

Compassionate Communities Project Evaluation Report

Item type	Report
Authors	McLoughlin, K
Publisher	Milford Care Centre
Downloaded	5-Nov-2017 18:03:57
Item License	http://creativecommons.org/licenses/by-nc-nd/4.0/
Link to item	http://hdl.handle.net/10147/621066

See discussions, stats, and author profiles for this publication at: <https://www.researchgate.net/publication/281465213>

Compassionate Communities Project Evaluation Report

Technical Report · January 2013

CITATIONS

4

READS

120

1 author:



[Kathleen Mcloughlin](#)

University College Cork

37 PUBLICATIONS 15 CITATIONS

SEE PROFILE

Some of the authors of this publication are also working on these related projects:



INSPIRE Study. INvestigating Social and Practlcal supportRs at the End of life. [View project](#)



Promoting and enhancing advanced communication skills in palliative and end of life care for healthcare professionals [View project](#)

All content following this page was uploaded by [Kathleen Mcloughlin](#) on 12 September 2015.

The user has requested enhancement of the downloaded file. All in-text references [underlined in blue](#) are added to the original document and are linked to publications on ResearchGate, letting you access and read them immediately.

Compassionate Communities Project Evaluation Report

PROJECT EVALUATION REPORT

Dr. Kathleen McLoughlin

September 2013

Contents –

Executive Summary	4
Health Promoting Palliative Care and Compassionate Communities	9
A brief overview of health promotion	9
Health promotion at the end of life?.....	10
Definitions of health promoting palliative care	12
Compassionate Cities / Communities.....	13
The Case for Funding	14
Here to Stay	15
Background to Evaluation	16
Evaluation Framework.....	18
Evaluation Methodology	19
Overview of Pilot Areas	20
Strand One: A Whole Population Approach	21
Compassionate Communities Website & Social Media.....	21
Communication Leaflets	25
Triple Call to Action - Media Marketing / PR Strategy	28
Think Ahead.....	29
Evaluation of Strand 1 – In Summary	30
Strand Two: Community Engagement	33
Forging Community Partners.....	33
Matched Seed Grant Scheme	37
Experiential Workshops	40
Community Education Programmes.....	42
Evaluation of Strand 2 - in Summary.....	43
Strand Three: Community Mentors/Social Model of Care	45
The 3 rd International Public Health and Palliative Care Conference	48
Discussion	51
Project Reach and Sustainability	52
Recommendations	54
References	566
Appendix A: List of Organisations Contacted: Limerick City	59
List of Organisations Contacted – Newcastlewest.....	62
Appendix C: Website References to Compassionate Communities	63
Appendix D: List of Organisations Attending Training	65



"This is a close, careful and skilled evaluation of a pioneering health promotion initiative in end of life care for Ireland. This evaluation is not only critically important to the local region, but if circulated publicly, will be read eagerly for lessons by sections of the international community also exploring these approaches. An important chronicling of an equally important innovation and change by a skilled and experienced team."

Professor Allan Kellehear

The Compassionate Communities Journey

The completion of this evaluation of Phase Two of the Compassionate Communities Project is a key milestone in the journey of the project that first had its first seeds scattered at Milford Care Centre by **Dr. Kathleen McLoughlin** upon her return from India in 2009. The seeds took root naturally within the Social Work department and the Chief Executive, **Mr. Pat Quinlan**, together with the Management Team of Milford Care Centre, quickly recognized that this was an important area of work for the Centre to develop and pioneer in the Irish context.

In the first phase of the project (2010-11) **Ms. Marie Richardson** worked passionately in North West Limerick with communities to gently explore the complexities of living with death, dying, loss and care. Back at base, in Milford Care Centre, she was supported by Kathleen and **Mr. Jim Rhatigan** to transform the theory of health promoting palliative care, outlined by **Professor Allan Kellehear**, into practical, tangible outcomes for the organization and communities within which she worked so tirelessly. Jim has since chaired the project steering committee providing direction and strategic leadership to the project, ensuring that project plans are developed and delivered, yet remain flexible enough to work with emerging new opportunities and challenges. The evaluation of the first Phase of the project was carefully conducted by **Ms. Mary Brereton**.

Central to the development of the project since 2010 has been the development of **Bill**, first through Bill United and now more strategically through the inspirational series of 'Let's Talk' films. The development of these films has been a team approach but would never have been possible without the design and production skills of **Ms. Rebecca Lloyd** who has been a special contributor and source of inspiration to the project.

In 2012, following an extension of project funding, the Compassionate Communities Project expanded to cover the whole of Limerick City and Newcastlewest. Marie became a member of the Steering Committee, providing direction and oversight from her experience working with the community and two part time Compassionate Communities development workers were employed - **Ms. Caroline Macken** who worked energetically with the project for just over twelve months, in Newcastlewest and **Ms. Carmelita McGloughlin** who continues to work passionately across Limerick City. Both Caroline and Carmelita have successfully engaged the respective communities in the diverse area of issues associated with death, dying, loss and care and the fruits of their labour are clearly demonstrated upon review of the sustainable initiatives associated with the project. Their steadfast work has been supported by numerous people, both within Milford Care Centre and within the communities of Newcastlewest and Limerick City, some of whom are clearly emerging as champions associated with the project.

Evaluation is never an easy process, particularly when it delves, quite intrusively into the work associated with a small team of people who are passionate about the work they do. However, the team has shared openly their experience and outcomes to date and as this evaluation highlights, they have achieved significant results, in a short period of time from a community development perspective. Their work is truly ground breaking in Ireland and evaluations such as this produce important evidence of worldwide significance to health promoting palliative care.

Evaluation is also time consuming and the author and the Compassionate Communities team at Milford Care Centre would sincerely like to thank everyone who has given so freely of their time and energy to engage in this important evaluation. Milford Care Centre is committed to learning from their progress and their experience to date, and we hope that the Compassionate Communities project will grow stronger as a result of your valued feedback.

Executive Summary

People facing death or experiencing loss, are a key group who, until very recently, were excluded from the health promotion discourse (Kellehear, 1999). This is despite the fact that a focus on health (as defined by maintaining a sense of wellbeing) is important for those facing the end of life (Kellehear, 1999).

Milford Care Centre is the first and only specialist palliative care provider in Ireland to consider strategically and invest financially in the area of health promoting palliative care. In 2011 a pilot Compassionate Communities Project (CCP) commenced in North West Limerick City. An evaluation of this initial pilot, completed by an independent research consultant highlighted, the views of people toward death, dying, loss and care in North West Limerick City, summarised the structure of the pilot and outlined the main outcomes and recommendations for further development (Brereton, 2012). Following the evaluation of Phase One of the CCP, Milford Care Centre agreed that the pilot project would be extended for a further twelve months, taking the project to Phase Two (June 2012-May 2013). Phase Two of the pilot extends the project to the whole of Limerick City and to Newcastlewest, thus providing two geographic areas that are diverse in their both their location and population. Two part-time community development workers were appointed to the project, supported by a Project Advisory Committee, and managed by the Principal Social Worker.

The aims of the CCP have remained consistent throughout Phase One and Two:

"To enrich and support society to live compassionately with death, dying, loss and care and to demonstrate and evaluate the process of developing a compassionate community model in an Irish context."

In order to achieve these aims, three core strands of activity were proposed for Phase Two:

Strand One: A Whole Population Approach

- Compassionate Communities website revised and updated.
- Agree and develop a Triple Call to Action: Think Ahead (personal and family) ... Talk Together (family, friends, neighbours and colleagues) ... Lend A Hand (wider community).
- Communication leaflets edited, designed, approved and printed.
- Marketing/PR strategy developed; to include extensive use of social media, computer and mobile technology, posters, appropriate engagement with newsprint and radio resources, partnership work with others on joint initiatives e.g. Think Ahead, targeted awareness raising initiatives e.g. beer-mat campaign.
- Marketing/PR strategy implemented.

Strand Two: Community Engagement

- Community organisations and statutory and voluntary groups within the pilot area identified and engaged with re: Project purpose and aims, and elicited as community partners.
- Café conversations for organisation specific participants and the general public on issues related to death, loss and care organised in conjunction with community partners.
- A matched seed grant scheme provided to communities within the pilot area to engage in projects related to death, dying, loss and care.
- Experiential workshops for staff and volunteers delivered as part of MCC's formal education project developed, delivered and evaluated.
- A community education project around death, dying, loss and care developed and delivered.

Strand Three: Community Mentors/Social Model of Care

- A model of the Community Mentor Project as part of a Social Model of Care agreed.
- Community Partners in two parts of the pilot area, one in Limerick City and one in NCW, identified in the development of a CM Project as part of a Social Model of Care.
- Voluntary Community Mentors recruited and trained.

- Community Mentors advertised in the designated areas and with all appropriate service providers.
- Community Mentor Project / Social Model of Care implemented and evaluated.

The evaluation of Phase Two of the pilot was completed using a mixed methods approach to data collection, focusing on the questions proposed within the Developmental and RE-AIM evaluation frameworks. These methods included:

- A comprehensive literature review of international evidence relevant to health promoting palliative care, compassionate communities and health promotion;
- A demographic review of the pilot areas based on published population data;
- An extensive desktop review of project outputs including the website, leaflets, workshop evaluation forms, seed grant applications and evaluations, conference evaluation forms, media and publicity, training project content and evaluation and community development worker contacts;
- Three focus groups and two telephone interviews with key stakeholders engaged in the project;
- One focus group with the project team employed by Milford Care Centre;
- Two one-to-one semi structured interviews with the Compassionate Communities community development workers;
- An online survey for stakeholders unable to attend a focus group or engage in an interview.

The data from these methods was weaved together to evaluate each activity within each strand of the project and data was cumulated to evaluate the project as a whole.

The evaluation has illustrated that a considerable amount has been achieved in the past twelve months, including:

- Funding and recruitment of 2 x part time Compassionate Communities community development workers.
- Development of the project identity and marketing via social media, and website (35,343 visits, 49,535 pages viewed, from people in 120 different countries) printed media, radio and direct contact with key stakeholders.
- Development and wide dissemination of a series of five communication leaflets to individuals and organisations in the pilot regions. They are also accessible to people throughout Ireland and across the world.
- Production of a series of short films, developed to complement the leaflets (these will shortly be launched and freely available as a world-wide resource).
- The Compassionate Communities Project took part in one of two regional pilots of the Think Ahead initiative, led by The Irish Hospice Foundation. Forms were disseminated throughout the pilot regions between September and December 2012. (The second pilot was in County Louth).
- Approximately 180 organisations/groups (see Appendix A) have engaged with the project in the last 12 months at varying levels of intensity. Many of these organisations work with the most vulnerable people living in the pilot areas and are organisations outside Milford Care Centre's usual sphere of contact and influence.
- Almost 100 people have engaged in Café Conversations specific to death, dying, loss and care.
- Eleven seed grants have been awarded to support community led projects in the field of death, dying, loss and care. Collectively, these projects have the potential to reach thousands of people within the pilot regions.
- 46 people attended training in grief and loss from a wide range of statutory, voluntary and community organisations.

