



THE
**NATIONAL
COUNCIL FOR
PALLIATIVE
CARE**

Dying Well Community Charter Pathfinder Project

Evaluation Report
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Glossary

In the context of the public health approach to end of life care, a variety of different terms are used to describe various types of activities. There is no agreed definition for each term. This means that there is a degree of lack of clarity as to their meanings. Below is a glossary of terms used in this document. We hope this helps to clarify our subject matter. They are not definitive terms but rather, are descriptions of what we are trying to make clear from a practical standpoint.

Community Engagement

This is a process of speaking about end of life care to people and groups in the public. These can be professional and public alike. Often, the process of engagement is one of awareness raising and information giving. In the longer term, the intention is that engagement leads to change in behaviours, which in turn leads to the increased capacity of communities being able to care for their dying.

Community Development

Community development relates directly to working with communities, whether this is in neighbourhoods, workplaces, educational institutions or any place where people gather, to build the capacity to look after people who suffer the experiences of death, dying and loss. The emphasis of community development is not awareness raising or information giving. Rather, it is practically based, setting a course of increased support at end of life for all.

Community Capacity Building

Community capacity is the ability of communities to look after their dying people. If someone develops a terminal illness, or is affected by the experiences of death, dying and loss, the community capacity is the practical and emotional support available. If we are going to care for people, there needs to be a network of support. The ability of that network to care is a marker of its capacity. The more resilient the network, the greater is its capacity. Building capacity is a conscious act that increases resilience, whatever the setting.

Co-production and Co-design

Co-production refers to the process of developing and running services, in which the people who use these services are involved in designing right from the beginning. It is more than consultation, in which the views of people are taken in to account. Co-production assumes an iterative process. Design and running of services is not static but requires change and adjustment dependent on how successful these services are. Co-design is similar, except that the focus is around a problem and a solution. Co-production is broader in application.

Participatory Development

Participatory development is an overarching term which includes co-production and design. It relates more to whole communities and has a longer history of use in a variety of fields, outside health and social care. The principles of participatory development and co-production are similar. Communities are involved in the research, design, implementation and evaluation of any project.





Executive Summary

Public Health approaches to end of life care are becoming increasingly embedded as a part of the overall strategic direction of how societies, both within the UK and internationally, care for people affected by death, dying and loss. The publication of “Ambitions for Palliative and End of Life Care: A national framework for local action 2015– 2020” (during this project) recognised the fundamental importance of this. Ambition 6 ‘Communities Are Prepared to Help’, endorsed public health approaches to palliative care. The overarching practical application of how to do this is contained in the Compassionate Community Charter, by Professor Allan Kellehear and Dr Alik Karapliagkou.

Interest and practice examples in the public health approach to end of life care have been ongoing within England for a number of years. However, this has not been coordinated and has been sporadic in nature. As part of the strategic direction of development, Public Health England commissioned the National Council for Palliative Care to explore the practical application of a Charter approach in diverse settings across England. This report covers the development and outcomes from the projects.

This document is published in conjunction with **‘Each Community Is Prepared to Help: Community development in end of life care - Guidance on Ambition Six’**.

The guidance provides a theoretical framework and gives practical examples of how different health and social care organisations can start to use community development as a routine part of their provision of end of life care. The Pathfinder Report provides examples in different settings of how this implementation takes place and describes some of the early benefits of doing so.

The Dying Well Community Charter was published by the National Council for Palliative Care (NCPC) in 2014. It is intended to highlight a Public Health approach to end of life care, and is a set of principles by which individuals, organisations and local communities commit to work together.

Eight Pathfinder communities were selected to pioneer a public health approach to end of life care, following the Dying Well Community Charter. The term ‘Pathfinder’ was adopted as this was the first time in England that public health approaches to end of life care had been carried out on a national level.

The Pathfinders all held launch events to engage with the wider community, completed a baseline assessment process followed by prioritisation, and based on their prioritisation implemented local improvement work and/or a community based capacity building project. They were supported by clinical leadership and evaluation support provided by NCPC, along with face to face quarterly meetings to share success and learning.

Different approaches were taken by the Pathfinders to build capacity within their environments. Some areas had previous experience of public health approaches, including successful funding bids, to end of life care and community capacity building. Others had previously focused on community engagement. The Pathfinder sites continued with these projects and added in others.

All of the Pathfinders worked to raise community engagement. Awareness and conversation around death and dying were delivered via a wide range of initiatives including: reaching the public by delivering workshops aiming to increase community capacity, resilience and future life planning; and reaching professional groups, such as contributing to GP training, and engaging with law professionals.

Alongside community engagement activities, several Pathfinders made significant progress with capacity building projects within specific populations. These projects included building capacity within: a higher education setting via training volunteers who would come into contact with students; a local town via setting up an open caring network and closed buddy groups as part of a compassionate community Hub; and within the whole community setting up a Neighbours Network and rolling out companion support.

The examples and lessons learned within this report highlight the initial progress that Pathfinder sites have made in various environments. It is hoped that the initial experience and progress of the Pathfinders and their shared learning, will help inform other localities as they start to work with individuals, communities and organisations to increase capacity and adopt a public health approach to end of life care.





Introduction

The Dying Well Community Charter and the Compassionate City Charter

The Dying Well Community Charter (Appendix A) was published by the National Council for Palliative Care (NCPC) in 2014. It built on previous charter initiatives including *'What makes a good death? A North East Charter'* produced by the NHS North East Strategic Health Authority in 2010, the Royal College of Nursing and Royal College of General Practitioners' 2011 End of Life Care Patient Charter, and the Compassionate City Charter.

The Dying Well Community Charter incorporates the approach set out in the five Priorities for Care published by the Leadership Alliance for the Care of Dying People (LACDP). It was released in conjunction with the *'Public Health Approaches End of Life Care Toolkit'*, produced by Professor Allan Kellehear and Dr Aliko Karapliagkou. The toolkit can be used to complement the Charter, and is a valuable resource for anybody wanting to find out more about Public Health approaches to end of life care.

The Dying Well Community Charter is aspirational in nature. It focusses on core principles and challenges professional organisations on how to provide care that is relevant to communities. The Toolkit covers the broad range of public health approaches to end of life care and the concise breadth of this is contained in the Compassionate City Charter (Appendix B). It is very practical in nature, recommending specific areas for development and suggesting a strategic framework for development over a number of years.

The concept of using a Charter can be useful in providing a clear vision and principles for individuals and organisations to work to. The Charter is intended to highlight a Public Health approach to end of life care, and is a set of commitments for individuals, organisations and local communities to work towards. It was envisaged that this Charter approach would help local communities to work together to improve their response to people dying, their carers, and the bereaved. The Charter makes the key statement that:

'Dying and death do not happen in isolation from the rest of life. People who are dying may not wish to be isolated and disconnected from their communities. There is more to do to engage communities in the end of life so that those affected by dying and death do not feel abandoned and socially isolated. Care for one another at times of crisis and loss is not simply a task for health and social care services but is everybody's responsibility.'

The Dying Well Community Charter outlines five principles of care and support: **Recognition and Respect, Communicate, Involvement, Support** and **Help us to Plan, and Do.**

The Dying Well Community Charter should be seen as complementary to the Compassionate City Charter. The Compassionate City Charter and Toolkit focus on the 'what and where' and provides a list of potential capacity building initiatives. The Dying Well Community Charter focusses on the underlying principles.

The 'Pathfinders'

Along with developing the Dying Well Community Charter, NCPC was asked by Public Health England to identify localities to roll out and adopt the principles of the Charter. In September 2014 NCPC put out an open invitation to organisations and collaborations of organisations across England to express an interest in becoming one of six 'Pathfinder' communities.

Pathfinder areas would pioneer a public health approach to palliative and end of life care, using the Dying Well Community Charter as a framework. The term 'Pathfinder' was adopted as this was the first time in England that public health approaches to end of life care had been carried out at this scale across the country.

From the outset of this project it was recognised that this was uncharted territory and so the opportunity to learn about what did not work was seen as important as learning about what progress the Pathfinders were able to make. Although funding was made available for central co-ordination and support of the Pathfinder sites, there were no specific funds for the individual Pathfinder sites. This was accepted as a limitation and was made clear at the outset of the project. Despite the lack of financial resources, NCPC received a significant number of applications.

To apply interested localities were asked to describe their locality, the end of life care challenges that they faced, and their ideas to locally pioneer a Public Health approach to end of life care. There was great interest from across England, even with no national funding available to support the proposed initiatives.

NCPC received a total of 23 expressions of interest in becoming a Pathfinder community, and from these NCPC and Public Health England selected eight Pathfinders. The localities selected were:

- Birmingham
- Cheshire
- Dorset
- Hackney
- Hull and East Riding of Yorkshire
- Lancashire
- Liverpool
- North Somerset

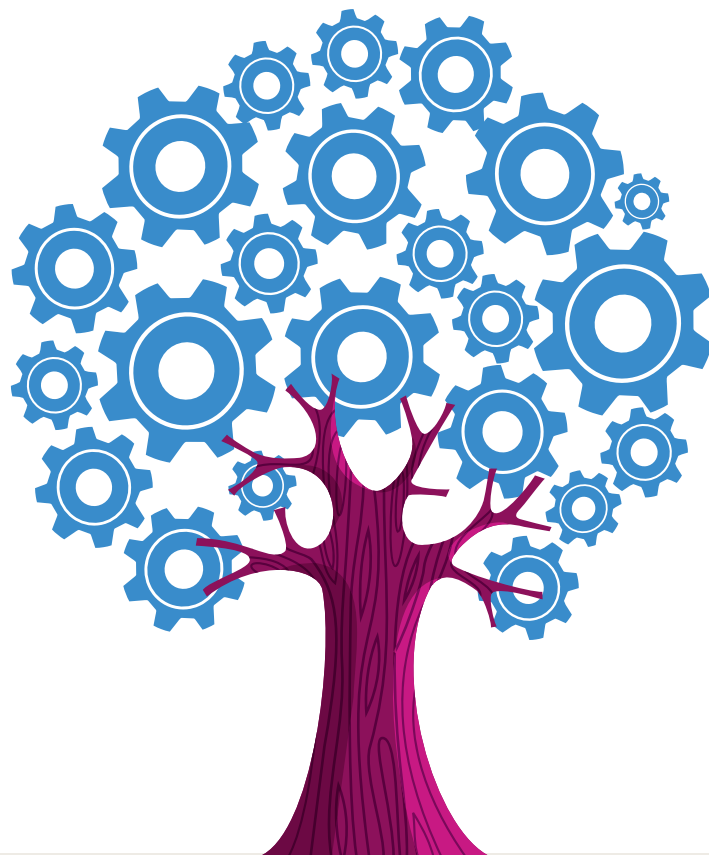
Upon being accepted as a Pathfinder, the eight localities all signed up to:

1. Hold a local event to launch the Charter approach in their area.
2. Work with organisations and individuals in the community to embed the principles of the Charter approach, through raising awareness and changing behaviour.
3. Raise awareness of the Charter approach in the community.
4. Support the evaluation of the impact of the Charter.

