through sustained and skilled advocacy and promotion.

Shared Identity

A shared identity is the foundation for any field of practice, without which individuals and organizations with similar motivations and goals may end up working in isolation or at cross-purposes. Do those working in the field identify as members of a field? Are they clear about

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[30] Through the global, interconnected Atlantic Fellows programs, Fellows collaborate to understand and address root causes of pressing problems. These include socio-economic and racial inequality; barriers to full participation in democracy; the social determinants of health and access to quality care.

what the field is collectively trying to accomplish? How well do diverse and distinct individuals and organizations in the field collaborate? Are there common approaches and practices to achieving an overall goal? According to the Strong Field Framework "shared identity" is an overarching component binding the other components in common purpose, as this graphic[31] shows.

Over the last twenty years palliative care has moved from a fragmented and disparate set of practices to a coherent and agreed set of values, approaches and evidence-based practices. The work of Atlantic has provided much of the research and knowledge on which these developments are based and has also supported the advocacy which has shaped the impetus for improved services. The need, application, relevance, and definitions of palliative care are increasingly agreed and documented and there are agreed mechanisms for measuring quality and implementation. The competencies required at different levels have been defined and are informing general and specialist training. There is a large and rapidly increasing body of research knowledge and international bodies which shape the development of the field.

Those working in the field identify as members of the field of palliative care.

There is ongoing attention to what the field is trying to accomplish, and this is having impact at local, national and international levels. Many early debates have been resolved and there is broad clarity and agreement about what the field of palliative care is and what distinguishes it from other specialist fields of practice. By contrast, members of the field do not necessarily agree on the details of execution, such as terminology or definitions of key concepts.

There are a number of key and emerging debates in palliative care, which are in evidence within and between individuals, organisations and countries. National and international conferences show evidence of an increasing capacity at field level to consider different perspectives in relation to contested ideas and to encourage openness to deepening understanding of different and conflicting positions in relation to these debates. Current debates include:

- Specialist vs generalist approaches to palliative care
- The development of palliative care beyond oncology
- The application of palliative care to chronic conditions
- The development of sub-specialities in palliative care (paediatrics, dementia, ID)

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[31] http://www.bridgespan.org/Publications-and-Tools/Advancing-Philanthropy/The-Strong-Field-Framework-A-Guide-and-Toolkit-for.aspx#.VqTnnLaLTRY

- Philosophical and legal challenges to the principles of palliative care, especially in the context of assisted dying.

These debates reflect and emerge from increased capacity and advances in practice. The knowledge generated by research and engagement over the period of Atlantic's involvement in the field have led to a rich and nuanced recognition of the complexity of palliative and end of life care

The articulation of contested ideas and the capacity to engage in discussion and argument around these ideas is a marker of a maturing field.

While there are common approaches and practices to achieving an overall goal, there are also challenges to collaboration as different organisational and individual field leaders compete for limited resources and field attention. In general, Atlantic's requirement for collaboration across disciplinary, institutional, and geographic boundaries has left a legacy of understanding of the value of multiple perspectives and a commitment to effective mechanisms for collaboration.

In Summary: Shared Identity

A range of stakeholders identify their membership of the field of palliative care and have a strong affiliation to it.

There is wide agreement about the goal of the field: to increase the access to high quality palliative care. Members of the field can easily and consistently articulate the goals and core elements of the field, even if this is from a range of perspectives.

Field members do not necessarily agree on a common approach to achieving the goal: there are tensions between voluntary and statutory service providers and there are differences in priorities between different actors.

There are several key debates within and between countries and approaches. These can be seen as important developments in a maturing field. There is a risk of polarising arising from these debates and strong, collaborative organisational approaches will be critical.

Atlantic in the Palliative Care Field: Some Conclusions and Observations

Introduction

We return first to the concept of field. This study is framed around the idea of a field and the definition and elements of a field that emerge in the capacity-building literature.[1] We then offer conclusions and observations about Atlantic's influence in this area of work and identify some challenges for the future.

Using the definition of 'a community of organisations and individuals, working together towards a common goal and using a set of common approaches to achieve this goal', there has been a strengthening of the field of palliative care since 2004.

The global scope and reach of Atlantic's work in diverse settings means that there is no one field-building framework into which the work in each jurisdiction will fit neatly. Several of these field building elements will be found in each jurisdiction. The richness of the Atlantic investment in this field in many ways resides in the way in which it has accommodated itself to these diverse policy, cultural, service, resource and practice contexts. This diversity will be reflected in the differing field building approaches highlighted in the different jurisdictions, while also demonstrating the shared vision, strategy and outcomes.