- A working group to oversee the development of the Volunteer Good Neighbour scheme has been established, comprising representatives from Public Health Nursing, Palliative Care Clinical Nurse Specialists and the CCP team.
- 19 people have expressed an interest in the Good Neighbour scheme and attended the initial orientation and training. Volunteer recruitment is commencing.
- A local action group for death, dying, loss and care has been established and is led by community representatives in Newcastlewest.
- In Limerick City Ms. Helen O'Donnell, a prominent business person has taken on the role of Compassionate Communities Champion and has committed to coordinating Friends of Compassionate Communities.
- The 3rd International Public Health and Palliative Care Conference was hosted in Limerick in April 2013 bringing 250 delegates from across the world to share their thoughts and work with regard to a public health approach to palliative care.
- As a result of Milford's strategic leadership in this area, the strategic plan for palliative care services for the Mid-West specifically makes reference to Health Promoting Palliative Care and the CCP (Milford Care Centre / HSE, 2013) and the area is a key dimension of the work packages of the All Ireland Institute for Hospice and Palliative Care.

Whilst there were areas of the project plan where planned targets were not met precisely, there has been substantial progress made against these activities. The delay can be explained, at least in part, by the project team's response to emerging innovative areas of work, including participation in the Irish Hospice Foundation's Think Ahead pilot, and the hosting of the 3rd International Public Health and Palliative Care Conference which took considerable time and effort on the part of the project team and highlighted their responsiveness and flexibility to adapt to emerging priorities, highly relevant to their area of focus. The project team have paid considerable attention to ensuring that relationships are nurtured and built steadily and that the project outputs are developed with due consideration to detail. This inevitably takes time, particularly when the project plan is multifaceted and ambitious and other elements of work emerge during the process. From a community development perspective this is an important period of development to enable long term sustainable change.

Each Strand of the project has been evaluated and recommendations have been made regarding potential development in further cycles of the project. Strong consideration should be given to extending the CCP, over a three year funding cycle, which should include the strategic development of a project plan directly aligned to the Ottawa Charter for Health Promotion. A three year model would require rigorous, focused evaluation, examining the impact of the project on key variables and the difference living in a Compassionate Communities area makes with regard to behavior and outcomes associated with death, dying, loss and care. The recommendations arising from this important evaluation are summarised below:

Project Governance, Funding, Staffing and Support

- Milford Care Centre commits to a 3-5 year funding model for the CCP.
- The Project Advisory Committee is expanded to include national / local stakeholders, with a range of skills and experience, meeting quarterly. The committee should include Professor Allan Kellehear and Dr Kathleen McLoughlin and invitations should be extended to senior representatives from the HSE's Population Health department, from a UL Department with expertise in business and marketing and from the Community Development sector. The Advisory Steering Committee should include both the external members and the CCP Project team (i.e. the MCC staff members) working with an inclusive and consultative structure.
- The Project Advisory Committee should explore mechanisms to obtain additional supplementary funding for the project over a three year period and consider involvement in development funding / research bids to agencies such as the AIHPC, the Irish Hospice Foundation, the Health Research Board and the Community Foundation of Ireland.

- The community development worker who resigned earlier in the year should be replaced and in doing so, consideration given to potential benefits of recruiting a project co-ordinator vs. recruitment of an additional 0.5 WTE Community Development Worker to increase the potential skill set available to the project team.
- A partnership approach between the CCP Project team and MCC's learning and development service should be developed and implemented in the delivery of the educational elements. The administrative components associated with advertising, and evaluating the educational strands of the project are transferred to Milford Care Centre's learning and development service.
- The findings of this evaluation are disseminated widely at both national and international conferences and submitted to a peer reviewed academic journal to be considered for publication.

Focus of Work

- The three strand model adopted by the CCP provides a comprehensive framework for guiding the work of the project team and for the delivery of a varied range of Health Promoting Palliative Care initiatives within the designated project area. It is vitally important each of the three strands is given **equal weight** and that each is fully developed.
- The strands of the project are explicitly and directly aligned to the Ottawa Charter.
- The three strands of work from this phase of the pilot are adapted as recommended within this report and are continued with an extended focus as follows:
 - **Whole Population Approach**
 - Extend the project tools, resources and supports to the whole of the Mid-West.
 - Develop a PR / Marketing Strategy centred on the tiered products associated with the CCP and the Triple Call to Action, that includes a social media campaign.
 - Revise the website and leaflets during their next update with the areas for improvement outlined in this report given due consideration.
 - Launch and roll out the series of short films.
 - **Engaging and Supporting Communities**
 - Extend the focus of engagement and support across the Mid-West, focusing on the development and organization, in association with community partners, of six major public events across the region within the first 12 months.
 - Engage the public / healthcare professionals with the CCP through linkages with other relevant national / international initiatives e.g. Think Ahead, What Matters to Me Training, Changing Minds, Conversations for Life.
 - Review educational inputs to ensure relevance across the life span and for groups working with death dying, loss and care in the broadest sense e.g. Vets, solicitors, funeral directors, florists etc.
 - Develop, deliver and evaluate the community death education programme.
 - Continue the links with teacher education and schools in the project area re: the development of training workshops for teachers and policy development within schools, linking with relevant national initiatives as appropriate.
 - Measure the impact of training workshops (based on the aims and objectives of the workshops), ideally using valid and reliable pre-existing measures.
 - Continue the seed grant scheme and make it available to applicants who commit to a project that impacts in the Mid-West. Ensure the scheme is widely advertised.
 - Consider the development of Milford Care Centre as a Compassionate Community, examining the use of the potential use of the standards for HPPC in specialist palliative care.
 - **Good Neighbour Scheme**
 - Devise / adopt an evaluation plan for the Good Neighbour Scheme.

- Implement the Good Neighbour Scheme in Limerick City and Newcastle West for 12-18 months.
- Depending on the evaluation, consider roll out across the Mid-West.
- Consider the model proposed by Abel (2013) with regard to the phased development of personal community networks.

Health Promoting Palliative Care and Compassionate Communities

It has been argued that the manner by which palliative care has developed in the Western world has led to the over-medicalisation of death and dying, where death is often construed as a failure by society (Kellehear, 1984: 1999; Clark, 2002) and tends to be used in health promotion campaigns as a negative outcome, associated with the non-compliance to a health behaviour (e.g. 'you must not smoke or you will die from cancer'; 'you must not have unprotected sex or you will die from HIV'). However, the reality is that death is a universal experience that society, particularly in the West, may more usefully reconstrue as a natural (rather than a medical) process (Zimmermann, 2004). Early leaders in palliative care placed a considerable emphasis on driving social change through individuals as opposed to evoking structural change and, subsequently, *"death, dying and loss are defined as personal problems rather than targets of social change in community attitudes, values and behaviour."* (Kellehear, 1999).

Health Promoting Palliative Care (Kellehear, 1999) offers society the opportunity to change the way it views death, dying, loss and care by taking a population-based health approach to change the ways in which: (a) people consider their own death; (b) communities care for people and their families as they encounter death; (c) healthcare service providers meet the needs of people facing the end of life; (d) palliative care services reach out to share their expertise in death, dying, loss and care; and (e) national policy and plans are developed and understood. The adoption of a health promoting approach to palliative care is gaining momentum internationally (Kellehear, 1999: 2005; Miller and Rynades, 2005; Meecham, 2006) and it has been suggested by a number of key players in the field that putting health promotion at the heart of palliative care can help to improve the quality of life of the dying (Miller and Ryndes, 2005; Meecham, 2006). This may also encourage those people who have the opportunity to make the transition to palliative care, to think more positively about the available services, thereby increasing the likelihood of early referral.

A brief overview of health promotion

In 1978, the World Health Organisation (WHO) defined health as: *"a complete state of physical, social and mental wellbeing and not merely the absence of disease or infirmity"* (WHO, 1978). It was recognised that the determinants of health, as defined by WHO, had physical, social and individual domains and were not purely determined in terms of an interaction with healthcare services for necessary interventions. Thus, according to the WHO, the core concepts necessary for improved health include: equity; community self-reliance; health promotion; disease prevention; and the involvement of government departments beyond health (WHO, 2000). Later, in 1986, the Ottawa Charter for Health Promotion (WHO, 1986) outlined five inter-related, but discretely defined action areas to promote physical, social and emotional aspects of well-being. Implicit in this Charter was the recognition that health is not solely the responsibility of healthcare services, but encompasses government, social and economic partners, industry and media, communities and individuals themselves. To summarise, health promotion aims:

- to be participatory;
- to recognise the importance of society in health and illness;
- to stress the need for information, education and policy development that extends beyond traditional healthcare boundaries;

- to encompass those who are healthy and unhealthy; and
- to make health a collective as opposed to an individual responsibility.

An understanding of the Ottawa Charter is key to understanding health promoting palliative care. This is discussed in more detail below.

Health promotion at the end of life?

People facing death or experiencing loss, are a key group who, until very recently, were excluded from the health promotion discourse ([Kellehear, 1999](#)). This is despite the fact that a focus on health (as defined by maintaining a sense of wellbeing) is important for those facing the end of life ([Kellehear, 1999](#)). For example, in an Irish context, and based on the researcher's personal experience, health promotion workers are typically assigned to a wide spectrum of services ranging from child and family services, travelling communities and mental health services, to cardiovascular health projects, lesbian, gay and bisexual services, and drug and alcohol intervention teams. However, there is a lack of any form of health promotion for those facing death, dying, loss or palliative care. Kellehear (1999) argues convincingly that the benefits of such an approach for the person facing the end of life might be:

- the maintenance of the immune system through a focus on maintaining a healthy mind, body and spirit;
- an acceptance of medical and complementary therapy to prolong life, increase quality of life and cope with treatment side effects;
- the provision of empowerment and support;
- the provision of information and education that can challenge personal fears and change attitudes toward death, dying, loss and care; and
- the renewal of a sense of confidence and agency that encourages hope and provides comfort.