There were no central funds available to the Pathfinders to support delivery of their initiatives. Central project co-ordination was provided by NCPC, along with some expert leadership (4 sessions a month) and evaluation support.

NCPC had also secured a limited amount of funding to cover travel costs for a Pathfinder representative from each site to attend face to face quarterly meetings. Several pathfinders kindly offered to host quarterly meetings in their workplaces at no cost to the project.

Due to the great interest in this work, 6 “buddy” sites were also identified, and it was hoped that Pathfinders and Buddies would be able to work together to build local connections and support. However, due to the need for Pathfinders to focus their energies and resources on capacity-building in their own locality, little progress was made through these “buddy” relationships.





Methodology

The Pathfinders Project

The Pathfinders were all asked to follow a set project lifecycle (Figure One). The cycle would take each locality through a launch event to engage with the wider community, a standard baseline assessment process followed by prioritisation, and based on the prioritisation the implementation of local improvement work and/or a community based capacity building project. At the heart of the process was shared learning captured via evaluation.

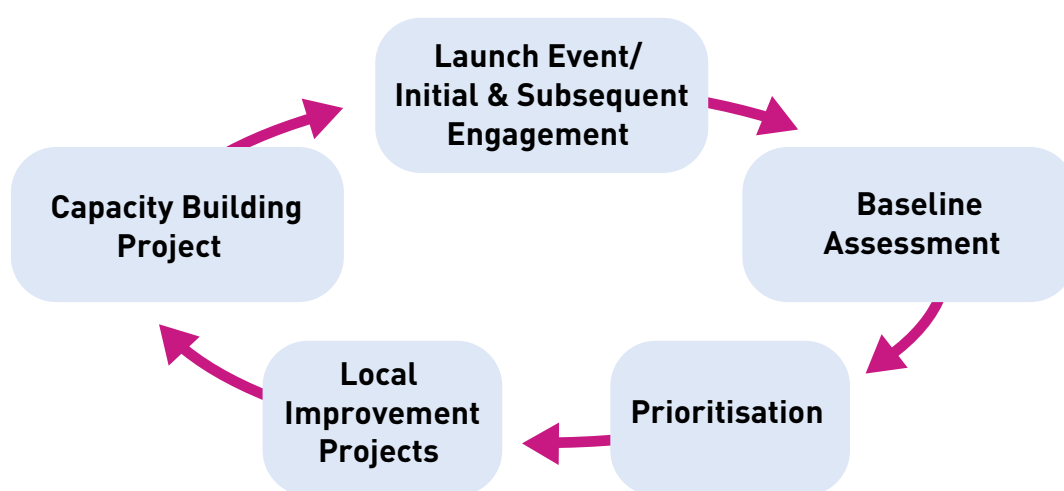


Figure One. The Pathfinder Project Lifecycle

To support Pathfinders quarterly face to face meetings were held, enabling Pathfinders to come together to share their progress, learning, and to support each other with challenges. Six meetings took place. The first took place in London in May 2015 as a scoping meeting and introduction to the project. Further meetings were hosted by Pathfinders in their locations: Cheshire, Hackney, Birmingham and Liverpool.

In addition to quarterly meetings, all Pathfinders were offered on-going support via Skype conversations with the Clinical Lead and Evaluation Lead. As part of the support for Pathfinders, the Clinical Lead visited six of the eight localities, with the exception of Weston super Mare and Hackney, who both had capacity building projects already up and running.

Launch events

The Pathfinders were all supported by NCPC to develop and run local launch events during the first half of 2015. NCPC provided advice and resources to support the development of the events, with a speaker offered from either NCPC or Public Health England, as well as local leaders and stakeholders.

Baseline Assessment & Prioritisation

Following the launch event all Pathfinders were asked to complete a baseline assessment review of end of life care and support in their community. This was supported via a standard template provided by NCPC (Appendix C). The template was designed to support an assessment of current provision of care and support to those at the end of their life and their carers. Pathfinders were asked to engage locally when completing the template, to include the perspectives of relevant stakeholders within their localities.

The tool enabled assessment of current services, and recorded ideas for potential new initiatives covering five fields of activity, each with two criteria, outlined in Table One.

Field of Activity	Criteria
Awareness & Conversation around Dying	Initial awareness of the need to engage the wider community in end of life conversations and care, including identification of local organisations and individuals as “champions” for wider community involvement
	Activities to promote conversation around dying, death and bereavement in local organisations and public spaces (e.g. shops, businesses, other)
Support in local organisations/ groups	Policies and activities to support people at the end of life and bereaved people in local organisations (e.g. schools, workplaces, other)
	Practical support at the end of life and activity in local groups (e.g. pensioners organisations, fellowship & faith groups, drama & creative arts, sports groups, trade unions, other)
Practical support	Availability of support groups for carers and bereavement support
	Other sources of practical support (e.g. dog-walking, befriending)
Meeting care needs	Involvement of local community in designing care services
	Making end of life care services accessible and culturally appropriate for everyone in the community
Prioritisation of end of life care	Engagement of ‘top-level’ partners to support developments (e.g. local Health & Wellbeing Boards), and prioritisation of end of life care in local plans and strategies (e.g. JSNAs, Health and Wellbeing Strategies, other)
	Activities to support, inform, and involve community groups to provide help for those at the end of life and their carers

Table One. Criteria for local baseline assessment.

For each of the ten criteria Pathfinders were asked to rate them to support prioritisation, using the scoring shown in Table Two.

Sites were supported to focus improvement on areas prioritised as **RED**. This was to ensure that projects remained focussed on areas where immediate benefit could start to be shown within the timescales of the project.

RED	Areas that are the highest priority due to lack of adequate activity and/or an immediate practical difference can be made.
AMBER	Areas where some existing activity is identified, but where there are clear identifiable areas for improvement.
GREEN	Areas where there was sufficient existing activity in place that localities were satisfied they are not currently a priority.

Table Two. Prioritisation scoring matrix.

Capacity Building Projects

Pathfinders were supported to identify, plan and implement a capacity building project within their locality. Some localities had experience of previously running such projects, whilst others were relatively new to public health approaches.

It was hoped that by focussing on a local capacity building project, each Pathfinder would be able to attempt to build capacity in small populations within their localities in a relatively short timescale.

Pathfinders were strongly encouraged to identify different populations to work with, to ensure a breadth of knowledge could be captured from the project as a whole. For example, Cheshire decided to work with staff from The University of Chester Students' Union, working to support a student population of approximately 18,000; Dorset decided to work with a town, supporting a local population of approximately 15,000.

Evaluating the Project

As part of the quarterly meetings the Pathfinders were involved in the development of an evaluation framework. From the outset it was agreed to follow an explorative participatory evaluation methodology. The methodology matched the underlying principle of the project: participatory development.

The Pathfinders co-designed an iterative approach to capture data relevant to the communities they were working with. They were supported to design their own individual logic models, supporting their initial focus on activities and outputs. There was a strong focus on keeping data collection simple and easy to collate.

The agreed evaluation approach consisted of:

1. **The NCPC baseline assessment tool (Appendix C)**

It was agreed to re-visit the baseline tool assessment after twelve months to assess progress against the identified priorities.

2. **A logic model and data collection spreadsheet (Appendix D)**

Sites were supported in developing their capacity projects by the co-production of a logic model, and a supporting spreadsheet for collecting data. The logic models outlined both process and outcomes measures relative to the individual circumstances of the Pathfinders capability building project. A supportive data collection spreadsheet was made available with built in run chart function.

3. **A progress and learning questionnaire (Appendix E)**

A template was made available to capture overall progress, future plans, and learning.





Pathfinder Progress

The Pathfinders have all attempted to champion and action the principles of the Dying Well Community Charter within their localities. With different demographics and varying experience of public health approaches, their stories highlight their initial progress with practical examples.

Birmingham

The Birmingham joint bid to be a Pathfinder was supported by Birmingham Cross City CCG, Birmingham Local Authority and End of Life Care Providers. It was led by a Palliative Care Clinical Lead and Commissioner. The original intention was to use the project to support the re-shaping of end of life care services across Birmingham.

An official launch event was held on 19 March 2015 at Birmingham City Football Club. The launch included an opening speech by the Chair of the Birmingham Health & Well Being Board as well as the Birmingham cross city CCG lay advisor for patient and public involvement. The launch was well supported with over 50 attendees.

Following the launch a core development group formed to look at how to take forward the principles of the Charter. The group included: CCG Commissioner, Public Health Officer, partner from Murray Hall Community Trust and the CCG Communication lead. The group collated baseline assessment data from providers across the locality.

Unfortunately, prior to agreeing priorities the Clinical Lead changed roles, followed by the Commissioner changing roles due to a CCG restructure. A new permanent CCG commissioner was not appointed until August 2015. Manjula Patel from Murray Hall Community Trust engaged with the new commissioner and there was enthusiasm to support the work. Initial plans were to engage with providers again to share ideas and learning; however in February 2016 the CCG withdrew from the Pathfinder project.

Despite Birmingham CCG withdrawing from the Pathfinder project, local end of life care providers were still enthusiastic for the Pathfinder status to continue. At an NCPC regional event later in 2016 many of the providers from the Birmingham locality were galvanized to continue with the Pathfinder and take forward the principles of the Charter under the umbrella of the regional NCPC group. In spite of not having a lead, some of the providers who attended the launch event had forged ahead adopting and practicing many of the principles of the Charter in their own way. For example, a funeral director had engaged with others to form a collective called 'BRUM YODO' and they have been involved in a variety of community engagement activities during Dying Matters Week.