Key themes emerging from the study that capture the influence of Atlantic in the field of palliative care are the following:

- **Field boundaries are not geographic: the international reach of Atlantic investment**

  Atlantic funding has enabled, supported and created expectations for active connections across and between countries. While establishing consistency of provision, access, and standards within jurisdictions remains an important goal of government departments and health service providers, the evidence to support this imperative is increasingly international. From 2008 onwards, Atlantic investments in palliative care supported cross-national studies,[32] and enabled the establishment of all-island institutes across Ireland and Northern Ireland.[33]

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[32] Cicely Saunders Institute: *Cross-National Study of Palliative Care Patterns and Costs*, 2008

[33] Institute of Public Health in Ireland (2008 – 2015) Institute of Palliative and Hospice Care in Ireland: Expert Advisory Group

Policy and practice are increasingly influenced by national and international as well as local considerations. Government and philanthropic funders attend to developments beyond the local and national and are concerned to recognise and reflect international best practice. Increased ease and speed of communication has supported ready access to developments across the world and global institutions are now able to make comparisons across world-wide jurisdictions. While individual countries develop their own practice standards, these are increasingly benchmarked against European and global standards.[34] [35] For example, the Palliative Care Competence Framework[36] for health and social care professionals working in various health care settings in the Republic of Ireland reflected the move to standardisation of undergraduate and postgraduate education in Europe and was informed by a review of Competence Frameworks from the United States, Australia, New Zealand, Northern Ireland, Scotland, and the U.K., among others.

Just as research and practice in palliative care seeks to recognise and build on international practice, so too is the need to acknowledge and address a global audience increasingly recognised. The Dissemination Engagement and Empowerment Programme of the CSI supported by Atlantic's BuildCARE programme, addresses both health care professional and the public to ensure 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.[37] CSI engages in a range of activities to ensure that palliative care education is available to support practice across the globe.

A grant awarded to the Center to Advance Palliative Care, also exploits technology to enhance the knowledge and skills of providers of palliative care through e-learning and the dissemination of operational resources to palliative care programme leaders to increase specialist access and educate non-specialists in basic principles and clinical skills. The initial U.S. focus of this grant is planned to lead to an international palliative care education pilot in collaboration with consortium partners through the Atlantic-funded Fellows program, which will then be used to evaluate global mechanisms for disseminating scalable online palliative care resources and skills training.

- **Building networks and connections: Atlantic's focus on relationships**

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[34] European Society for Medical Oncology, *Clinical Practice Guidelines: Supportive and Palliative Care*. http://esmo.org/Guidelines/Supportive-and-Palliative-Care

[35] European Standards of Care for Children with Cancer. 2009. http://www.siope.eu/wp-content/uploads/2013/09/European_Standards_final_2011.pdf

[36] Ryan K, Connolly M, Charnley K, Ainscough A, Crinion J, Hayden C, Keegan O, Larkin P, Lynch M, McEvoy D, McQuillan R, O'Donoghue L, O'Hanlon M, Reaper-Reynolds S, Regan J, Rowe D, Wynne M; *Palliative Care Competence Framework Steering Group.* (2014). Palliative Care Competence Framework. Dublin: Health Service Executive

[37] *Building Palliative Care Globally: The Cicely Saunders Institute Journey*, 2017

Direct and interpersonal relationships are important and Atlantic funding has supported connections between current leaders in the field and future leaders. Beyond personal connections, Atlantic funding has provided opportunity and requirement for international and global connections, linking centres of research excellence, practice expertise and healthcare policy across the world. Atlantics culminating grants have connected individuals and institutions within and between different countries.

Those grants enhance the impact of these connections by also connecting different perspectives on palliative care. Research may focus on elements of palliative care and this will continue to be needed. The unique influence of Atlantic's final grants in palliative care was to recognise the multi-faceted nature of palliative care and to focus simultaneously on the development of leadership and research capacity alongside skilled multi-professional care, cutting-edge research, and innovation in engagement, education and dissemination.

The Fellowships Consortium supports international collaboration and the building of a palliative care community and leadership development; Project GlobalCARE provides global access to evidence-based palliative care tools and training programmes to support their use; IARE II builds on an international comparative study which highlights differences in access, rights, practice and impact. Together, these programmes support an integrated approach to the important dimensions of palliative care and a focus on mechanisms for dissemination and learning.