[Kellehear \(1999\)](#) also argues that there are additional benefits – over and above those for patients and their families – for the development of both palliative care and health promotion as disciplines. For instance, the application of health promotion principles to palliative care enables the integration of social science and public health workers into the palliative care team and, therefore, offers greater potential for meeting the holistic needs of patients and their families.

The transition of a patient to palliative care services, is complex and referral is often delayed ([McLoughlin, 2012](#)). The implementation of a health promoting approach would provide an ideal opportunity for early stage care to be provided to patients who face life-limiting illness through, for example, the provision of education and information about palliative care services/illnesses that may, in turn, challenge personal fears and change attitudes ([Scott, 1992](#)). However, Kellehear (2009) warns against merely understanding health promoting palliative care purely as an approach to changing attitudes through awareness raising, education provision and increasing access to services as suggested by [Rao et al. \(2005\)](#). He emphasises the need to work in partnership with communities to stimulate community change and develop community led supports. For example, this is well demonstrated by Kumar (2007) in Kerala, India and through models of community development highlighted in Australia (Kellehear and Young, 2007; Kellehear and O'Connor, 2008) and the UK (Murray-Hall, 2013), all of which focus on evoking real social and behavioural change and not simply changing attitudes.

Whilst the concept of health promotion and palliative care had been discussed prior to Kellehear's defining work in the late 1990s, references to the concept were often 'fleeting' and 'un-operationalised' (Rosenberg, 2007). Kellehear (1999) defined the goals of the approach with reference to the Ottawa Charter for Health Promotion (Table 1). He proposed that health promoting palliative care should aim to: combat death-denying health policies and change wider attitudes toward death dying, loss and care in society; provide social support, information and education (health and death) for individuals and communities dealing with end of life issues; and re-orientate palliative care services to enable them to better understand and appreciate the potential of a health promoting approach.

Regular Health Promotion	Health Promoting Palliative Care
Build Healthy Public Policy Develop policies to remove the obstacles to health and empower people to make healthy choices	Combat death denying health policies and attitudes in wider society Engage in development of public policy relating to palliative care and the support of dying people
Create Supportive Environments Make all environments conducive to health – workplace, schools, leisure facilities, health services	Provide social supports – individual and community For example, this might involve establishing support groups for those facing death, dying, loss and care and support structures for wider society involved in relevant issues (e.g. funeral directors, florists). Encourage inter-personal reorientation to provide people with the skills to cope with life limiting illness
Strengthen Community Actions Healthcare should be participatory where professionals work with as opposed to on others, recognising the importance of social relationships and strengthening existing networks	
Develop Personal Skills Development of personal skills through provision of information and education to enable people to prepare for and cope with maintaining health and dealing with illness	Provide education and information for health, dying and death Include health and death education at all life stages
Reorient the Health Services Health promotion should not be confined to health services and needs to involve many groups and disciplines	Encourage reorientation of palliative care services To enable palliative care services to better understand and appreciate the potential of health promoting palliative care

Table 1: Health promotion as outlined in the Ottawa Charter and Health Promoting Palliative Care from McLoughlin (2012) based on Kellehear (1999).

Definitions of health promoting palliative care

Interestingly, despite Kellehear's (1999) ground-breaking work in this area, health promoting palliative care remains difficult to define and operationalise concisely. Indeed, Rosenberg (2007) highlights a high degree of conceptual 'blurring' around health promoting palliative care that represents a significant risk to the effective implementation and practice of the approach. In the UK, a recent study has highlighted the need to develop common definitions and frameworks with regard to health promoting palliative care and compassionate communities to ensure a common, agreed understanding (Murray-Hall, 2013). The operational definition used by the Milford Care Centre is as follows:

"Health Promoting Palliative Care seeks to work with people, individuals and groups, to enhance the social, emotional and practical support available to those living with a serious life-threatening illness, facing loss, experiencing bereavement or providing care. It not only focuses on death as a result of illness, but considers death caused by the broadest circumstances (e.g. as a result of violent crime, suicide, accident, neonatal death). It is an approach that seeks to work in partnership with communities to:

- *provide information about health, dying, death and grief*
- *explore and develop a range of personal and community supports*

Health Promoting Palliative Care does not replicate or displace service provision but builds on a community's ability to provide supportive care as neighbours, family and friends, recognising that services are not enough on their own and cannot provide all that people need". (McLoughlin, Rhatigan and Richardson, 2010).

This definition is based on an understanding of health promoting palliative care obtained from Kellehear's writings, lectures and the work of other authors in the field (e.g. Conway and Rumbold). It is recognised that this definition is more closely aligned to the 'Compassionate Communities' (Kellehear, 2005) concept of health promoting palliative care. Thus, it lacks any reference to public policy and one might assume that the palliative care services have already been re-orientated to embrace the importance of this approach. Other studies have also operationalised definitions of health promoting palliative care utilising perspectives from research interviews or personal experience (Richardson, 2002).

The standards for health promoting palliative care units developed by Kellehear and colleagues, (Kellehear, Bateman and Rumbold, 2003) provide a useful benchmark against which to assess the extent of health promoting activity in palliative care services, as well as a basis upon which to develop a strategic approach to health promoting palliative care. To date, these standards have not been utilised in an Irish context, but have been successfully operationalised and implemented in Australia (Rosenberg, 2007). Furthermore, a recent review by Conway (2008) showed that health promotion interventions in UK hospices were extremely limited with respect to their potential under a health promoting palliative care philosophy and a greater contribution could be made by palliative care in understanding and developing community capacity related to death, dying, loss and care, acknowledging that carers of the dying and bereaved are an important group who have their own significant needs in end-of-life care, and often bring with them knowledge, expertise and tradition. Hence there would appear to be considerable scope to further develop health promoting palliative care in these islands.

Compassionate Cities / Communities

The term 'Compassionate Communities', came from the concept of 'Compassionate Cities', developed by Professor Allan Kellehear (2005). It takes the Ottawa Charter, the WHO concept of Healthy Cities and the WHO emphasis on community development into the field of death, dying, loss and care, thus raising the profile of end of life in public health using a life stages approach. A Compassionate City:

- Has local health policies that recognise compassion as an ethical imperative.
- Meets the special needs of its aged, those living with life threatening illnesses, and those living with loss.
- Has a strong commitment to social and cultural differences.
- Involves grief and palliative care services in local government policy and planning.
- Offers its inhabitants access to wider variety of supportive experiences, interactions and communication.
- Promotes and celebrates reconciliation with indigenous peoples and memory of other important community losses.
- Provides easy access to grief and palliative care services.

(Kellehear 2005 pp. 46)

Through the Compassionate Cities (Communities) approach:

- Death, dying and bereavement would cease to be taboo subjects and would become more normalised within society.
- People's expectations of death and dying would change, as would how death is managed.
- Palliative care would re-orientate, supporting health and social care staff to work with the community in providing care to those at the end of life, and their loved ones.

Such outcomes are difficult to measure easily. A recent scoping study of Compassionate Community projects emerging in the UK has indicated that there are over 32 different projects / projects in action in the UK, led by a variety of stakeholders including individuals, academics, faith and voluntary organisations, funeral consultants, hospices and mainstream health agencies (Murray-Hall, 2013). The projects highlight both the diverse ways communities are engaged in supporting those facing end of life, loss, and bereavement, and the ways in which professionals are working closely with communities to support them deal more effectively with death, dying, loss and care. The UK study indicates that communities do have the skills, knowledge, expertise and a role to play in building strong partnerships in end of life care. This was a similar finding by Brereton (2012) in the evaluation of the first phase of the Irish Compassionate Communities pilot in North-West Limerick. Murray-Hall (2013) urges that the strengths within the community need to be recognised and embraced wholeheartedly. They note a growing recognition of the need for sustainable approaches to end of life care and increased popular interest in death and dying in the UK, which are all positive enablers of a health promoting approach to palliative care.

Experience in the UK also highlights the challenges and potential barriers for developing the Compassionate Communities approach including taboo around death, professional attitudes, concerns of trust and risk, lack of resources, changing strategic environment and uncertainty about definition and approaches to develop Compassionate Communities.

On reviewing the CCPs that have developed in the UK, the diversity in approach is striking, ranging from the development of academic centres for research and education in death and dying (e.g. CDAS, Bath) to specific interventions to increase access to hospice care amongst minority groups (e.g. St Mary's Hospice, Birmingham) to developing a good neighbour scheme (St Luke's Hospice, Cheshire). Many models have a number of strands to them e.g. Diocese of Lichfield is rather similar to that developed by Milford Care Centre based on three strands to provide training, increase capacity of existing organisations and developing / using resources. St Nicholas Hospice Care have developed a neighbour scheme that to date has supported over 200 patients, providing over 1,500 hours of social care in their own homes and are currently supporting approx. 90 patients at one time with completion of practical tasks such as gardening, taking the dog out, offering companionship, or getting out of the house. People in the community interested in having support of a neighbour can refer themselves, or be referred by a health professional. The aim is to increase self-referral, moving out into the wider community and shift the balance away from hospice based referrals. The impact of schemes such as these has been demonstrated by Severn Hospice, in their collaboration with a GP who was keen to explore a model of care within the community, for frail elderly and those at the end of life. Initial community meetings showed interest in this approach, and a partnership with the local charity, the Mayfair Centre developed. The centre now has an established network of local volunteers, keen to offer practical support to people within their own homes. The GPs gain informed consent from a person needing support, and refer them to the co-ordinator who will then link them to a volunteer. Following agreement with the person, the volunteer will provide practical, non-clinical support e.g. going for a walk, chatting, support with paperwork etc. 80 volunteers have been trained to date, and currently over 40 people are being supported. Volunteers act as a 'citizens' extension' of the primary care multidisciplinary team, and any issues of concern can be raised with the team. Severn Hospice acted to support the initial community engagement, and provide two days training for volunteers, on all aspects of end of life, communication skills, and boundary recognition. Support to volunteers continues with advice, and provision of monthly group reflective practice sessions. Evaluation by the PCT of 38 participants gaining support through the project showed a substantial reduction in contacts and use of unscheduled health care services through GP phone calls and appointments, emergency and unplanned admissions following six months support from a volunteer. Qualitative data has shown that there is a reduction in loneliness, a positive impact on carers, and increased ability for patients to self-manage their condition with this type of support.