The Birmingham Pathfinder group is now re-organising itself with providers and the CCG Commissioner has asked to be kept informed. It is clear that for Birmingham the principles of the Charter approach have and continue to be championed amongst

providers, and the Pathfinder project has provided a focal point to bring together the front line providers to take on board the principle of a public health approach to end of life care in Birmingham.

Cheshire

The End of Life Partnership is a charitable collaborative in Cheshire aiming to transform End of Life Experience and Care. Stakeholders include: four CCGs, two local authorities, three hospices, three hospital trusts, the University of Chester, and the charitable sector.

The dedicated Cheshire Living Well, Dying Partnership enables wider community voices to be heard and provides an additional public facing branding for the organisation.

The collaborative applied to be a Pathfinder as they were already embracing the principles of the Dying Well Community Charter. The Cheshire Partnership already had an established programme of using public health approaches to end of life care.

A launch event was held in March 2015 with over 90 attendees. These included: community organisations, local councillors, local authority, businesses, university, schools, faith groups, housing organisations, CCGs and the public. The day enabled the partnership to engage and scope attendee's priorities, along with mapping community assets.

Supported by the baseline assessment tool, the partnership reviewed end of life care and support in the community. The review included representatives from across the Partnership. They agreed the key priority was **Awareness and Conversation around Dying** as an immediate practical difference could be made. In addition they noted that there was existing activity with potential for further development in the following areas: support in local organisations/groups; practical support; and prioritisation of end of life care. Plans for development included:

- Development of a Champions Framework
- Community consultation of priorities/assets
- Review of the My Wishes Folder and use with community groups
- Community capability building project

The Cheshire Partnership has made significant progress in increasing awareness and conversation around dying. A wide range of public and community projects and workshops have aimed to increase community capacity, resilience, and future life planning. Over a period of twelve months **12 public sessions** were held **reaching 120 attendees**.

Training sessions were delivered to enable people who work with the public to engage them to think, talk, and take action in relation to life, age, death and loss.

In total, **27 training sessions** in providing peer support (including bereavement support) **reached 293 attendees**.

As part of the Pathfinder project, The Cheshire Partnership identified a new opportunity to work with The University of Chester Students' Union. The Union represents and supports the welfare of over 18,000 students, so was considered to be an excellent opportunity to build capability and supportive networks in a University higher education setting.

The overall approach to the work with The University of Chester Students' Union is outlined in a summary Logic Model (Figure Two).

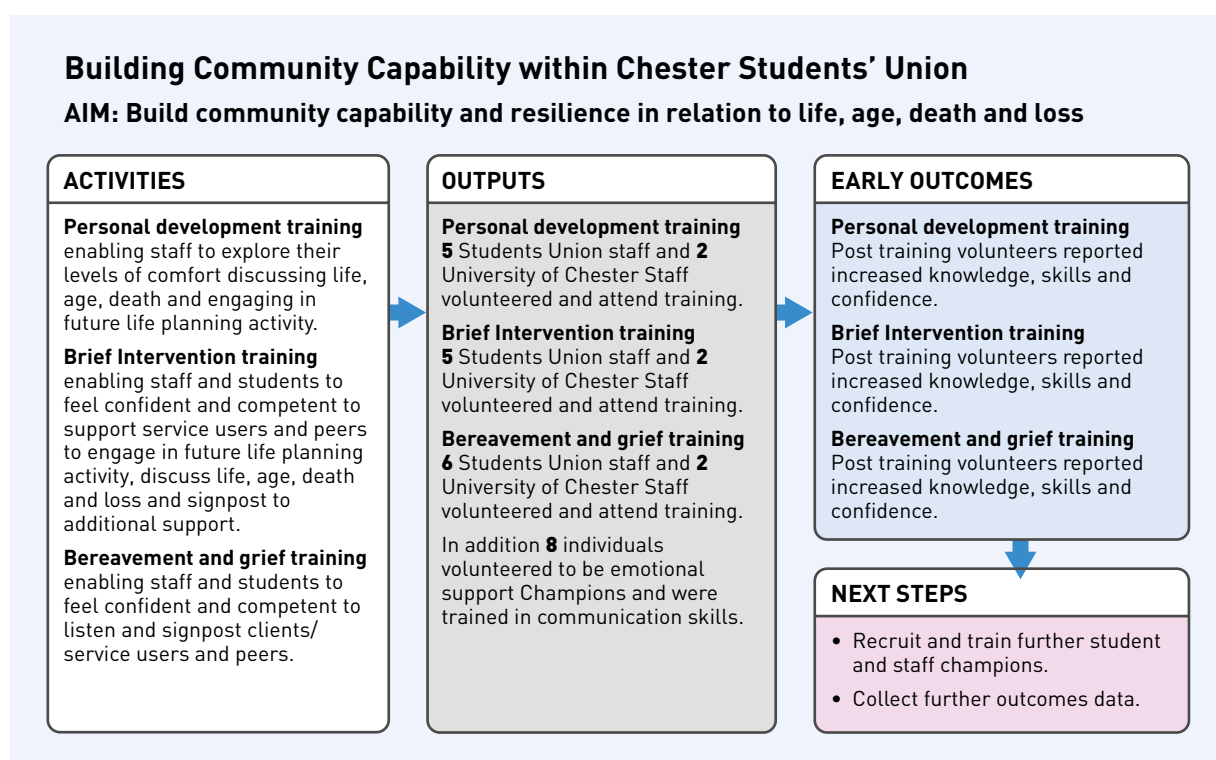


Figure Two: Logic Model

The Cheshire Partnership has embraced the Charter, and has used their involvement in the Pathfinder Project to champion the principles of the Charter in a higher education setting. By providing personal development and training they now have **eight emotional support champions** volunteering at the University. These volunteers have access to support a student population in excess of 18,000 students.

Early outcomes have shown that the training provided to the emotional support champions has led to a positive change in their knowledge, skills and confidence. The Partnership and the Students' Union will continue to collect outcomes data over the coming twelve months. This will enable further insight into the number of contacts the volunteers have, and the support they are providing.

Dorset

The 'Diealog Compassionate Community' (renamed from 'Diealog Dorset') is a pioneer health and social action project. It is an innovative community-owned and led, person-centred and network-centred approach. It promotes better experience, good practice and more compassionate care for all our ageing, dying and caring. Diealog Dorset was already an end of life care pioneer, with a charity partnership, and wanted to use the Charter to implement to a greater effect.

The project was and remains an independent and locally owned project, led by Dr Max Mackay-James a retired GP. A series of engagement activities were undertaken over a nine month period to disseminate information on the Charter and 'Diealog Compassionate Community'. Engagement activities included: contacting database members, newsletters, local radio, social media and local community events. Alongside this public health professionals, councillors involved in Health and Wellbeing Boards, NHS staff, local hospices and charities were approached with a view to promoting co-working.

A launch event was held in March 2015 at Poole General Hospital Education Centre. Prior to the launch event local activists were invited to join steering groups to support the launch. There were two steering group meetings with over 20 attendees. Over 200 contacts were invited to attend the launch, opened by the Mayor of Poole. There were 63 attendees, the majority being from the local NHS, hospice and end of life organisations. The launch day aimed to bring together and reactivate pre-existing networks.

Supported by a baseline assessment tool, a review of end of life care and support in the community was conducted. They identified **Awareness and Conversation around Dying** as a key priority. Plans for development included: initiation activities and promotion of 'grassroots up' approach in communities; co-creation and co-production of community centred 'Dying Well' initiatives; and engagement of community development activists, palliative care providers, NHS and end of life care representatives with public health approaches.

Following the launch event there was little engagement from attendees. The launch event for the Charter did not generate further buy-in and engagement from the local NHS and end of life care organisations or the general public. As a result, six months into the Pathfinder project the strategic direction of the Diealog project moved to developing Compassionate Community Hubs. The new key priorities set for the Diealog Compassionate Community Hubs were **Practical Support** and **Meeting Care Needs**.

The town of Bridport, Dorset, was selected as the first Diealog Compassionate Community Hub. An important aspect of the Diealog Compassionate Community Hubs is that they are locally owned, being both designed and led by local people. With this in mind two Hub initiator meetings were held, leading to the local community wanting to initiate: an open to all caring network forum, closed buddy/peer support groups, and local community engagement.

The overall approach to the development of the hub is outlined in a summary Logic Model (Figure Three).