The model of granting required field leaders from different areas of professional practice to work together, overcome professional and cultural differences and share in the creation of knowledge which could not have been achieved by any one of them by themselves. The work of CSI illustrates this approach. The development of the Cicely Saunders Institute embedded this integration in the unique design of the building and the institute. The case study describing the journey of developing the global influence of the Institute emphasises the opportunity provided by CSI to locate clinical and academic palliative care pathways in the same place. Traditionally, hospice-based clinicians operate outside the main healthcare system. There have also been tensions between the perspectives of clinicians and academics.

> *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*. (Dix and CSI, 2017)

- **Atlantic focus on supporting palliative care in developing countries**

Some grants specifically addressed the issue of global access to palliative care in order to initiate investment in countries with no existing leadership or palliative care resources and build on existing initiatives.

Atlantic has worked in Viet Nam in a range of its programmes, supporting key developments, building infrastructure, and influencing policy. The Harvard Medical School Center for Palliative Care already had significant expertise in fostering leadership and offering outstanding educational programs in palliative care. The Center serves as a national and international resource for the best practices in palliative care education. The International Program of the Center, based at Massachusetts General Hospital, has collaborated since 2005 with the Ministry of Health of Vietnam to develop policies, guidelines, and curricula that provide a foundation for implementing palliative care throughout the country.

Making use of the experience of the existing expertise, infrastructure, and relationships of the Center, in 2010 Atlantic invested $5 million in a pilot project to integrate sustainable palliative care into Viet Nam's healthcare system through the establishment of a palliative home-care model, a palliative care clinical training centre, and a specialty training programme, and through the formation of a Vietnamese Palliative Care Foundation over two years.

A field leader in palliative care in Northern Ireland, Professor Max Watson was involved in palliative care teaching work in India and the creation of the Indian Association of Palliative Care Certificate Program. This eight-week home study programme had already trained more than 12,000 health care professionals at 32 centres across the sub-continent. The Board of the Atlantic Philanthropies heard about this work and arranged a grant to Professor Max Watson to support a Belfast based fellow through the Dame Cicely Saunders Institute (CSI). This project within the Fellowship Programme set out to provide clinical training and qualification to experiences clinicians to support the development of leaders in palliative care in under-resourced countries.

The inclusive approach of the CSI, and in particular Professor Irene Higginson and Dr. Richard Harding, allowed the Northern Ireland component of the fellowship program to combine clinical with academic training. This combination of clinical and academic learning for fellows from under-resourced countries was the focus because of the vision to create palliative care leaders with both the academic as well as the clinical skills which will allow them to work as respected pioneers in their countries of origin. See Prof Watson's case study for details[38]

- **The impact of Atlantic's investment beyond the funded jurisdictions**

The World Health Organization's (WHO) resolution at the World Health Assembly (WHA) in 2014 was a defining development for palliative care across the world. It recognised that most people in the world who needed palliative care had no chance of accessing it. It called on all national member states to integrate palliative care and pain relief into their health systems. The WHA resolution marked the first time all 194 member states had joined to make a unanimous commitment to palliative care. Ministers acknowledged that palliative care needed to be available for all people of all ages with all diseases. The resolution recognised that action was especially urgent in settings

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[38] Professor Max Watson (2017); *The International Dimension of the Palliative Medicine Fellowship Programme*

where access to early detection and treatment was a long way off. The resolution addressed both the WHO and member countries. The WHO would continue to focus on supporting countries to implement these commitments, but delegates also had an important role to play in reminding their governments of their commitments and were encouraged to look for opportunities to ensure palliative care remained on the agenda.

The All Ireland Institute of Hospice and Palliative Care (AIIHPC), an Atlantic grantee, hosted the Global Colloquium on Palliative Care[39] which was co-sponsored by the World Health Organisation in 2015. The Colloquium gathered an assembly of national level policy and clinical experts from across the world to explore palliative care issues and to provide a context for purposeful discussion of the World Health Assembly Resolution (WHA67.19) which calls on member states to strengthen the integration of palliative care services into national health services. The colloquium was the first international opportunity for the WHO to discuss and try to advance the implementation of the resolution on palliative care that had been passed by the World Health Assembly (WHA), and was an opportunity to push both from the disease perspective and from an integrated, people-centred perspective.