The Case for Funding

The development of models of health promoting palliative care is new and therefore the evidence base continues to grow and this can present a challenge with regard to securing funding to start an initiative that may make intuitive sense, but can be difficult to justify in the current economic climate. It is therefore crucial that health promoting palliative care continues to stir the hearts and minds of health and social care professionals, but also creates a robust evidence base of compelling evidence to ensure that funding is made available for projects to commence and be maintained. Community development work can be a slow process. For example in the area of community development in Traveller Health, Peggy Flanagan described her work in Navan with Irish

Travellers on a year-long empowerment project. Throughout the time she worked on this project, Peggy found that she was continually asking herself *'is this project of any use?'* *'are we the right people to be doing this?'* In hindsight, Peggy felt her involvement in the project and her continual questioning was actually extremely positive, because it forced her to constantly reflect on her own practice and prejudices. Ten years later, some of those young travellers who participated in the project are now in leadership positions in Traveller organisations. This shows how long a process community development is, and how difficult it can be to demonstrate impact to funders at the time (Lewis, 2006).

Here to Stay

Milford Care Centre is the first and only specialist palliative care provider in Ireland to invest financially in the area of health promoting palliative care. Following attendance at the 1st Public Health and Palliative Care Conference in Kerala, India in 2009, the former Head of Education, Research and Professional Development returned passionately convinced that Milford Care Centre was the right organisation to drive such an approach to working with communities, empowering them to live better with death, dying, loss and care. Many of the seeds had already been sown in the organisation that was committed to community outreach work through the social work and bereavement service, vibrant education projects and the multidisciplinary Hospice at Home service. The organisation had already performed a play, *Cancer Tales* (www.cancertales.ie), to a general public audience and staff had produced documentaries (e.g. *Donnelly – Going Home*) and conducted research in the broader applied aspects of death, dying, loss and care (e.g. [Donnelly, 1999](#), 2010; [McLoughlin, 2012](#); [Culhane 2004](#)). In 2010 funding was allocated by Milford Care Centre to commence a pilot CCP in North-West Limerick City in 2011. Since then, other organisations in Ireland have also demonstrated an interest in a public health approach to palliative care. This topic is a key theme within the All Ireland Institute for Hospice and Palliative Care (arguably a focus shaped by Milford Care Centre's involvement with the Institute at the planning stage) and is central to the work of The Irish Hospice Foundation in many of its initiatives, particularly with regard to education, The Forum on End of Life and Think Ahead. This growing interest nationally and internationally suggests that health promoting palliative care is here to stay.

Background to Evaluation

In 2011 a pilot CCP commenced in North West Limerick City. An evaluation of this initial pilot was completed by an independent research consultant and highlighted the views of people toward death, dying, loss and care in North West Limerick City, summarised the structure of the pilot, the main outcomes and recommendations for further development (Brereton, 2012). Following the evaluation of Phase One of the CCP, Milford Care Centre agreed that the pilot project would be extended for a further twelve months, taking the project to Phase Two (June 2012-May 2013). Subsequent development of the project is dependent on additional resource availability and completion of an evaluation of Phase Two.

Phase Two of the pilot takes the project to the whole of Limerick City and to Newcastlewest, thus providing two geographic areas that are diverse in their both their location and population. Two part-time Community Development Workers were appointed to the project, supported by a Project Advisory Committee, and managed by the Principal Social Worker.

The aims of the CCP have remained consistent throughout Phase One and Two:

"To enrich and support society to live compassionately with death, dying, loss and care and to demonstrate and evaluate the process of developing a compassionate community model in an Irish context."

In order to achieve these aims, three core strands of activity were proposed for Phase Two:

Strand One: A Whole Population Approach

- Compassionate Communities website revised and updated.
- Agree and develop a Triple Call to Action: Think Ahead (personal and family) ... Talk Together (family, friends, neighbours and colleagues) ... Lend A Hand (wider community).
- Communication leaflets edited, designed, approved and printed.
- Marketing/PR strategy developed; to include extensive use of social media, computer and mobile technology, posters, appropriate engagement with newsprint and radio resources, partnership work with others on joint initiatives e.g. Think Ahead, targeted awareness raising initiatives e.g. beer-mat campaign.
- Marketing/PR strategy implemented.

Strand Two: Community Engagement

- Community organisations and statutory and voluntary groups within the pilot area identified and engaged with re: Project purpose and aims, and elicited as community partners.
- Café conversations for organisation specific participants and the general public on issues related to death, loss and care organised in conjunction with community partners.
- A matched seed grant scheme provided to communities within the pilot area to engage in projects related to death, dying, loss and care.
- Experiential workshops for staff and volunteers delivered as part of MCC's formal education project developed, delivered and evaluated.
- A community education project around death, dying, loss and care developed and delivered.

Strand Three: Community Mentors/Social Model of Care

- A model of the Community Mentor Project as part of a Social Model of Care agreed.
- Community Partners in two parts of the pilot area, one in Limerick City and one in NCW, identified in the development of a CM Project as part of a Social Model of Care.
- Voluntary Community Mentors recruited and trained.
- Community Mentors advertised in the designated areas and with all appropriate service providers.
- Community Mentor Project / Social Model of Care implemented and evaluated.

The Project Advisory Committee had initially commissioned an evaluation of Phase Two of the CCP in June 2012. However the plan was not fully signed off and the external research consultant subsequently moved location. A second evaluation was commissioned in June 2013, with a view to completion within a two month timeframe. This report outlines the findings from the evaluation of Phase Two.

Evaluation Framework

A combination of the RE-AIM and Developmental Evaluation Framework were used to evaluate Phase Two of the CCP. These approaches are explained briefly below.

Developmental Evaluation

Developmental Evaluation (DE) is an emerging approach to the evaluation of models of social innovation. The approach is an evolving concept, originally conceptualized and described by [Patton \(2011\)](#):

"Developmental evaluation informs and supports innovative and adaptive development in complex dynamic environments. DE brings to innovation and adaptation the processes of asking evaluative questions, applying evaluation logic, and gathering and reporting evaluative data to support project, program, product, and/or organizational development with timely feedback."

Common questions asked as part of the DE approach include:

- What is developing or emerging as the innovation takes shape?
- What variations in effects are we seeing?
- What do the initial results reveal about expected progress?
- What seems to be working and not working?
- What elements merit more attention or changes?
- How is the larger system or environment responding to the innovation?
- How should the innovation be adapted in response to changing circumstances?
- How can the project adapt to the context in ways that are within the project's control?

The developmental evaluation approach is suited to the CCP since it enables the structures, processes, influencers and decision making factors behind the project to be explored and recorded for the purposes of understanding the development of the project and capturing new directions and developments, that may have led the project to new places.

REAIM Framework

The activities proposed in the CCP development plan are public health orientated, working within a Public Health and Palliative Care theoretical perspective (Kellehear, 1999). The activities proposed lead to specific outcomes and there is a need balance the new method of innovative enquiry offered by the DE approach with the RE-AIM Framework ([Glasgow et al., 2007; 1999](#)) to provide an almost internal framework to DE to consider the characteristics of the specific activities/interventions that can:

- Reach large numbers of people, especially those who can most benefit
- Be widely adopted by different settings
- Be consistently implemented by staff members with moderate levels of training and expertise
- Produce replicable and long-lasting effects (and minimal negative impacts) at reasonable cost

Using RE-AIM we can consider questions regarding Reach, Effectiveness, Adoption, Implementation and Maintenance and these have been used to frame the evaluation questions and areas of focus.

Evaluation Methodology

The evaluation was completed using a mixed methods approach to data collection, focusing on the questions proposed within the DE and RE-AIM framework above. These methods included:

- A comprehensive literature review of international evidence relevant to health promoting palliative care, compassionate communities and health promotion;
- A demographic review of the pilot areas based on published population data;
- An extensive desktop review of project outputs including the website, leaflets, workshop evaluation forms, seed grant applications and evaluation, conference evaluation forms, media and publicity, training project content and evaluation and community development worker contacts;
- Three focus groups and two telephone interviews with key stakeholders engaged in the project;
- One focus group with the project team employed by Milford Care Centre;
- Two one-to-one semi structured interviews with the Compassionate Communities community development workers;
- An online survey for stakeholders unable to attend a focus group or engage in an interview.

The data from these methods was weaved together to evaluate each activity within each strand of the project and was cumulated to evaluate the project as a whole.

Overview of Pilot Areas

Phase Two of the pilot CCP focused project activity equally on the whole population of both Limerick City and Newcastlewest. Two 0.5 WTE community development workers were employed, one assigned to each area to co-ordinate and to implement the project plan within their designated area.

Limerick City

Limerick City has a population of 57,106 (CSO 2011) people and approximately 500 deaths each year (CSO, 2010/2011) are registered for Limerick City residents. A comprehensive area analysis was recently conducted for the Paul Partnership (2010), noting that whilst there had been little or no population increase in Limerick City over the last 10 years there has been significant migration of people from older or disadvantaged communities to suburban areas either just inside or outside the city boundary, presenting a challenge for social inclusion with the City. The city has a number of residential areas (Moyross, Ballynanty and Kileely, St. Munchin's, St. Mary's/Kings Island, Our Lady of Lourdes, Southill, Garryowen, St. Saviours, and Queen of Peace) with high concentrations of disadvantage. The Paul report states *"Most of these communities have been identified as RAPID areas, and some designated for regeneration under the Limerick Regeneration Process. These areas have some of the highest concentrations of local authority housing in the country, and are experiencing considerably high levels of deprivation, population decline, unemployment, early school leaving, lone parenthood, youth and elderly dependency rates and anti-social behaviour – and in almost all cases, to a much higher degree than is being experienced in other parts of the city, or across the country as a whole. It must be noted here also that these communities are not static communities. The movement of people from the geographic areas has implications for the communities and as such the issue of addressing social exclusion remains an ongoing and challenging task"*. 11% of population in Limerick City are non-Irish, the Polish community accounting for the largest single group. The rate of disability (13%) in the City is 4% higher than the national average (CSO, 2006) and rates are higher in areas which also reported higher rates of older people, i.e. Garryowen, parts of St. Mary's, and Our Lady of Lourdes. As identified in Brereton's report (2012), violent / high profile deaths as a result of serious criminal activity (often drugs related) are a problem for the city, and suicide rates are the highest in Ireland (CSO 2012). These issues are important for the project to consider with regard to how it engages with these areas and responds to their identified needs.