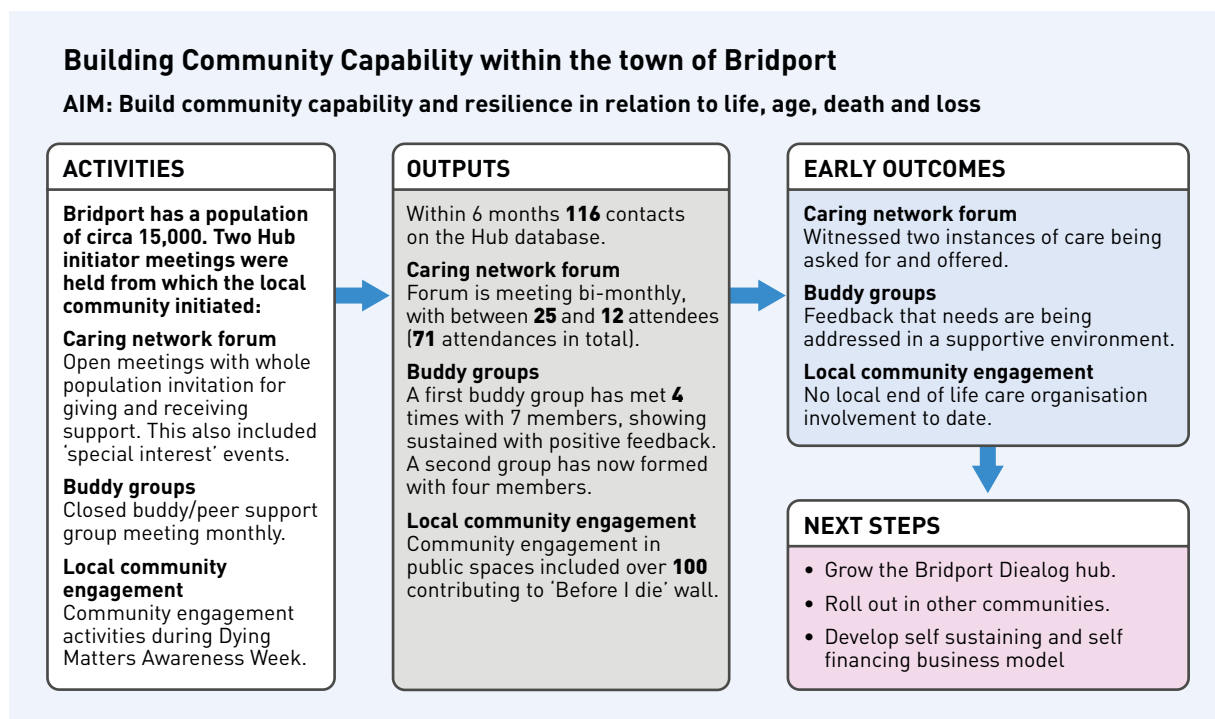


Figure Three: Logic Model

Over six months 116 people have been added to the Diealog Compassionate Community Hub database. The caring network continues to meet bi-monthly with good levels of attendance (to date has **71 attendees in total**). The first closed **buddy group has met four times with 7 members**, and is becoming a sustained group with positive feedback from members. A second buddy group has now formed with four members.

After seven months of support the first Diealog Compassionate Community Hub is becoming sustainable and self-supporting. This project has clearly shown that with local ownership it is possible to support the set-up of local compassionate communities. Diealog Compassionate Community now plans to grow the first Hub including ensuring participation from the hard to reach and socially isolated, and to replicate their successful model approach in other local communities.

Hackney

St Joseph's Hospice is a large urban hospice providing care for the diverse boroughs of East London. The principles of a new public health approach had already been incorporated into the organisation's strategic priorities and they were some way down the road in exploring meaningful ways of engaging with local communities. St Joseph's applied to be a Pathfinder site with the Hackney Health and Wellbeing Board, in order to promote a more broad based understanding and approach to end of life care and to

promote and develop partnerships within the voluntary and statutory sectors. Changes were happening within the borough, including the launch of a new integrated care endeavour, One Hackney, which meant that public health approaches needed to be aligned and included in end of life provision. The launch event was held in May 2015 in Hackney and the Dying Well and Compassionate City Charters were presented.

At the same time as the Pathfinders application, other applications opened for funded projects related to the new public health approach and the hospice was successful in obtaining funds to develop compassionate communities work further. This was in the shape of 'Compassionate Neighbours', a project which supports community members to develop the skills, confidence and capacity to actively change the way death and dying are experienced in their local community. The training develops a supportive peer network through the training and the compassionate neighbours are matched up to community members who could benefit from support, be they carers or individuals facing the end of life. The project goes beyond a traditional befriending project both because the compassionate neighbour actively tries to develop a supportive network around the individual and mobilise the local community where connections may have been lost, but also contribute to a groundswell of local support for the work, to lead to a social movement and increasing community control of the project.

The funding secured in 2015 meant **Compassionate Neighbours grew significantly from 4 compassionate neighbour volunteers at the start to over 120 at the end of the year.** The project has succeeded in becoming widely known amongst local people and healthcare professionals and a valuable component of the care delivered through the integrated care project, One Hackney, with waiting lists for referrals and for those wishing to undergo the training. Due to staff changes, the link with Hackney Health and Wellbeing Board did not progress work specifically related to the Dying Well Charter but the broader scheme of work has ensured that the new public health approach has been embedded in end of life care in Hackney.

The Pathfinders quarterly meetings have provided the opportunity for national networking between sites undertaking the same work and have allowed for mutual support and sharing of resources and learning. The relationships that this has fostered have been a key part of progressing this work nationally.

Hull & East Riding of Yorkshire

Dove House Hospice was already committed to embedding a public health approach to end of life care, before they applied to be a Pathfinder. They have a hospice community engagement project involving staff from across their clinical services, education, marketing and income generation teams. Hull and East Riding applied as they were keen to support individuals, organisations and communities to recognise that everyone has a part to play in end of life care.

A launch event was held in June 2015 to introduce the Charter to both staff and external organisations. It was hoped that the launch would stimulate thinking about how external organisations could implement the principles of the Charter. The launch

event was well attended with representation from: Hull CCG, East Riding CCG, Hull City Council, East Riding Council, Hull & East Yorkshire Hospital Trust, Humber NHS Foundation Trust, the University of Hull, charities and end of life care support services. The launch was successful in sharing the principles of the Charter. Following the launch an Internal Pathfinder Steering Group has met bi-monthly, with an External Partners Group meeting quarterly.

Supported by the baseline assessment tool, the Internal Pathfinder Steering Group reviewed end of life care and support in the community. They agreed the key priority was **Awareness and Conversation around Dying** as an immediate practical difference could be made. It was felt that there was a significant gap within their area for awareness of end of life care, death and dying. Initially the Hospice led a series of engagement activities, including:

- Increasing awareness with staff, and in particular non-clinical staff at the Hospice. As a result of this training staff feel more confident in discussing death, dying and bereavement.
- Introducing **'Before I die' boards in six of the commercial shops**, with plans to introduce them to other Hospice shops across the locality.
- Holding Death Cafes at the Hospice with **between 15 to 25 attendees**. Plans are in place to take these out into the community.
- Working with Hull Truck Theatre to deliver a Death Café prior to a performance 'Learning how to die' **with 22 attendees**.
- Highlighted the Pathfinder work and held a Death Café at the Specialist Palliative Care Forum, **with over 60 attendees**.
- Highlighted awareness amongst local GPs via attendance at a practice learning time event, **reaching 125 attendees**.
- Attended Bridlington World Café, a group involved in changing how services are delivered in the local area, with 150 attendees.

Following the series of engagement activities, the Hospice held an 'Ideas Day' in November 2015. The day was aimed at Hospice staff and volunteers, and included six partner organisations including the Health and Wellbeing Board. The day received positive feedback, and led to further meetings with two external organisations: Cruise Bereavement and City Health Care Partnership. Both organisations are now involved in the Hospice 'Dying for Change Project'.

The Dying for Change Project will focus on introducing the taboo subject of dying, and the celebration of life. It is hoped that this project will be funded as part of the Hull City of Culture 2017 programme. Art will be used to promote discussion and creative interpretation with children, young people and adults. The project will involve 20 local

primary schools promoting them to link and collaborate with partners from different cultural, educational, health and community groups (this is dependent on gaining funding).

Alongside the Dying for Change Project, the Hospice are currently developing content to support compassionate organisations. By supporting local companies to introduce policies around death, dying and bereavement, this work should enable local organisations to better support their staff in their time of need.

Liverpool

Liverpool Clinical Commissioning Group (LCCG) along with Liverpool City Council (LCC) expressed an interest in becoming a pathfinder for implementing and championing the charter to build on the shared vision of the leaders, influencers and decision makers of Liverpool of elevating the quality of supportive and end of life care (S&EoLC) to a standard of excellence across Liverpool.

With a new End of Life lead having just taken over the role at the CCG, the charter was an ideal enabler to help re-launch S&EoLC in Liverpool following the demise of the Liverpool Care Pathway and shape the future S&EoLC model.

The CCG and LCC already had good working relationships with local communities prior to the charter, it was hoped the charter would enhance these relationships and enable our communities to share knowledge and experiences with each other and develop mutual support.

The charter launch event took place March 20 2015 at The Florrie, with over 40 attendees. These included representatives from the Clinical Commissioning group, Public Health England, the Local Authority, Health & Social Care, voluntary/third sector organisations, broader community groups and members of the public.

Supported by the baseline basement toolkit, a live interactive system enabled the audience to vote how they felt Liverpool's communities was doing to provide care and support to people at the end of their life and their carers, this highlighted three main of focus: **Community Involvement, Awareness of conversations around dying and end of life, and Practical support available in Liverpool.**

At the launch, the findings of insight work done by the CCG and the Public Health team in partnership to establish how people in Liverpool want to be communicated with around death, dying and loss were also introduced. This piece of work complements the charter work, in particular around raising awareness of conversations around dying and end of life and providing practical support for people in Liverpool.

The main outcome of the insight was that there needed to be a central online resource that would give practical advice and guidance on how to take 5 simple steps to prepare for death, which would provide written guidance and support for members of the public in Liverpool to have conversations around death and dying, which will include information for individuals which are planning for their death and information for

family members on the importance of doing this.

To ensure momentum was kept an output of the lunch was to set up a community group, from those that attended the launch and a wider audience. The vision of this group was:

To help communities work together to improve their responses to people who are dying, and those who are bereaved. To ensure everyone is well supported and cared for through dying, death, grief and bereavement

The group is still meeting on a monthly basis, but has struggled with what it should be delivering due to there being some confusion over the charter, and how it fits in with Compassionate Cities. The group has reviewed the principles of the charter and is working on adapting the charter for Liverpool which will be aimed at communities, organisations and individuals, with a toolkit that sits behind it. This work has stalled a little whilst a better understanding of Compassionate Cities is being developed.

The Capacity building project identified by the CCG was for Liverpool CCG to become a compassionate organisation, through adopting a compassionate workforce policy, training staff to act as emotional support to workplace colleagues and to have a bank of volunteers who are prepared to help people who are carers for family members/friends at end of life or who have recently been bereaved.

There has been a strategic decision within the CCG to align the work initiatives in order to optimise resource, looking at and working towards Liverpool becoming a compassionate city, the development of the new S&EoLC strategy and the online resource and media campaign. The aim is to launch the capacity building project identified through the charter work, alongside the launch of the website and media campaign.

Lancaster

The locality applied to be a Pathfinder as they felt it would act as a catalyst to further build on their existing initiatives, seeking to establish North Lancashire as a Compassionate Community. Involvement as a Pathfinder would build on existing links established through the Dying Matters coalition.