Atlantic has invested over €1 million in the palliative care cluster to support Global Advocacy for Implementation of the 2014 World Health Organization Palliative Care Resolution. This grant, held by the United States Cancer Pain Relief Committee, enacted the focus on improving global access and building field leadership. It targeted twenty-five countries to support the removal of barriers to palliative care, resulting in better availability and increased awareness among the general public, healthcare professionals, and government representatives. In addition, these twenty-five countries will regularly report opioid consumption increases to the International Narcotics Control Board, and review and revise national laws and regulations constricting access to pain medications.

The WHO published the draft thirteenth general programme of work 2019−2023 in January 2018.[40]As well as including palliative care among the range of measures to support healthy aging, access to palliative care is specifically addressed in the draft plan:

> *There is limited availability of palliative care services in much of the world, which contributes to much avoidable suffering for millions of patients and their families. WHO will emphasize the need to create or strengthen health systems that include palliative care as an integral component of treatment within the continuum of care? The organization will promote the adequate availability of internationally controlled*

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[39] ALLHPC (2015) *Report of the Proceedings of All Ireland Institute of Hospice and Palliative Care Global Colloquium on Palliative Care* http://aiihpc.org/wp-content/uploads/2016/01/03.-AIIHPC-Colloquium-Report-web.pdf

[40] http://www.who.int/about/what-we-do/gpw13-expert-group/Draft-GPW13-Advance-Edited-5Jan2018.pdf?ua=1

> *essential medicines in palliative care, including for the management of pain, while preventing their diversion and abuse*."

The work of Atlantic and its grantees have, without doubt, directly and indirectly, contributed to the increased explicit global focus on palliative care and the nuanced and appropriate language on end of life and palliative care as a dimension of global health.

The learning from Atlantic's investment in the field of palliative care

Atlantic has worked to strengthen the field of palliative care since 2004. Its grants supported efforts to train care specialists, create new care facilities, and to raise awareness about the need for quality palliative care services in the Republic of Ireland, Northern Ireland, the United States, and Viet Nam.

As a philanthropic funder, Atlantic has demonstrated an understanding of the need for both system transformation and the role of organisations and individuals in enabling that transformation. Although Atlantic's investment is dwarfed by state and private healthcare funding for healthcare, its strategic investments in palliative care and end of life have fostered system change. Grantmakers In Health, exploring health philanthropy's role in transforming systems, identifies six overarching goals for system transformation: affording access to all, promoting higher quality care, improving efficiency, empowering individuals and communities, designing services to reflect patient values and needs, and addressing the root causes of morbidity and mortality.[41] Atlantic's investment has addressed all of these goals. The work of cultivating talented leaders; building the knowledge base; strengthening the infrastructure; establishing partnerships and enhancing dissemination and communication have combined to advance the field of palliative care.

The Atlantic Philanthropies' investment in palliative care has strengthened the field in specific dimensions. It has helped to focus attention on the requirement to address practice at the level of the individual practitioner, professional groups, policy, funding, and service design. Its work in supporting important connections and collaborations across professional orientations, areas of knowledge, organisations, and geographies has helped to coalesce organisations and agencies. It has helped to frame important differences and distinctions as well as area of shared and common understandings. It has reflected and amplified fundamental questions about access, quality, and value of palliative care across the life span and in a range of health care and community settings. It has helped to articulate and address the challenges for palliative care leadership, research, education, and practice. It has stimulated thinking and responded to opportunities in the global health arena.

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[41] Grantmakers In Health (2005), *Agents of Change: Health Philanthropy's Role in Transforming Systems.* http://www.gih.org/Publications/MeetingReportsDetail.cfm?ItemNumber=4087

This study has illustrated the field building efforts through specific Atlantic investments and the concrete areas of buildings, organisations, and knowledge are clearly amenable to organised involvement and investment. Yet many of the ways in which the field has changed are less tangible. Atlantic was alert to the dynamics and forces that determine success, attended to the changes in context which inhibited or created opportunities, and drew on their learning in other fields to inform their investments. It supported new opportunities and directions that emerged, unplanned, from initial work and facilitated and connected insights and learning.

The financial investments and the work they produced are documented. Less easy to document are the deep relationships with actors in the field which framed the work on dimensions of the field but also mobilised new connections between leaders and lead organisations. Together, this combination of explicit and tacit forces created the essential dynamics that allow a field to form, develop, and sustain.