Newcastlewest

Newcastlewest has a population of 6,327 (CSO, 2011) and whilst death registrations are not available specifically via CSO, they can be estimated at approximately 9-10% of the total for Limerick County based on the population statistics, totaling approximately 80 per year. The town of Newcastlewest serves a hinterland collectively referred to in the field of regional community development as West Limerick. Many of these agencies operate under the umbrella of West Limerick Resources (WLR), originating from a local initiative undertaken by individuals and groups in West Limerick to establish a rural resource organisation that could collectively address the issues, changes and challenges impacting on the community and life of the area.

Within both regions, the community development workers engaged with a range of statutory and community groups. A list of these is available in Appendix A. The average age of the population in Limerick West is above the national average and the share of the population aged between 20 and 39 years is well below the national average. People in Limerick West are much more likely to have left education earlier and with fewer qualifications than people nationally. Again, the main employers are within the manufacturing sector. In contrast to Limerick City there is less ethnic and religious diversity and less disability in the region as a whole, with figures closer to national average in both respects. Interestingly there is a strong volunteer base within the field of sport, higher than in other regions of volunteering locally and higher than the national average.

Strand One: A Whole Population Approach

The CCP, in Strand One indicated that it would take a *whole population approach* by:

- **Revising and updating the Compassionate Communities website.**
- **Agreeing and developing a triple Call to Action: Think Ahead (personal and family) ... Talk Together (family, friends, neighbours and colleagues) ... Lend A Hand (wider community)...**
- **Editing, approving, designing and printing Communication leaflets.**
- **Developing and implementing a marketing/PR strategy based on the triple Call to Action; to include extensive use of social media, computer and mobile technology, posters, appropriate engagement with newsprint and radio resources, partnership work with others on joint initiatives, targeted awareness raising initiatives e.g. beer-mat campaign.**

Each of these deliverables is evaluated in detail below.

Compassionate Communities Website & Social Media

The Compassionate Communities logo, website (Figure 1) and Facebook page (Figure 4) were updated following Phase One and were made available online in August 2012 (limited) with full access from November 2012. Training was provided by the website designers, to the community development workers in January 2013 and the website and Facebook page remain subject to constant update based on project activity by the community development workers.

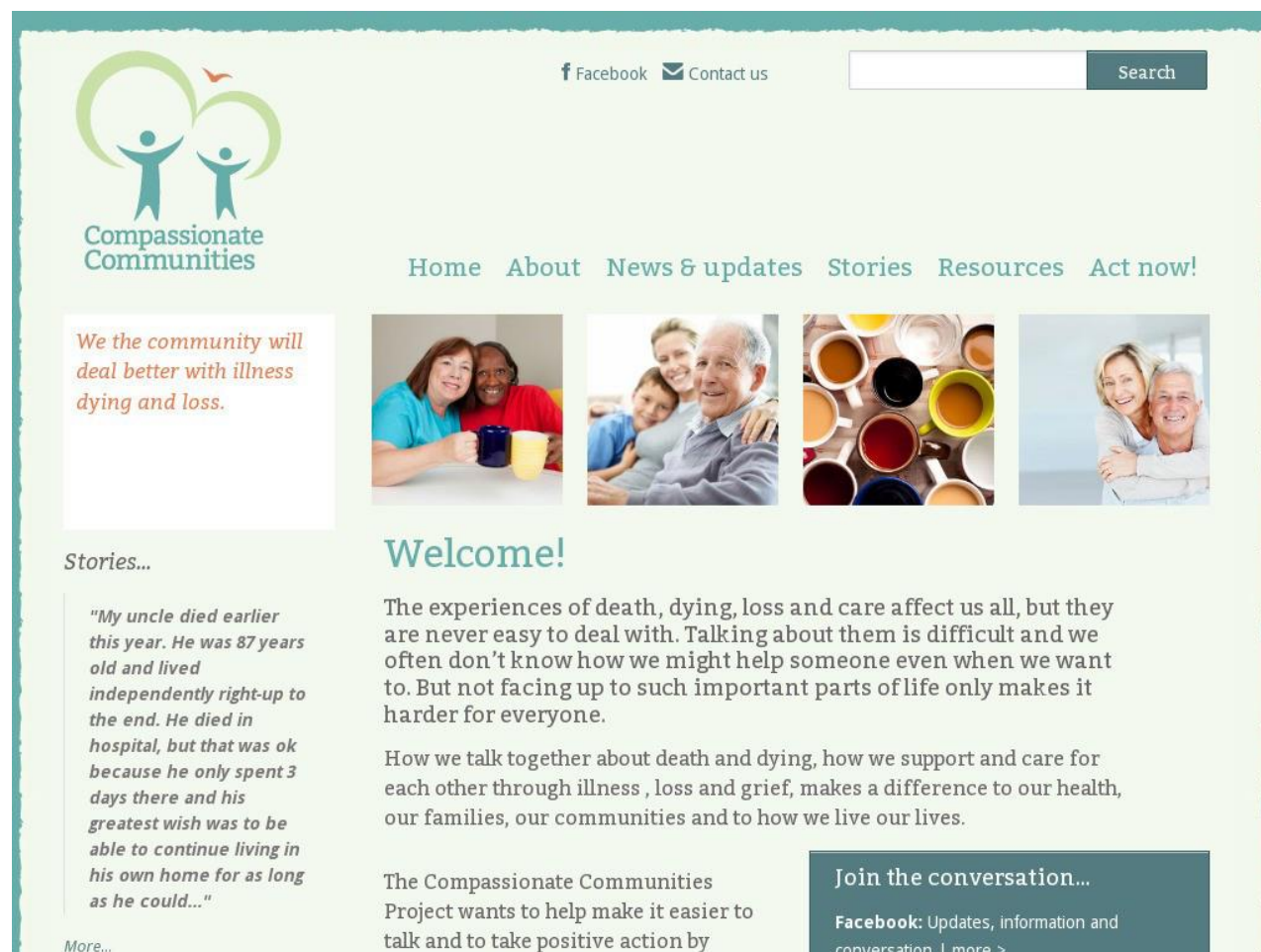


FIGURE 1: SCREENSHOT FROM THE WEBSITE

35,343 visits were logged to the Compassionate Communities website and 49,535 pages viewed, across 120 different countries between August 2012 and July 2013. The top ten countries visiting the site are outlined in Figure 2. The vast array of countries accessing the site may reflect visits associated with the 3rd International Public Health and Palliative Care Conference and the internationally growing momentum to a public health approach to palliative care. This would require further analysis over time and against traffic to similar sites.

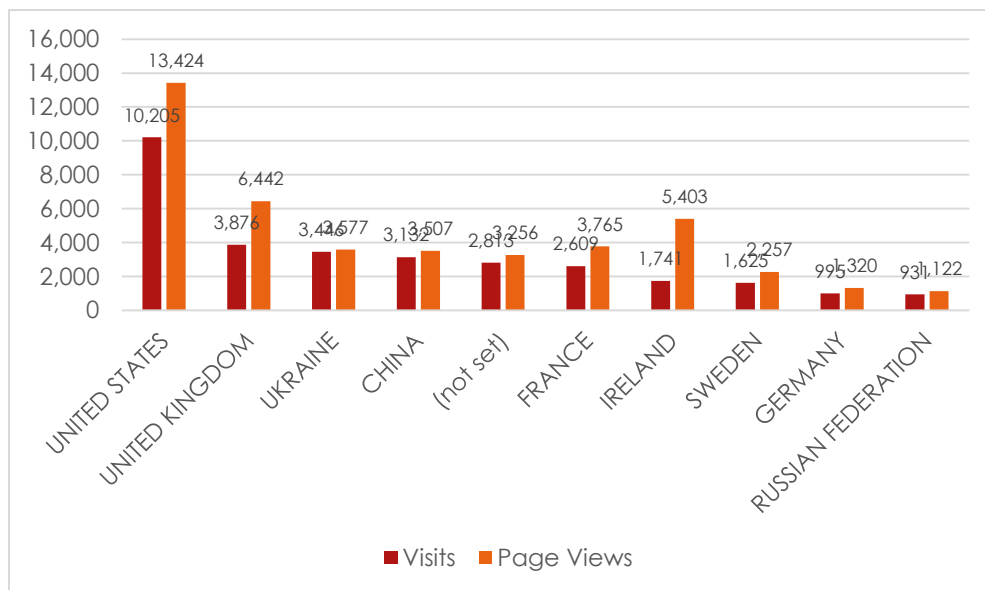


Figure 2: Bar Chart Highlighting the Top Ten Countries Visiting the Compassionate Communities Website

Website activity has progressed steadily on a month by month basis over the year (Figure 3).

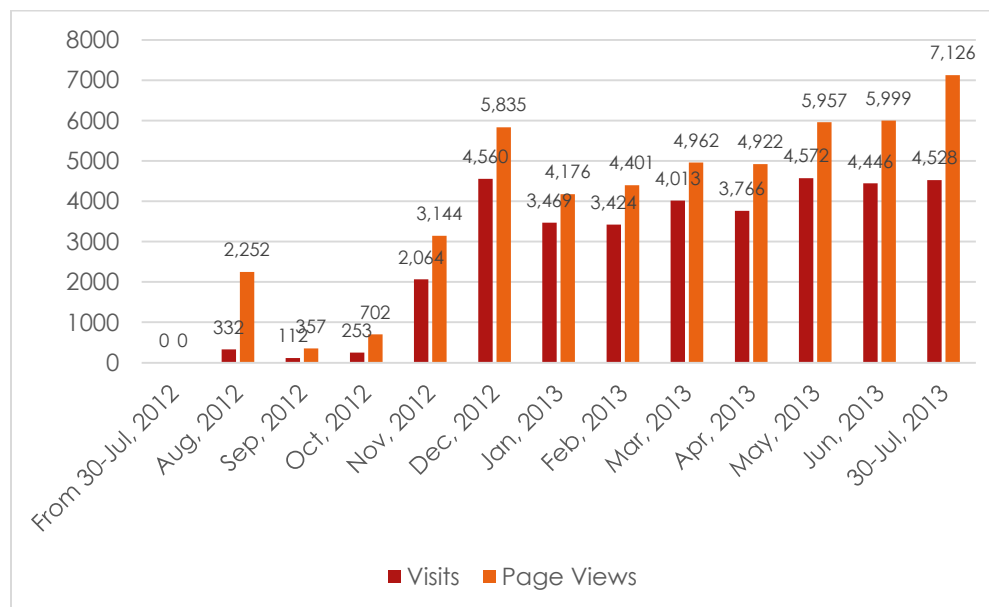


Figure 3: Bar Chart Highlighting the Website Activity Month by Month

The number of website visits indicates the potential power of the website in terms of communicating the project message and informing others of the work in this area, in Ireland and throughout the world. The Sitebeam package was utilised to conduct an evaluation of the Compassionate Communities Website. The overall evaluation score for the site was 5.9/10 indicating that the website could benefit with further structured development. Accessibility to the website from mobile devices and for disabled users rated 7.7/10 which is a good score. However, the marketing of the website on line requires greater focus with a score of 5.1/10. A marketing strategy for the website could potentially increase the overall use and popularity. Dedicated time and personnel are required to enable the necessary links to be made to the site. It must also be considered that the project site is relatively new and has been developed to support a project in a small pilot area in just one county of Ireland and therefore popularity on a worldwide scale may not be relevant to the aims of the project.