A launch event was held in March 2015 at The Storey Institute, with local system leaders and the public invited. The event was advertised with an image of a local landmark to attract attention, and the programme for the day included time for group interaction and local stories. The day was a success with over 60 attendees, who became more aware of the ambitions of the local steering group.

Following the launch event a workshop was held to review the current end of life care services across the locality. The group prioritised: **Practical Support via Partner**

Organisations, Awareness and Conversation around Death and Dying, and Support in local groups and organisations. An underpinning strategy was developed for the steering group to work towards, with the key objectives to: Lobby, Learn, Live well to the end and Link together.

Pathfinder organisations have delivered a series of awareness and engagement activities across the locality:

- Continued working with a local theatre company to use art as a tool for conversation, running questions and answer sessions after a number of productions, **reaching over 200 people.**
- Built on the 'Dead Good Read' reading group project, linking with Lancashire Library Service.
- The International End of Life Observatory team took over an empty shop in the City centre promoting Dying Matters week with **a footfall of over 150 people.**
- Plant sales at the Hospice act as a mechanism to get local people into the Hospice for a tour, and to take away information. These sales have **reached over 300 people.**
- Hosted a Law Commission consultation event with **over 100** mainly law professional attendees.
- Plans in place to hold a Compassionate Employers conference.

Prior to becoming a Pathfinder, Lancaster had received funding from the Prime Minister's Challenge Fund for a one year Neighbours Network Project at the Hospice. The project aimed to build a support network to support people living with a life shortening condition in isolation. It was envisaged that network support would reduce those in isolation making frequent calls to their GPs. Project funding enabled the Hospice to employ a co-ordinator to: recruit and train volunteers, speak to community teams and GPs to recruit people in need of support, and promote the project in the media.

Over a year the Hospice has achieved a volunteer led, self-supporting neighbourhood group. To date there have been **28 volunteers** who have **worked with 35 clients, providing practical support** including: dog walking, gardening, shopping, signposting to other agencies and respite for carers. Plans are in development to build on this work by recruiting and training further Neighbourhood Network Volunteers.

Weston

Weston Hospicecare is based in Weston-Super-Mare and serves patients in North Somerset and Somerset, with a population of circa 192,000. Weston Hospicecare applied to be a Pathfinder as they were already trying to pioneer the principles of the Dying Well Community Charter, and were adopting Public Health approaches to end of life care.

A launch event was held in March 2015 with invitees including: GPs, the local MP, and the major and mayoress. There were over 35 attendees including staff from the Hospice. The launch day was successful and led to many attendees engaging and volunteering to be part of the steering group.

Supported by a baseline assessment tool, the Hospice reviewed end of life care and support in the community. They agreed the key priorities **Support in local organisations/groups** and **Practical support**. Plans for development included:

- Facilitate discussion about end of life care, death, dying and bereavement.
- Provide information and training to enhance the confidence and capability of individuals to provide practical help and 'acts of kindness'
- Recruit network co-ordinators to support development of supportive networks.

To ensure community engagement a steering group was set up, including those volunteering to be involved following attending the launch event. The Compassionate Communities Charter Implementation Group (CCCIG) engaged widely and grew with new organisations joining each meeting. Within a year **29 organisations were represented** at the CCCIG meetings. The group was led and supported by Weston Hospicecare and successfully engaged with organisations and professionals that support the public. Unfortunately the project was limited in developing further networking due to organisational changes at the Hospice.

Weston Hospicecare were experienced in public health approaches to end of life care, and already had compassionate community work underway. They hoped that joining the Pathfinders Project would enable them to further build and spread their work. They decided to focus their capability building in three areas:

1. **Increasing their companions** to enable them to support more individuals, with volunteers acting as a listening ear supporting the de-professionalising of dying
2. **Further developing their existing buddy groups** to include others who had no previous involvement/connection with the Hospice.
3. **Developing compassionate organisations** by training volunteers within the workplace, and supporting the compassionate policies.

The overall approach to the work is outlined in a summary Logic Model (Figure Four).

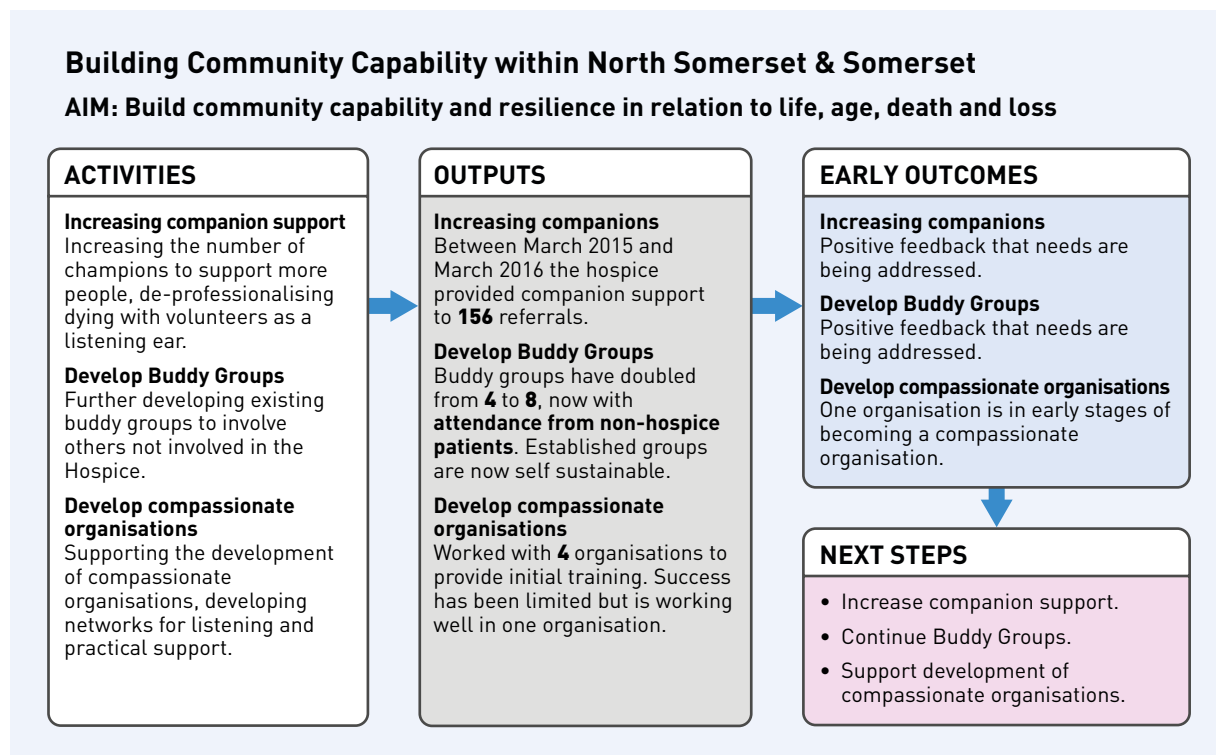


Figure Four: Logic Model

The Hospice has made significant advances in their community development approaches over the past twelve months. Between March 2015 and March 2016 (Figure Five) **the hospice provided companion support to 156 referrals.**

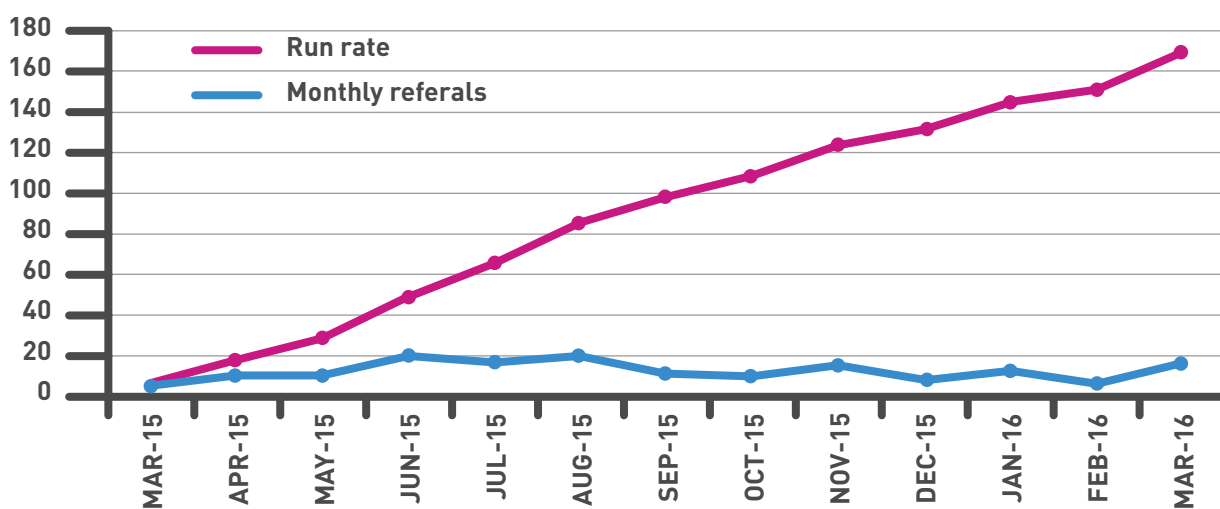


Figure Five: Companion support

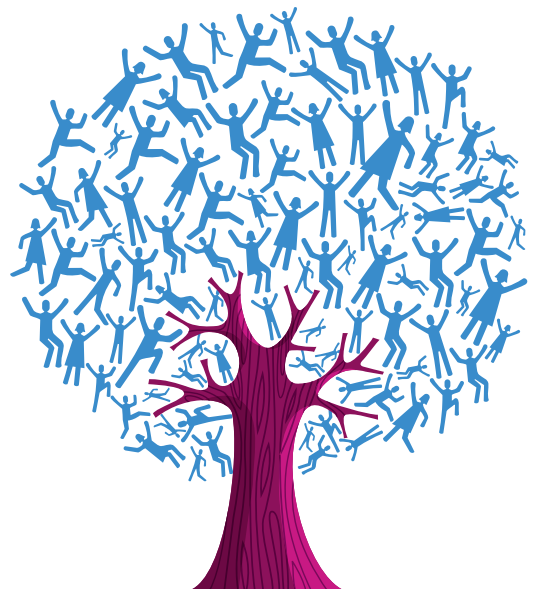
The **buddy groups have doubled** from four groups to eight groups, and they now include individuals with no previous involvement/connection with the Hospice. Alongside this the Hospice has also established a bereavement group in a nearby town, offering them training and supervision. The bereavement group is now self-sustained. The buddy groups have received positive feedback.