Atlantic invested deeply in a relatively small cohort of grantees, enabling the building of complementary bodies of knowledge and expertise, and networks of relationships. The work cut into the nascent field at multiple levels, both geographically (Republic of Ireland, Northern Ireland, all island, regional and international) and in terms of focus (infrastructure, network building, quality and standards development, physical infrastructure.) The emphasis here, as appropriate to a strategic focus, has been to invest in initiatives with the capacity for sustainable and systemic change. A further feature of the strategic approach has been to build on and make optimum use of work already done by grantee organisations with a track record, and a body of research already completed that could provide the evidence base on which new initiatives could be built.

Ending well

As it anticipates the end of its own life as a philanthropic fund, Atlantic's final investments in palliative care have been coherent with its lifetime investment in the field. Reflecting the principles of palliative care, Atlantic has taken care to maintain a focus on the field and its needs, to strengthen linkages and connections across professional, institutional, geographical, and practice boundaries in the service of the field, to attend to both individual parts and the field as a whole, to locate every element within a wider, global context, and to shape direction without prescribing the detail of development.

Atlantic has made a unique and critical contribution to a transformation in attention to and capacity for ongoing development in the field of palliative care. As it exits the field, it leaves a legacy of enhanced clarity, commitment, capacity, and collaboration.

Appendix 1: Atlantic Palliative Care Grants

Date and amount	Grant	Focus
2004-2005 **€200,000.00**	Marymount Hospice *Planning Grant for Applied Research on Best Practice in Palliative Care Services*	To assist Marymount Hospice to research best practice in palliative care services and hospice building design
2006 – 2009 **€2,750,000.00**	Milford Care Centre Hospice-at-Home Project	To provide evidence of effective ways to care for older people dying at home by supporting Milford Care Centre develop their hospice at home project
2006 **€251,000.00**	Irish Hospice Foundation Care for the People Dying in Hospitals Project	to support the Irish Hospice Foundation to roll-out their Dying in Hospital programme on a national basis by supporting them to develop a comprehensive and actionable plan for full national implementation.
2005- 2007 **€275,000.00**	Milford Care Centre *Palliative Care Accreditation Project*	To raise the standards of quality and safety in palliative care settings by supporting Milford Care Centre achieve Quality and Safety Accreditation and disseminate the learnings there from.
2005 **€130,000.00**	Irish Hospice Foundation *Review of Palliative Care Services*	To support a baseline study of current palliative care service in Ireland.
2006-2010 **€10,000,000.00**	**St Patrick's Hospital, Cork** *Marymount Hospice Capital Support*	To improve the standard of palliative care services in the HSE southern region by supporting the construction of a new prototype hospice building.
2006-2007 **£4,000,000.00**	**Cicely Saunders Institute** The Cicely Saunders Institute of Palliative Care	To enhance the quality of end of life care by providing matching funds to build The Cicely Saunders Institute of Palliative Care.

2007-2011 **€5,000,000.00**	**Irish Hospice Foundation** *Hospice Friendly Hospitals Project*	To transform the dying, death and bereavement experience of older people in ROI by supporting the IHF to roll-out on a national basis their Hospice Friendly Hospitals Programme.
2007 **€57,724.00**	**Irish Association for Palliative Care** *Strategy and Implementation Plan*	To develop a strategy and implementation plan by contracting a consultant to undertake a strategic review of the organisation.
2007 **€89,736.00**	**Irish Hospice Foundation** *Business Plan for an All-Island Institute of Hospice and Palliative Care*	To produce a business plan for an All-Island Institute of Hospice and Palliative Care by contracting a strategy consultant.
2007-2009 **€2,350,000.00**	**Milford Care Centre** *Capital Support*	To help improve community care for end of life care in ROI by supporting MCC to build a state-of-the-art community care centre.
2008 – 2016 €4,000,000.00	Our Lady's Hospice and Care Services *To establish an all-Ireland Institute for Hospice and Palliative Care*	To establish an all-Ireland Institute for Hospice and Palliative Care that will support the strategic and coordinated development and delivery of high-quality services, education, training and research within the hospice and palliative care environment.
2008-2008 **£39,000.00**	Cicely Saunders Institute *Cross-National Study of Palliative Care Patterns and Costs*	Comparison of patterns of palliative and hospice care, costs and experiences of older people in London, Dublin and New York.
2008 – 2015 **€318,000.00**	Institute of Public Health in Ireland Institute of Palliative and Hospice Care in Ireland: Expert Advisory Group	To support an Expert Advisory Group for an all-island Institute of Palliative and Hospice Care that will develop and deliver strategic and coordinated high quality services, education, training and research on palliative and hospice care.
2009-2014 €502,000.00	Irish Association for Palliative Care Implementation of 5-Year Strategic Plan	To advance palliative care policy on the island of Ireland by supporting IAPC to build its capacity and to implement 5-Year Strategic Plan (2009-2013)
2010- 2011 €180,000.00	Trinity Foundation *End of Life Programme in Ireland - Evaluation and Strategic Learning*	To support an evaluation of the End of Life Programme in Ireland and capture the strategic learning for the field