Sitebeam website evaluation ratings for the Compassionate Communities website compared favourably to four other Irish and UK related websites, scoring particularly highly on accessibility and content (Table 2).

	Compassionatecommunities.ie	Site A	Site B	Site C	Site D
Overall The overall scale for the website	5.9 AVERAGE	7.0 GOOD	6.2 GOOD	3.8 POOR	6.8 GOOD
Accessibility mobile and disabled users	7.7 GOOD	7.0 GOOD	6.2 GOOD	5.4 AVERAGE	7.2 GOOD
Content The quality and volume of content	6.4 GOOD	7.1 GOOD	4.7 POOR	4.8 POOR	6.3 GOOD
Marketing online	5.1 AVERAGE	7.0 GOOD	4.7 POOR	4.3 POOR	6.0 GOOD
Technology How well designed and built	6.0 GOOD	6.8 GOOD	7.7 GOOD	3.9 POOR	7.3 GOOD
Readability	6.8	7.0	8.2	6.3	7.5

Table 2: Comparison of Compassionate Communities Website with other relevant websites

Focus group and one-to-one interview participants were generally aware of the website, and had visited it early in their first contact with the project – but had rarely returned. One person commented that they had told someone else to look at the site since it contained useful information. There was an apparent lack of awareness regarding the project's Facebook page.

The Compassionate Communities website and Social Media Activity has a number of strengths:

- The site uses Adobe Business Catalyst Content Management System, making it easy to keep up to date and allows non-technical users to control the content of a website.
- The site uses CSS for layout, the preferred technology for building webpages
- The site is written using HTML5 – the latest standard for website development it is safe to use, and represents the most cutting edge approach to web development.
- The site is reasonably well linked to, and therefore performs well in search engine rankings – 10 other sites link directly to the website – this could be further increased, particularly if community partners were asked to link their site directly to the project site and vice-versa.
- The site is quick to load, encouraging users to browse and increasing search engine rankings - On average pages take 2.6 seconds to download (on a simulated 2Mb broadband connection). On average individual pages are extremely quick to respond (0.3 seconds per page).
- The site has a search facility, enabling users to access required information easily

- The site has been updated regularly over the last year, promoting search engine rankings. On average, this site appears to be updated every 1.6 weeks. Up-to-date content creates a positive impression of a website and gives visitors more reason to visit often,
- Sites headings and URLs are well defined and fairly clear – however some titles are quite long and lack associated descriptions.
- The site uses analytics to enable a detailed analysis of user behavior.
- The site includes contact details to enable further interaction and follow-up.
- Bills Story is particularly popular with over 3,600 hits on You Tube since it was uploaded in July 2011. This film has been utilised in other projects internationally and adapted for local use by other agencies. Further promotion of this film could be explored.

Potential areas for development of the website are outlined as follows:

- The website has a very low social media following and website updates are not flowing through onto the



FIGURE 4: SCREEN SHOT OF THE PROJECT'S FACEBOOK PAGE

Facebook page, where they would have greater real time impact. The website and associated Facebook page should therefore be updated simultaneously. Facebook can be an excellent channel for communication and brand building, however the Facebook page (Figure 4) has just 119 likes and minimal level of activity – in the last 12 months a total of 66 posts have been made by the project team, 10 photos have been

posted, 2 posts have been contributed by page followers – from 1 user and 104 other relevant Facebook pages have been liked by the Bill United page. 1 person is talking about the Facebook page. 4 pages of the website have been shared via Facebook and there have been 29 likes for pages on the website. The community development workers have indicated that they spend a maximum of 15 minutes per week on social media and no structured Facebook advertisements have been placed. The use of paid advertising may increase the number of followers and at least 15 minutes **per day** is required for social media marketing by the team.

- There is minimal Twitter activity for the page and as a result, the project is missing the opportunity to target up to 190 million users generating 65 million tweets a day. 9 tweets have linked to this website in the last 12 months.



On 30th July 2013 a Google news email alert emailed links to 10 stories published about death in the last 24 hours. One of these stories was a piece about death in the age of social media published in Forbes magazine about a man tweeting the death of his mother. This story could be linked on Facebook / twitter with a question such as "Would you tweet the death of your mother?" or "Who would you like to present at your moment of death to write it on your Facebook wall?" Or "Is social media an appropriate place to announce death and grieve?"

BOX 1: USING GOOGLE ALERTS

other social networks how to share content on this site. Because they are not used here, it is likely that pages from this site will not look attractive when they are shared. This makes it less likely content from this website will be shared or clicked on. Adding Open Graph tags is relatively straightforward for most sites. At a minimum, there should be a title, description, image, type and site name for every page.

- The writing used on the website is quite hard to understand – easy to understand text benefits users and search engines. This website has an average reading age of 16. Readers need to have been educated to around age 16 to understand this site. In developed countries the average reading age of adults is about 14. Albert and Chadwick (1992) recommend a readability target of 12 for health information, other authors recommend aiming for a target of 9 years. Readability could be improved by simplifying language and reducing the length of sentences e.g. the term "literature" is used instead of "leaflets". Ensuring accessibility to the website information is crucial, particularly when we consider that 1 in 4 Irish adults have difficulty reading and writing (NALA, 2013).
- Link styles could be improved – Links should change appearance when they are hovered over, visited and selected.
- The site could be optimized for printing. All content pages in the site should have print-specific styles defined using CSS. Use this style sheet to hide navigation and other irrelevant areas of the page (such as Flash, which doesn't print).
- Whilst the website's content management system makes it easy for a novice user to update material, and Facebook is very user friendly – these can be time consuming activities for staff who may have insufficient time to develop the necessary skills or interest in this aspect of the role. It is important to ensure that a member of the project team is trained in the technical aspects to using these systems, but is also aware of social marketing methodologies and strategies to maximize the return on the time invested. CPD opportunities are available in this area for NGOs are advertised widely on Active Link (www.activelink.ie).

- Establishing daily Google alerts for news associated with funerals, death, dying, loss, care, hospice and palliative care would be particularly beneficial. These daily news alerts would be automatically emailed to the community development worker by Google, and used to create new Compassionate Communities Facebook / Twitter news. This in turn may engage users in contemporary debate (see Box 1 for example). The website is not W3C compliant – thus reducing accessibility. W3C compliance is an international standard for measuring code quality, accessibility and browser compatibility.

- Open Graph is not utilised – thus reducing social media sharing. This site does not use any Open Graph tags, although some basic information can be inferred from other tags. Open Graph tags tell Facebook and

Communication Leaflets

A series of five leaflets have been developed to help people talk together about serious illness, death and dying (Figure 5).



FIGURE 5: EXAMPLE OF A LEAFLET

- Let's Talk - Communicating with children about illness and death...
- Talking helps - When someone you love is seriously ill
- What to say? - When someone you know is very seriously ill...
- Talk about it - When you are seriously ill...
- Dying to talk... - Why do we need to talk about dying and loss?

The leaflets were all made available in pdf format on the Compassionate Communities website and 1,000 copies of each were printed in October 2012, slightly later than anticipated in the project plan. A further print run of 2,000 copies of each leaflet took place in April 2013 to meet the demand for copies. Over 2,000 printed copies of the leaflets have been distributed widely throughout secondary schools, GP practices and Primary Care Teams, University Hospital Limerick, Milford's Specialist Palliative Care MDT, libraries, churches and at public and project events e.g. the 3rd International PHPC Conference, Cycle Against Suicide. Figure 6 highlights leaflet downloads since they were available on the website in October 2012. It is clear from Fig 6 that there has been a steady increase in leaflet downloads from the website and the increase in May and June 2013 may reflect increased awareness of the resources following the 3rd International Public Health and Palliative Care Conference.

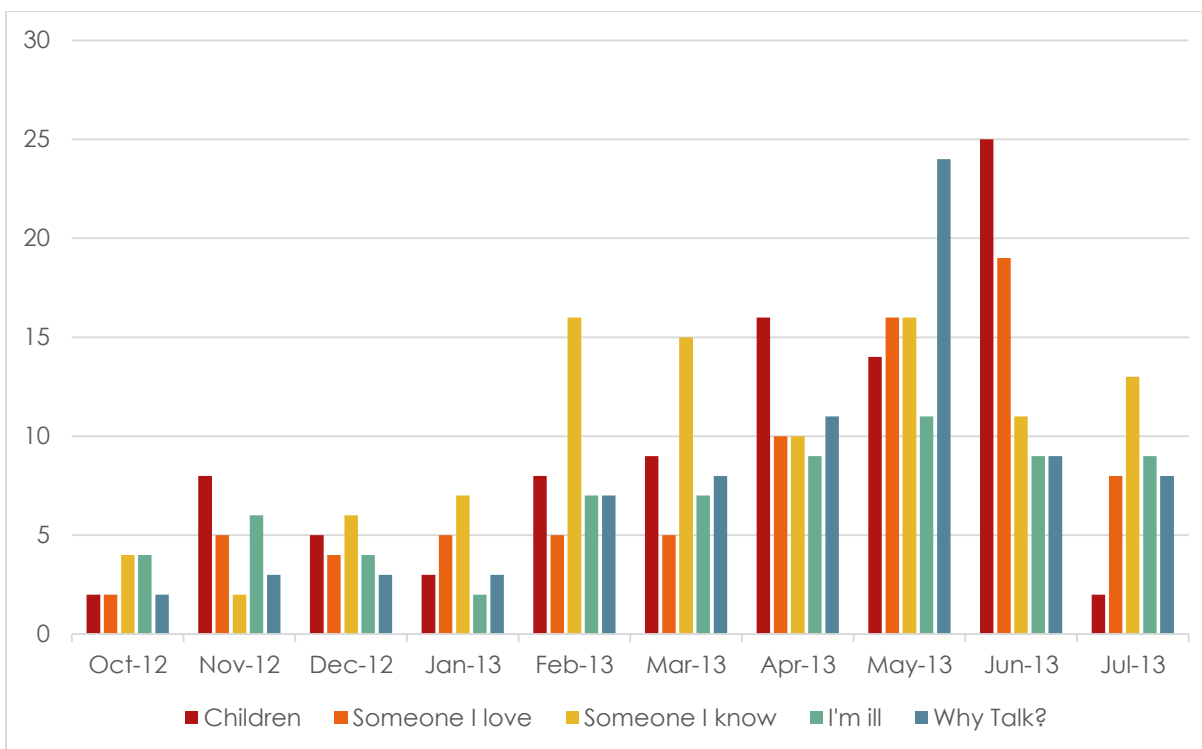


Figure 6: Leaflets Downloaded from the Compassionate Communities Website

Analysis of the leaflets and the experience associated with their use, highlighted a number of strengths