'I am able to talk about my spouse. It is hard to go out with friends who are couples. In the Buddy Group we are new friends, sharing grief, memories and we do not feel so isolated'

'Going out with family and friends without my wife was difficult. They didn't want me to talk about her as they felt uncomfortable. I liked to talk about her with happy memories too. I can do this in the Buddy Group'

'We are all at different stages of grief and understand what we each go through. It is normal to grieve. I don't need counselling, just empathy and sympathy from someone who has been through a caring role and lost a spouse through death'

Staff at the Hospice met with four organisations to identify staff and provide training to enable them to become compassionate organisations. Organisations (and their individual staff members) were keen to become compassionate organisations, however local changes at the Hospice and in community health services led to limited progress. The development of an organisation as a compassionate one requires an internal co-ordinator to drive the process, and in times of change staff with designated time is not always available. One of the four organisations is now developing itself as a compassionate organisation, as a result of training and support provided as part of this project.





Discussion

The central question for those involved in developing Public Health approaches to end of life care is how to implement it in the real world. The Pathfinders Project has provided a structure to support eight localities to explore and initiate community development, or build on their current community development activities.

Community development is defined by the United Nations as 'a process where community members come together to take collective action and generate solutions to common problems'. It is a broad term given to the practices of both professionals and the public to improve aspects of their community, to build it stronger and more resilient.

In terms of end of life care, community development relates directly to working with communities, whether this is in neighbourhoods, workplaces, educational institutions or any place where people gather, to build the capacity to look after people who suffer the experiences of death, dying and loss. The emphasis of community development is not awareness raising or information giving. Rather, it is practically based, setting a course of increased support at end of life for all.

In September 2015 The National Palliative and End of Life Care Partnership (made up of statutory bodies including NHS England, the Association of Adult Social Services, charities and groups representing patients and professionals) published the national policy document *'Ambitions for Palliative and End of Life Care: a national framework for local action'*.

The Ambitions document sets out six key ambitions, including ambition six: **Each community is prepared to help**. The ambition is underpinned by the statement *'I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways'*.

The approach described in ambition 6 is at the heart of the work of the Pathfinder Project. The Pathfinders have worked to adopt a Public Health approach by: increasing awareness and conversation around death dying and bereavement; improving support (both emotional and practical) in the wider community; and making end of life care a local priority.

Initially, some conceptual difficulty became apparent concerning the difference between community development and community engagement. Many organisations were familiar with engagement, based around conversations on death and dying. However, they were less familiar with community development, in which the capacity of communities to care for their dying and bereaved is enhanced. Community capacity is more than being able to talk freely about the difficult subjects of death, dying and loss.

It is the practical difference within networks, whether these are in neighbourhoods, educational institutions or organisations, plus others as described in the Compassionate City Charter, that provides support and help on the ground. The shift of community engagement skills to those of community development proved to be challenging. Centres who struggled with this were supported by NCPC leads and encouraged to develop and supported to develop the necessary skills.

Different approaches were taken by the Pathfinders to build capacity within their environments. The Pathfinder localities were purposely selected due to their different demographics and experience in public health approaches to end of life care, and their different leadership structure. Some areas had previous experience of public health approaches to end of life care and community capacity building. Others had previously focused on community engagement.

Over a period of 15 months the Pathfinders designed and implemented community engagement and development activities. At the heart of the project was the acceptance that as 'Pathfinders' the localities were exploring approaches. Learning from both success and failure was as important as delivering activities within the community.

All eight Pathfinders negotiated local challenges to deliver, with initial progress and achievements shared in this evaluation. One Pathfinder led by a commissioning body withdrew from the project as a result of internal changes in infrastructure. Following this the local providers harnessed the energy from the launch event and have come together to take the work forward collectively. This highlights the importance of the involvement of a multidisciplinary group, with collective ownership avoiding any potential failure due to changes with one individual or organisation.

All of the Pathfinders worked to raise community engagement, with **increased awareness and conversation around death and dying** delivered via a wide range of initiatives, focussed at both the general public and professionals.

Public awareness was increased via delivering workshops and events aiming to increase community capacity, resilience and future life planning. For example in Cheshire **twelve public sessions reached over 120 members of the public**. Other initiatives included the Hull Pathfinder attending Bridlington World Café, a group involved in changing how services are delivered in the local area, reaching 150 attendees.

Pathfinders also engaged successfully with professional groups with Lancaster highlighting the Pathfinder work holding a Death Café at the Specialist Palliative Care Forum, **involving over 60 attendees**. Hull attended **GP practice learning reaching 125 attendees**, and Lancaster held a **Law Commission consultation event reaching 100 professionals**.

Alongside community engagement activities, several Pathfinders made significant progress with capacity building projects within specific populations. These projects aimed to **improve support in the wider community** and included successfully building capacity within: a higher education setting via training volunteers who would come into

contact with students; a local town via setting up an open caring network and closed buddy groups as part of a Compassionate Community Hub; and within the whole community setting up a Neighbours Network and rolling out companion support.

The Pathfinders have had success in **making end of life care a local priority**.

In Cheshire partner engagement events have supported the development of a collaborative strategic plan for end of life care and palliative care in Cheshire. Weston have used their Compassionate Community Charter Implementation Group to develop a bereavement policy (available to 29 member organisations), and are supporting the development of a carers policy with a local charity.

In Lancashire the Health and Wellbeing Board have not yet engaged in the Pathfinder Project, and the current Lancaster Health and Wellbeing Board strategy unfortunately does not refer to death, dying and bereavement. However, the local Steering Group now attend the Health and Wellbeing Board Partnership Group. The Hospice has also been asked to be part of a voluntary sector steering group to develop the local Sustainability and Transformation Plan.

In Dorset the Pathfinder Project has engaged widely gaining buy-in from the local public, but there has been no interest amongst hospital-orientated individuals. It is hoped that engagement occurs as a result of the success of the Diealog Compassionate Community Hub.

The examples and lessons learned within this report highlight the initial progress that Pathfinder sites have made in various environments. It is clear that both sites new to capacity building and public health approaches to end of life care, and those with previous experience, can make significant progress. By each initially focusing on a specific population, the Pathfinders have collectively provided examples of the implementation of public health approaches in a series of different environments. Several Pathfinders already have plans in place to continue and further develop and roll out their capacity building projects.

This project has importantly shown the value of ensuring that evaluation methods are consistent with the principles of the Charter approach. As a new concept, the evaluation methodology followed a participatory development approach, whereby it was not specified at the outset what the outcomes would be. Instead, Pathfinders co-designed a more iterative approach to capture data relevant to the communities they were working with. The use of logic models supported the initial focus on activities and outputs. By focussing on these rather than pre-determined KPIs the Pathfinders have been able to evidence outputs and early outcomes.

As part of the participative evaluation, discussions led to the development of the Capacity Building Growth Model (Figure Six). The concept of the model is that there is an initial requirement for a resource input as a catalyst for change. In time the resources required reduce as the project becomes self-sustainable (eventually leading to embedding social change).

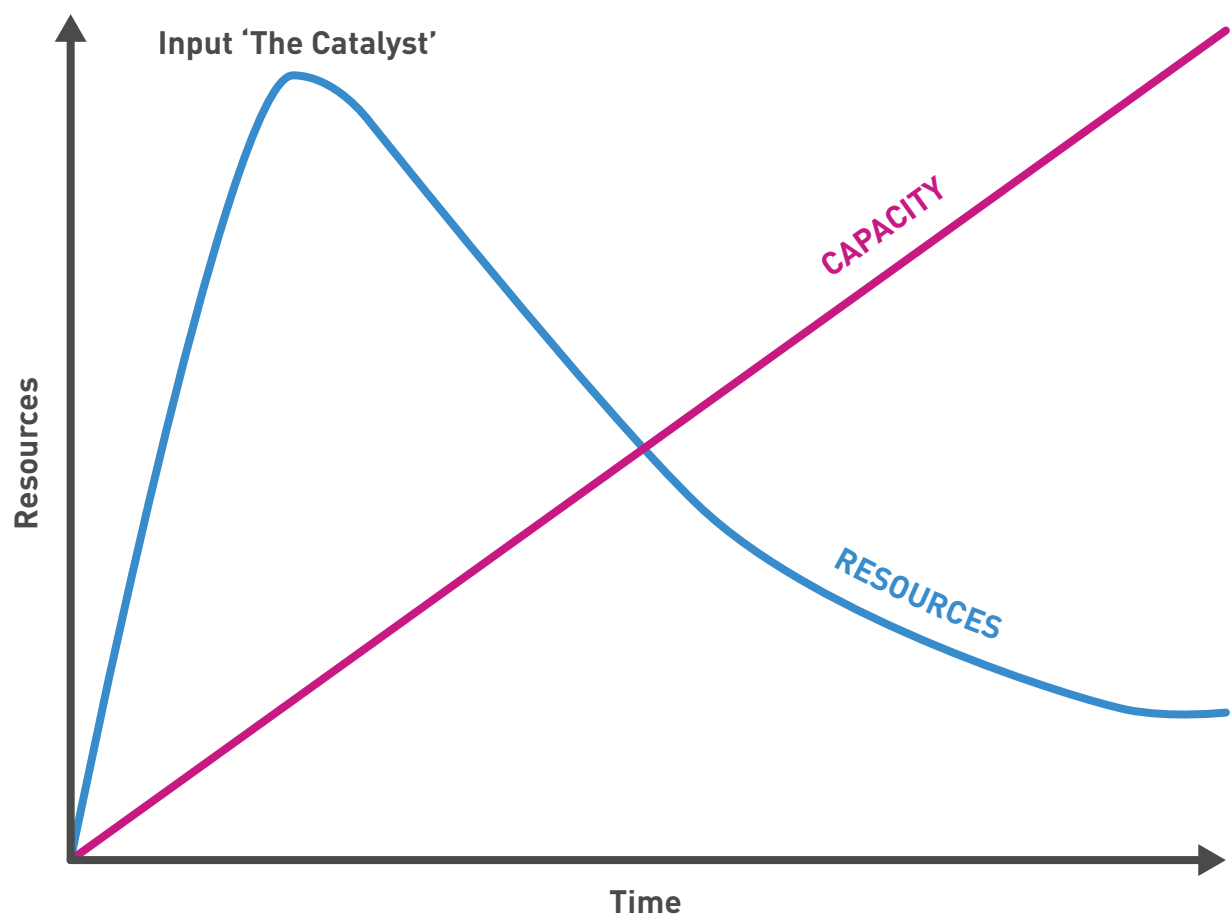


Figure Six: The Capacity Building Growth Model

The public health approaches showcased by the Pathfinders will need to become the norm to ensure that the UK continues to provide high quality end of life care to all. By de-medicalising death communities can come together to support family, friends, colleagues and neighbours through death, dying and bereavement.