2010 – 2017 **£2,799,786.00**	Cicely Saunders Institute *Project BuildCARE - Building Capacity, Access, Rights and Empowerment*	To build capacity in the field of Palliative Care by supporting the creation of PhD Studentship and Faculty Scholarship Programmes and the expansion of a unique Research study.
2010 – 2013 **€344,038.00**	Trinity Foundation *End of Life Cost Benefit Analysis*	To support a phased set of studies on the cost-effectiveness of palliative care services in the Republic of Ireland.
2010- 2013 **$500,000.00**	Massachusetts General Hospital Palliative Care Service	To sustainably integrate palliative care into Viet Nam's healthcare system through the establishment of a palliative home-care model, a palliative care clinical training centre and a specialty training programme, and through the formation of a Vietnamese palliative care foundation over two years.
2009 – 2011 $6,000,000.00	Partnership for Palliative Care *General Operating Support*	to support the Palliative Care National Center (PCNC) implementation of its 10-year strategic plan. (U.S.)
2009 – 2013 €491,154.00	Irish Hospice Foundation *Audit of End of Life Care - Hospice Friendly Hospitals Programme*	To transform how older people die in hospital by supporting the development and expansion of IHF's Hospice Friendly Hospitals National Audit System for End-of-life Care.
2013 – 2016 **€1,500,000.00**	Irish Hospice Foundation *Dementia Palliative Care*	To enable more older people with dementia to live and die at home with dignity, by supporting the development and dissemination of best practice models of innovation and care.
2013 – 2016 £2,305,936.00	Northern Ireland Hospice *Hospice and Palliative Care for Dementia*	To enable people with dementia to experience the end stages of life with dignity and free from pain by providing best practice dementia palliative care in hospices and the community.

Culminating grants in palliative care, totalling $7.6 million, focused on improving global access and building field leadership for the future.

2014 – 2017 $1,030,000.00	United States Cancer Pain Relief Committee *Palliative Care Cluster: Global Advocacy for Implementation of the 2014 World Health Organization Palliative Care Resolution*	To implement the World Health Organization's resolution to strengthen palliative care as a component of comprehensive care throughout the life course, calling on all national member states to integrate palliative care and pain relief into their health systems.
2014 – 2017 €740,000.00	Trinity Foundation *Palliative Care Cluster: Development of Academic Palliative Medicine in Ireland*	To strengthen the academic infrastructure of palliative medicine in Ireland by supporting development of academic leaders, incentivising collaboration, and promoting contribution to academic research both nationally and internationally.
2014 – 2017 £1,600,366.00	Cicely Saunders Institute *Palliative Care Cluster: Fellowships Consortium*	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.
2014 – 2017 £625,783.00	Cicely Saunders Institute *Palliative Care Cluster: Project GlobalCARE*	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.
2014 – 2017 £636,839.00	Cicely Saunders Institute *Palliative Care Cluster: International Access Rights and Empowerment Study (IARE II)*	To influence policy, funding and practice and to integrate palliative care into chronic care settings by supporting Phase II of an international comparative study.
2014 – 2017 $1,000,000.00	Center to Advance Palliative Care (CAPC)	To enhance the knowledge and skills of providers of palliative care through e-learning and the dissemination of operational resources to palliative care programme leaders to increase specialist access and educate non-specialists in basic principles and clinical skills.

		Over the grant term, Atlantic would expand its U.S.-based constituency and launch an international palliative care education pilot in collaboration with consortium partners through the fellowships’ proposal, which would then be used to evaluate global mechanisms for disseminating scalable online palliative care resources and skills training.