- Participants attending the focus group / one-to-one interviews were all aware of the leaflets and those working for other agencies described how they had left the leaflets accessible to those within their organisations. One community worker said *"I left them on the desk in the office, and I noticed a couple of weeks ago that there weren't many left. So someone is obviously finding them useful"*.
- The leaflets have been used extensively by members of the Specialist Palliative Care team and are widely available throughout Milford Care Centre and the external bases.
- The project evaluator has received positive feedback from health professionals working in the field of end of life care regarding the usefulness of the leaflets developed by the Compassionate Communities team.
- The community development workers indicated that the leaflets were useful in terms of providing a tangible resource they could give to people or refer to. There have been requests for additional stocks of leaflets.
- The font used in the leaflets is clear and clean and the text is a good size.
- Paragraphs are generally short and information is broken up in a thematic manner.
- Bullet points and subheadings have been used effectively.
- Clear contemporary imagery has been used depicting both men and women, young and old and difference races.
- The development of the suite of films based on the leaflets is probably one of the most powerful tools to date in the field of health promoting palliative care. These films were premiered at the 3rd International Public Health and Palliative Care Conference in April 2013 and requests have been received from around the world to access the films and to translate them into Spanish and Russian. The project team have been requested to make additional films on other aspects of communication e.g. for pediatric

palliative care in the UK and care of the elderly in Canada. The films now require international distribution via social media as soon as possible.

Potential areas where the leaflets could be improved in subsequent print runs include:

- Whilst colour has been utilised appropriately, keeping with the project thematic colours and style on the leaflets, NALA (2013) advise “yellow, orange and pastel shades are best avoided” on health information leaflets. Unfortunately, pastel colours are in keeping with the project logo and imagery and this might be an area for further development, ensuring that the project branding is bold and noteworthy and therefore using a colour palette in keeping with the national Plain English Campaign.
- Consider eliminating the use of italics as this font style can make it difficult for people with reading difficulties to decipher the words.
- For clarity, it would be useful to ensure that the leaflet titles are the same on both the leaflets and the website.
- Consider referencing bibliotherapy materials on the leaflets.
- It would be useful to include a link to download Adobe Reader on the website, for those who may not have the programme available.
- There may be opportunity to simplify the language used in the leaflets to ensure it is accessible. Consider submitting the leaflets for NALA's Plain English Mark – NALA will make recommendations and edits for a minimal fee.
- Guidelines for the use of the communication films should be developed and made available with them through the website.
- In general, international evidence regarding the usefulness of leaflets as a tool for the delivery of health information is mixed. Research by Budd and McCron (1982) has shown that despite agencies relying on leaflets to communicate with the public, the public does not like information communicated in this way. They suggest that leaflets containing general information are the least effective and leaflets should be associated with a clear theme. These thematic information sources should be given to a person in association with an intervention or contact to maximize their effect – therefore targeted strategic use of the leaflets is recommended, ideally handed to a person by a health professional to maximise impact. This is the case with the Compassionate Communities leaflets and GPs and members of the PCTs have been encouraged to use this approach. Guidelines for the use of the Compassionate Communities leaflets by the community development workers / other agencies needs to be developed to ensure maximum return for investment.

Triple Call to Action - Media Marketing / PR Strategy

The 'Triple Call to Action' informed all aspects of the project's work and was a theme running through its activities, but an explicit media marketing / PR strategy was not developed within this phase of the CCP. A number of reasons for this have emerged from the evaluation for the absence of a more focused marketing approach relating to a lack of time and a concentration on the day to day engagement in project related activities.

The benefits of the development of such a strategy are multiple. From a health promotion perspective, media advocacy is an important tool to enable public health goals to be used by the media to strategically apply pressure for policy change (Wallack and Dorfman, 1995). There is considerable opportunity to educate the public and raise awareness of key issues via media such as newspapers, the internet, radio and television. Practically, planned engagement with the media enables people to know about events and opportunities associated with the project thus maximizing the potential for people to attend. From a fund raising perspective, highlighting the work of Compassionate Communities via the media, may reach out to potential donors, interested in supporting a novel approach to work in this area. The original plan for the development of the strategy was centered on the development of a *Triple Call to Action – Think Ahead, Talk Together, Lend a Hand*

and this was to include extensive use of social media, computer and mobile technology, posters, appropriate engagement with newsprint and radio resources, partnership work with others on joint initiatives, targeted awareness raising initiatives e.g. beer-mat campaign. This area is one where specialist skills, outside of the project team may be required, together with time and space for the team to work together on key messages, imagery and the direction of focus. The development of such a strategy may require the development of additional competencies and/or skills to enable effective implementation e.g. development of writing or public speaking skills, guidance on writing a press release, effective engagement through media interview. This may require time and additional resources for professional development.

The evaluation of project resources indicates that the Triple Call to Action was not an overt theme within Phase One of the project and remained more as a subtle guide to the actions of the project. As outlined earlier in the review of social media, the lack of an agreed strategy may explain why social media has not been particularly effective or embraced by the project team. Despite the lack of a formal strategy, the CCP did receive media coverage, particularly in local press, on local radio and on websites (e.g. Figure 7). At least 32



FIGURE 7: EXAMPLE OF MEDIA COVERAGE

websites have referred to the CCP in Limerick, two of which are linked to academic journals and some with a national remit e.g. AllHPC (A full list of websites referring to the project is available in Appendix B). Six articles have been published in the Limerick Leader about the project and there has been some coverage in the Limerick Post and Limerick Chronicle along with parish newsletters. Media coverage has led to increased contact to the project e.g. an initial article in the Limerick Leader resulted in a contact from Mary Immaculate College to engage with them and submissions were made from two secondary schools for the poetry event following coverage in the Limerick Leader. Opportunities to communicate about the CCP via local radio were also taken during the course of the project. Radio interviews were used by the development workers to communicate with listeners about forthcoming events and to discuss the key issues associated with the project.

The community development workers noted that the development of posters and flyers can be time consuming, particularly given their skill set with regard to design and IT. This would suggest that alternative mechanisms for art and design work need to be explored that are both professional and cost effective. The project team might consider liaising with local higher education art and design / desk top publishing courses or professionals living in the pilot regions who might like to volunteer for the project to assist with the design of such materials. Ensuring that thought is given to professional print runs and design can ultimately save time and money and may reduce frustration.

Think Ahead

The Compassionate Communities Project took part in one of the two regional pilots of the Think Ahead initiative, in partnership with the Irish Hospice Foundation, in Limerick from September to December 2012 (the second pilot was in County Louth). The aim of Think Ahead is to provide a structure for members of the public to think about, talk and record their preferences for end of life care and practical issues associated with it (Murphy, 2013). Engaging with the Think Ahead pilot had been agreed at the start of Phase 2 of the Compassionate Communities Project, but a number of factors were experienced as challenging. The Compassionate Community Project Workers were both part-time and were getting to grips not only with the CCP itself, but were also juggling and

balancing activities required in furtherance of Think Ahead. They experienced a lack of clarity and sometimes confusion regarding roles and responsibilities associated with the Think Ahead pilot in the Mid-West. Engagement in this initiative may therefore have been more manageable a little later in the life of the CCP.

There was considerable interest in the Think Ahead forms, distributed as part of the pilot and one family support worker has indicated that since the pilot of the initiative in Limerick, they have successfully engaged with three members of disadvantaged communities in Limerick City to complete forms. It is interesting to note that the Compassionate Community Development workers also continued to receive requests for the Think Ahead form and information about Think Ahead for months after the Think Ahead pilot concluded. While the Think Ahead pilot was a successful initiative, the number of evaluation forms associated with the use of the form was small and therefore its impact is difficult to quantify. Overall, the Think Ahead initiative is considered by the project team and focus group attendees, a useful tool to engage the public in advanced planning conversations and decision making.

Evaluation of Strand 1 – In Summary

Strand 1 has commenced the process of developing and employing multiple strategies and mechanisms for public involvement in the CCP across the target population and beyond. This is one of the necessary steps toward the development of a whole population approach in any public health project. A lot has been achieved through the development of a series of leaflets, a website and the early stages of social media platforms such as Facebook, presenting tools and vehicles for the Compassionate Community project to work with and engage the population living in the pilot areas, and for potential utilization in other regions of the Mid-West, Ireland and internationally. There are opportunities as outlined above to further develop these tools in a bid to increase their effectiveness and reach, particularly within the target areas and beyond, highlighting the innovative work by Milford Care Centre in this emerging field of public health and palliative care. Most importantly, this will improve the capacity and ability of people when faced with the experiences associated with death, dying, loss and care.

The Compassionate Communities "brand" in the mid-west benefits by through its association with Milford Care Centre. This opens doors and elevates the importance of the work in the minds of community groups and the public who hold the organization in high regard – this was also a key finding from the evaluation of Phase One of the pilot project (Brereton, 2012). This is of course positive, however the project needs to ensure that it also develops its own strong identity so that is recognized in the field of community development and not seen as just an additional service offered by Milford Care Centre.