It is hoped that the initial progress of the Pathfinders and their shared learning, provide a pathway for other localities to engage with individuals, communities and organisations to increase capacity and adopt a public health approach to end of life care. This was all achieved without any funding for individual Pathfinder sites; there is enthusiasm for this work, and if properly funded and part of an overall strategy much more could be achieved.





Limitations

The change of approach to include public health is challenging. The Pathfinder project highlighted a number of recurrent themes experienced by a number of sites. As has been discussed, understanding capacity building proved to be problematic during the first phase of the project. The central NCPC team provided skills and support helping to extend the community engagement skills to include community development.

A number of sites did not have resource already allocated for their projects. This meant that they relied on the enthusiasm of involved individuals for progress. This lack of resource limited overall coordination and the speed at which projects could progress. Community development workers made an enormous difference to those sites who already had them. They brought with them skills, enthusiasm and local knowledge. This made connecting with the broader community much easier.

Change of personnel during the project meant that momentum was lost and at times, caused significant delays. For example, the Hackney Pathfinder site benefited from existing participation with their local Health and Wellbeing Board. As personnel changed, this connection was lost and finding another voice on the board proved to be difficult. Other sites suffered from similar difficulties as personnel changed. There is a need for this work to be made sustainable and embedded into organisational strategies, so that it is not dependant on the enthusiasm of single or a few individuals.

Commissioning organisations struggled to embed community development into their overall end of life strategic frameworks. Shifting from a professional service approach to that of community development is conceptually challenging. It is hoped that the publication of the Ambitions Framework for end of life care, along with the guidance to Ambition 6, will help to bridge this gap. We also hope that this report will encourage commissioners to see practical use of application of public health principles in a variety of different settings.





What have we learned from the Pathfinders Project?

- **Enthusiasm is high** and there appears to be good commitment for individuals and organisations to take a public health approach to end of life care.
- **The principles of community engagement are well understood across localities.**
- **However knowledge of community development theory and practice varies greatly between localities.** Lack of knowledge limited initial Pathfinder progress in some localities. However, the progress of the Pathfinders shows both areas with and without knowledge and experience of community development can make significant progress.
- **The Dying Well Community Charter caused confusion** amongst some Pathfinder sites, with some focussing on it, rather than using it to support delivery of the Compassionate Cities Charter.
- **Focussing on capacity building projects supports delivery of the principles of The Dying Well Community Charter.**
- **Lack of funds for a community development worker has limited the speed of project delivery,** particularly in sites with no previous capacity building projects in place. Those sites who had capacity building projects underway had already committed funds specifically for this. Some of the funds were external grants and other internal strategic decisions. Those pathfinders who did not have resource allocated struggled to maintain momentum for their projects. This limitation was a recurring theme within the quarterly meetings. Despite this, many sites were able to develop capacity building projects.
- **Keep it simple!** Community development and capacity building is a simple process so needs to be kept simple, remembering that there isn't a one size fits all approach. The initial progress of the Pathfinder sites shows how community development can be initiated and supported in a range of environments.
- **Bring together an implementation team.** A team approach reduces dependency on individual leads. Community development can and should be initiated by commissioners and providers working together.
- **Participatory development is key.** Once initiated, projects work best when they are owned and run by local communities. The progress of the Pathfinders shows local individuals have the capacity and capability to build strong supportive networks.
- **Engage at individual, community and organisational levels.** Engaging widely increases your chance of success. **Take time to network and build relationships.**

- **Gain buy in with a great launch event and harness energy.** Remember not to confine your engagement to the health and social care arena, capacity building is a whole population approach. Community development requires specific skills which are different from community engagement. Seek training from those with relevant practical experience of community development at end of life.
- **A network is invaluable.** One of the strengths of this project was developing a national network that hadn't existed before. The group came together and openly shared and learned from each other.
- **Identify and link with other projects/initiatives.** Identify projects/workstreams that link closely to end of life public health, and embed community development approaches to enhance capacity and capability.
- **Evaluation methods should represent project principles.** Participatory development projects need participation! With early stage participatory development projects you can't specify outcomes in advance. Exploratory evaluations enable you to focus on outputs that in time deliver outcomes.
- **Logic models can be helpful** in supporting and communicating the focus on outputs and early outcomes. **They support the concept of participatory evaluation.** They enable successful collection of early stage data (rather than focussing on complex Key Performance Indicators (KPIs)). Achieving early outcomes paves the way for more structured randomised control trials (RCTs).
- **Be clear about data collection and continuous improvement from the outset.** Whist aspiration is important; ensuring robust evidence is collected which demonstrates improved practical outcomes of any project is essential. During project planning, identify both process and outcome measures and start data collection right from the beginning. Use this data for regular review to continuously improve and refine projects. Be clear about what needs changing and how this change can be demonstrated. Include costs of data collection in any funding bids.
- **Only collect the required data.** Data collection needs to be easy – don't overcomplicate by collecting data you don't need.
- **Remember this isn't a quick fix!** Developing community capacity takes longer than you might think, and should be seen as a long term project to change culture.
- **Above all... Be brave, be positive, and enjoy what you are doing.** If it doesn't work, learn from what did work, learn from what other localities have achieved, and try again.





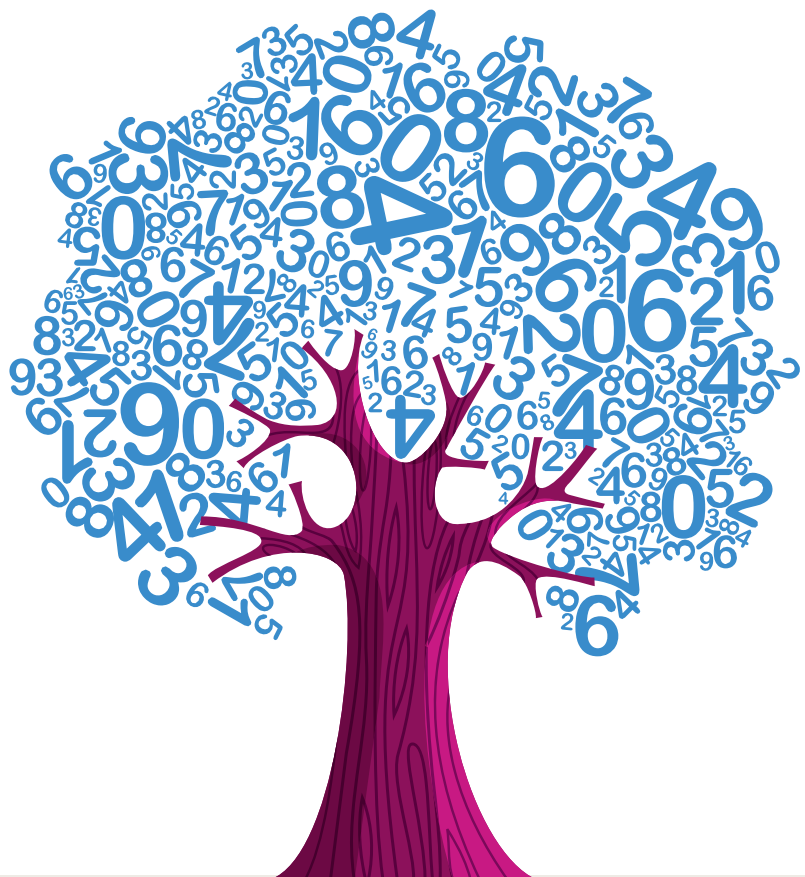
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This project was led at NCPC by Simon Chapman, Director of Policy & External Affairs, and Andrew Grey, Senior Policy & Public Affairs Officer.

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Appendix A

The Dying Well Community Charter

The Dying Well Community Charter Principles of care and support

Dying and death remain significant social taboos, despite the inevitable fact that all of us will die one day. Some of us will experience death suddenly; others will die after a period of illness or frailty, which can sometimes be protracted over years.

Whilst many of us hope to die peacefully with dignity, compassionate care, and support for our carers and the people who are important to us, sadly too many people do not have that experience. This continues to be a subject that is frequently perceived as 'too difficult' for individuals, communities and civic society to discuss and so dying is not given priority. Consequently, whilst many people, and carers, understand what is needed to improve the end of life for themselves and the people who are important to them, they struggle to access care and support in coherent and connected ways when they need it.

Dying and death do not happen in isolation from the rest of life. People who are dying may not wish to be isolated and disconnected from their communities. There is more to do to engage communities in the end of life so that those affected by dying and death do not feel abandoned and socially isolated. Care for one another at times of crisis and loss is not simply a task for health and social care services but is everybody's responsibility.

The Dying Well Community Charter provides a visible commitment by individuals, communities and organisations to work together towards the following principles, which should apply for all of us and our communities as we are affected by dying and death.

Recognition and respect

- See dying and death as an important part of our lives.
- Respect each of us and our carers for who we are, how we have lived our lives, the relationships and things that we value, and the legacies we leave behind us.
- Recognise the contribution we may still wish to make to our family, work or community.
- Do everything possible to give us and our carers the level of independence control and participation in decision-making that we wish.
- Treat us always with dignity, respect and compassion.

Communicate

- Communicate with us, our carers, and those who are important to us in kindly words and appropriate manner so that we understand what we are facing and know that you understand.

- Be clear and honest with us, answer our questions as best you can, and tell us what to expect. Where possible and appropriate explain clearly and compassionately the reality that death is coming.
- Talk to us and the people important to us about what we might need in the future, as often as we need you to do this. Respect our pace and recognise that we might not always want to talk about things when you want to.

Involvement

- Listen well to our wishes for the remainder of our lives, including our final days and hours.
- Help and support us and our carers to think ahead to the choices we may face, make decisions about care and support, and give us as many opportunities as we need to do this.
- Remember that we can change our minds about our wishes
- Make sure that our wishes are recorded so that everyone involved in our care and support knows what we want.
- Where we are unable to participate in planning and decision-making, support anybody who has to make decisions on our behalf and ensure they know and understand our wishes and values.

Support

- Make every possible effort to help us to get the end of life support and care we want, including in the place we want to be.
- Encourage and support us to talk about any emotional, cultural, or spiritual needs we may have. Ensure they are respected and met wherever possible.
- Make sure that our carers and people who are important to us are supported before and after we die, including offering information about grief and bereavement and appropriate professional support where possible.
- Recognise and foster sources of care and support within our community.

Help us to **Plan, and Do**

- Give us opportunities to plan our care for the end of life.
- Provide us with someone to coordinate and organise care and support for us and our carers.
- Tell us, those close to us and our carers who to contact for information and support, at any time of day or night, if needed.
- Provide practical support as quickly as possible.
- Do everything possible to alleviate physical, emotional, social and spiritual distress and suffering. Comfort us, our carers and those important to us.

THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE





Appendix B

The Compassionate City Charter

- Compassionate Cities are communities that recognise that all natural cycles of sickness and health, birth and death, and love and loss occur every day within the orbits of its institutions and regular activities. A Compassionate City is a community that recognises that care for one another at times of crisis and loss is not simply a task solely for health and social services but is everyone's responsibility.
- Compassionate Cities are communities that publicly encourage, facilitate, support and celebrate care for one another during life's most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail, ageing and dementia, death in childhood, grief and bereavement, and the trials and burdens of long term care. Though local government strives to maintain and strengthen quality services for the most fragile and vulnerable in our midst, those persons are not the limits of our experience of fragility and vulnerability. Serious personal crises of illness, dying, death and loss may visit any us, at any time during the normal course of our lives. A compassionate city is a community that squarely recognises and addresses this social fact.
- Through the auspices of the Mayor's office or equivalent body, a compassionate city will by public marketing and advertising, by use of the city's network and influences, by dint of collaboration and co-operation, in partnership with social media and its own offices – develop and support the following 13 social changes to the cities key institutions and activities.
- Our schools will have annually reviewed policies or guidance documents for dying, death, loss and care.
- Our workplaces will have annually reviewed policies or guidance documents for dying, death, loss and care.
- Our trade unions will have annually reviewed policies or guidance documents for dying, death, loss and care.
- Our places of worship will have at least one dedicated group for end of life care support.
- Our city's hospices and nursing homes will have a community development program involving local area citizens in end of life care activities and programmes.
- Our city's major museums and art galleries will hold annual exhibitions on the experiences of ageing, dying, death, loss or care.

- Our city will host an annual peacetime memorial parade representing the major sectors of human loss outside military campaigns – cancer, motor neuron disease, AIDS, child loss, suicide survivors, animal companion loss, widowhood, industrial and vehicle accidents, the loss of emergency workers and all end of life care personnel, etc.
- Our city will create an incentives scheme to celebrate and highlight the most creative compassionate organisation, event, and individual/s. The scheme will take the form of an annual award administered by a committee drawn from the end of life care sector. A 'Mayors Prize' will recognise individual/s for that year who most exemplify the city's values of compassionate care.
- Our city will publicly showcase, in print and in social media, our local government policies, services, funding opportunities, partnerships, and public events that address 'our compassionate concerns' with living with ageing, life-threatening and life-limiting illness, loss and bereavement, and long term caring. All end of life care-related services within the city limits will be encouraged to distribute this material or these web links including veterinarians and funeral organisations.
- Our city will work with local social or print media to encourage an annual city-wide short story or art competition that helps raise awareness of ageing, dying, death, loss, or caring.
- All our compassionate policies and services, and in the policies and practices of our official compassionate partners and alliances, will demonstrate an understanding of how diversity shapes the experience of ageing, dying, death, loss and care – through ethnic, religious, gendered, and sexual identity and through the social experiences of poverty, inequality, and disenfranchisement.
- We will seek to encourage and to invite evidence that institutions for the homeless and the imprisoned have support plans in place for end of life care and loss and bereavement.
- Our city will establish and review these targets and goals in the first two years and thereafter will add one more sector annually to our action plans for a compassionate city – e.g. hospitals, further and higher education, charities, community & voluntary organizations, police & emergency services, and so on. (Kellehear 2015)





Appendix C

NCPC baseline assessment template

Field of Activity	Community Resilience Criterion
Awareness & Conversation around Dying	Initial awareness of the need to engage the wider community in end of life conversations and care, including identification of local organisations and individuals as “champions” for wider community involvement
	Activities to promote conversation around dying, death and bereavement in local organisations and public spaces (e.g. shops, businesses, other)
Support in local organisations/ groups	Policies and activities to support people at the end of life and bereaved people in local organisations (e.g. schools, workplaces, other)
	Practical support at the end of life and activity in local groups (e.g. pensioners organisations, fellowship & faith groups, drama & creative arts, sports groups, trade unions, other)
Practical support	Availability of support groups for carers and bereavement support
	Other sources of practical support (e.g. dog-walking, befriending)
Meeting care needs	Involvement of local community in designing care services
	Making end of life care services accessible and culturally appropriate for everyone in the community
Prioritisation of end of life care	Engagement of ‘top-level’ partners to support developments (e.g. local Health & Wellbeing Boards), and prioritisation of end of life care in local plans and strategies (e.g. JSNAs, Health and Wellbeing Strategies, other)
	Activities to support, inform, and involve community groups to provide help for those at the end of life and their carers

What exists already?	Evidence (e.g. strategies) & examples/ case studies of where existing activity has worked well	How could these existing areas be developed? Including examples of shortfalls	What new initiatives / projects could be started?	Status (Red, Amber, Green)

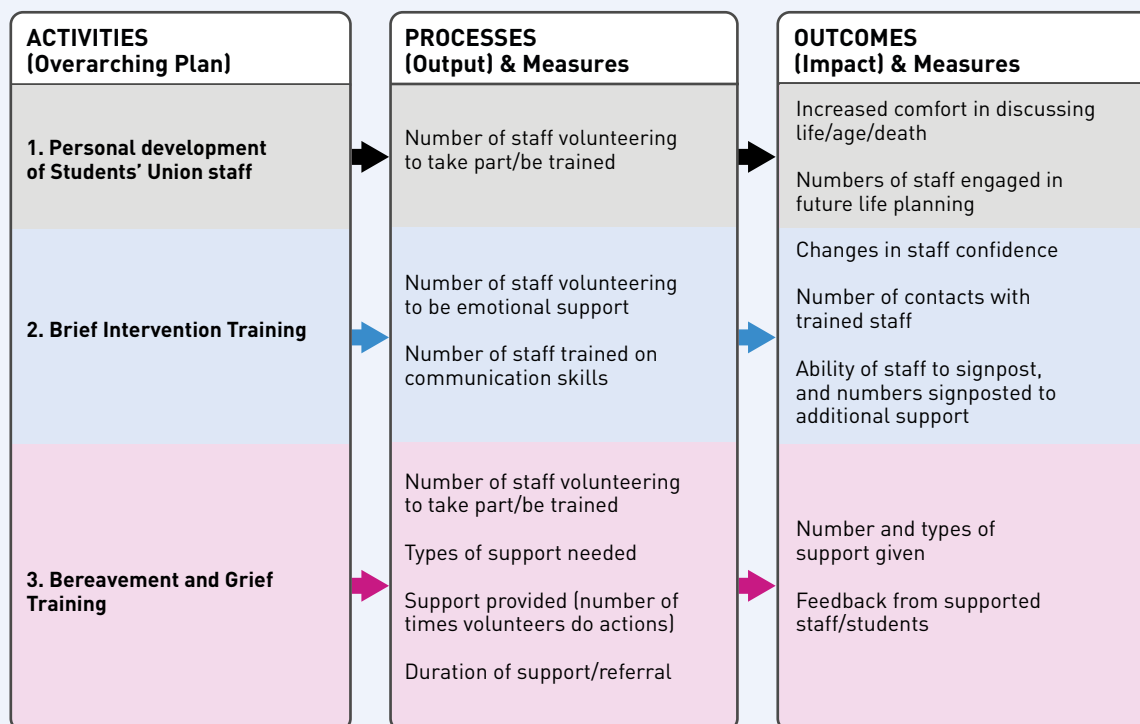


Appendix D

Example Logic Model

Evaluation Logic Model: Building capability in a Students' Union

Aims and Objectives: Increasing capacity in Chester University Students' Union setting by May 2016





Appendix E

Progress and Learning Questionnaire

Context

- Why did you apply to be a Pathfinder?
- Please give details of your launch event: When did it happen, who did you invite, how did you engage people, how many attended, was it a success? Why?
- From the NCPC baseline assessment you completed, which key areas did you identify to improve? How did you prioritise them?

Delivering the Charter

- Did you engage the local community to increase awareness and conversation around dying, death and bereavement?
- Did you improve support, including practical support, around dying, death and bereavement in the wider community?
- Have you involved people in designing end of life care services and/or ensured that they are culturally appropriate to the community?
- Have you helped to make end of life care a priority in your local area?

Lessons

- Thinking about your overall experience as a Pathfinder, is there any learning or advice you would give to other organisations trying to implement a public health approach to end of life care?
- Can you share any advice on how you have gained buy-in from people with influence?
- Can you share any advice on how you have engaged the wider community?
- Did you manage to secure any funding for your projects? If so, from who and how did you go about this?

Capacity Building

- What did you choose as a capacity building project, and why?
- What were your baseline measures?
- What did you do?
- What did you achieve?
- What are the next steps?



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