Developing campaigns for public involvement takes time, space for reflection and creative thinking, an understanding of what needs to be achieved, an appreciation of the target groups and their needs, energy and enthusiasm. As the work associated with this strand of the project has developed, the community development workers skill base and confidence with technology has grown. There is a need to develop these skills further to conduct marketing and PR associated with the project in a time efficient, strategic manner. The project team has the potential to engage in the development of innovative work in this area, as has been demonstrated in the work associated with Bill United and the series of films based on the leaflets. Outputs associated with this work require strategic direction and leadership that can be guided through the development of a PR / Marketing Strategy for the project. In the absence of a dedicated project manager with these skills, it may be necessary to invest in external consultancy or input from good willed professionals in the local community to develop the ideas and concepts, taking them to the next stage and to ensure that resources are used to their full capacity. CPD for the existing project team in areas of social media, technology and presentation skills may be useful to strengthen the impact of the areas developed.

Strand One represents a vital base layer of the CCP, on which all other strands of the project are communicated and appropriately framed within the context of the project. This Strand has the potential to reach the largest number of people, to raise awareness around death, dying, loss and care and therefore requires time, consideration and strategic direction to ensure that the outputs are as effective as they can be, are implemented appropriately, reaching as many people as possible within the target population in a cost effective, sustainable manner to maintain awareness of issues associated with death dying loss and care.

The tasks assigned to Strand One generally took longer than anticipated due to:

- The resignation of a pivotal member of the project Advisory Committee.
- Emerging work associated with the roll out of Think Ahead in Limerick.
- The need for the community development workers to develop their understanding of the role and vision for the project in order to influence PR / Media associated with project messaging.
- The skill base of the project team with regard to technology and design and the early preparation work associated with the development of websites and marketing materials,
- The substantial work associated with the 3rd International Public Health and Palliative Care Conference.
- Delays experienced in the development of the website and leaflets due to factors external to the project.

These delays, were at times frustrating, since the community development workers needed the tools in order to progress the other complementary strands of the project. In hindsight, the team now consider that the time spent in on the ground community engagement, even during the period when the tools had not been developed, was time well spent. Whilst initial results may have been perceived as slow in Strand One, it is clear from activity data associated with the website and leaflet downloads that awareness of the materials is building and the focus must turn to innovative ways to further develop the resources and maximize their impact.

In any health project, a key element of success has to be in achieving optimal contact with the defined target population (Nutbeam, 1998). No specific targets for reach were set in the CCP plan, and other than counting direct contacts, reach is actually difficult to quantify precisely, since we do not know how many people may have read a leaflet that was taken, or the number of conversations that people may have engaged in with others following attendance at an event, or how many people read a newspaper article or heard a radio interview. However, it is clear that the resources developed are being utilised in Limerick, Newcastlewest, Ireland and internationally, potentially by tens of thousands of people. Requests have been made to further develop the short film series made based on the leaflets. The impact of these films over the next few months will be important to capture in future evaluation. Media promotion and ensuring the project team and Milford Care Centre receives credit for the development of the films will require careful planning, and this may form part of the media / PR strategy in the next phase of any development. Such films (and other project tools) require guidelines for use - to set the context, reduce the risk of them causing distress, ensure that there is adequate debriefing and discussion and that learning points emerge from them. The development of such guidance enables a comprehensive toolkit to be made available for people to take the films (and any other resources) and use them appropriately. External funding opportunities should be examined to enable such toolkits to be developed and evaluated, thus adding to the evidence base of health promoting palliative care.

Whilst it may be tempting to focus mainly on technology and media within this strand, it is important to also consider the fact that in the Mid-West 20% of households do not have access to a computer and 23% of households do not have access to the internet. 13% of the population in Limerick City, and an even larger percentage in Newcastlewest are over the age of 65 and may not have the skills required to utilise technology or media developed within the project. It is therefore important that media such as newspapers, radio, local newsletters and parish bulletins are utilised effectively and creatively to attract people to events or to consider a message from the project. Potential alternative ways to utilise the media would be to consider the development of a fortnightly / monthly column around death, dying, loss and care in a local paper e.g. The Limerick Leader,

considering issues relevant to the project in a creative, sensitive manner. Such a column might invite questions from the public to be considered and feedback/ongoing discussion around the content could be continued on social media / blogging sites to engage those who may not read local press.

The project team should consider the development of practical thought pieces, ready to roll, in the event that a national story enters the media associated with death, dying, loss and care so that the project can respond and eventually be considered as an expert source of advice and commentary in the light of such events. For example, in the media cases regarding assisted suicide, there is an opportunity to respond regarding common myths about hospice and palliative care. Or in the event of the death of a high profile figure who has children e.g. Michael Jackson, advice can be given at a general level regarding how to discuss death with children, how to include them in ritual and ceremony etc. Such suggestions are endless and require strategic direction and agreement prior to the next phase of project development.

Strand Two: Community Engagement

Strand Two of the CCP ran alongside Strand One, building on contacts already made in Phase One of the pilot project in 2011 and developing new contacts and engaging with new community groups and people across Limerick City and Newcastlewest. In this strand, the project plan outlined the following activities / outputs:

- **Community organisations, statutory and voluntary groups within the pilot area identified and engaged with re: Project purpose and aims, and elicited as community partners**
- **Café conversations for organisation specific participants and the general public on issues related to death, loss and care organised in conjunction with community partners**
- **A matched seed grant scheme provided to communities within the pilot area to engage in projects related to death, dying, loss and care**
- **Experiential workshops for staff and volunteers delivered as part of MCC's formal education project developed, delivered and evaluated**
- **A community education project around death, dying, loss and care developed and delivered**

This strand of the project continues to develop multiple strategies to collaborate across multiple sectors and levels, using evidence based approaches to engage the community in issues associated with death, dying, loss and care in an attempt to shape behavior or make a positive change.

Forging Community Partners

A core part of the community development workers role was identifying and engaging with community organisations, statutory and voluntary groups within the pilot areas to engage with them regarding the purpose and aims of the CCP. The community development workers were advised to complete a mapping exercise to determine the key agencies within their catchment area. This appears to have been easier for Newcastlewest, which is a clearly defined area with a relatively small number of potential groups and partners to work with. As the community development worker assigned to Newcastlewest commented *"Newcastlewest is special, unique really, there is a real sense of community already there"*. She reported that most people engaged in community groups were already members of multiple groups so there was a natural networking and communication flow. Interestingly, a seed grant applicant from Newcastlewest actually described a lack of community and a reluctance from the people in the town to engage in new initiatives and development *"It's always the same old people going to everything and after a while, interest wanes. I think the CCP needs to spread to the neighbouring rural communities, they support events in the town more than the locals do."* This contrast in perspectives may be explained by ones definition of community engagement, which in its broadest sense can be defined as engagement with the public at all levels within the community. This is how the researcher interpreted the reflections of the seed grant applicant, whereas the community development worker was more centred on existing groups and organisations, led by a core group. In contrast, Limerick City was described as *"vast, so so vast...a huge area"* by the assigned community development worker. The city is made up of many diverse groups and there are so many organizations existing there that it can be difficult to work with the groups in an intense way *"I feel like I am just out there scattering seeds thinly and hoping some of them take root"*.

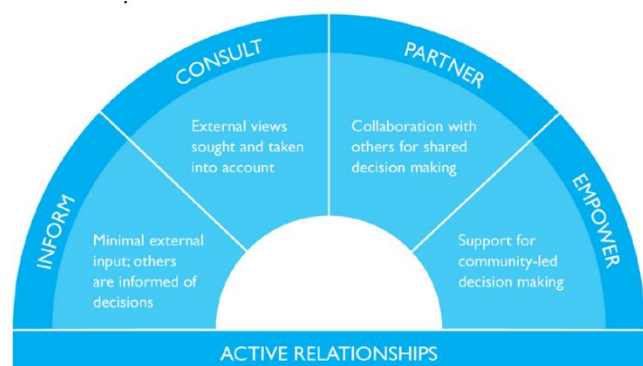


FIGURE 8: LEVELS OF ENGAGEMENT IN COMMUNITY DEVELOPMENT

Networking and relationship building can be a slow and time consuming activity. It requires considerable time in the assigned area and there was often a tension for the community development workers with regard to the time available to them for the project (2.5 days per week each) and the time expected for them to be present at Milford Care Centre for meetings and other work versus the time available to be present in the area. This was particularly difficult for the person assigned to Newcastlewest due to the distance involved travelling back and forth. It may have been beneficial for the community development worker to have an office or a base in the region, which in turn may have been supported at low/no cost by one of the community agencies. This would have the added benefit of raising the visibility of the community development worker and project locally. It could, however, have been a disadvantage with regard to ensuring support from MCC staff for the role and the other community development worker, assigned to Limerick City. Whilst networking can take time, it is a vital first step in engagement and the development of active relationships from a community development perspective (Figure 8).

This part of the project plan is built around informing people of the purpose and aims of the project and engaging with them about the issues of death, dying, loss and care, using a variety of approaches. The plan called for a focus in this area to enable people to determine their own needs, partner with the project to address them and to support empowered people / groups to make necessary change. Both community development workers reported that they were most comfortable with this aspect of their role and once they were clear about the project aims, and had concrete tools to frame engagement with people / groups e.g. leaflets, seed grant scheme, education programmes, they were confident in this aspect of their work. *"It's obvious after a few moments if someone is interested. They either get it or they don't."* Those reported to most likely "get it" were those who had had a significant experience with death, dying, loss and care in their own life and could therefore relate the project to their personal/professional experience.

Over the course of the year at least 140 distinct contacts were made throughout Limerick City with agencies and groups across a diverse range of sectors including schools, higher and adult education providers, children and family community services, parishes, emergency and defense services, HSE services, GAA, Garda , voluntary and community NGOs such as Le Chéile, Paul Partnership, City Council, Employment services, Lions Club, Macra, Traveller agencies, probation services, libraries, local politicians, potential high profile champions and members the general public (Appendix A). Whilst some of these contacts did not reach fruition, the majority of the contacts reached at least the INFORM level of engagement where there was joint communication between both them and the community development worker regarding their role and work. For some this is where their contact ceased, following what appeared to be a high level of initial interest, contact with the community development worker appeared to stop, despite considerable effort on the part of the community development worker. However in some cases, the seeds of contact appeared to reach fertilization and the impact of contacts shows a clear trajectory of positive development. Whilst progress in Limerick City may have been perceived as slow, it is important for the project team not to be discouraged.

Important examples of successful engagement include:

- a. Following the establishment of a bibliotherapy resource in a library in the north-west of Limerick City, during phase 1 of the project, discussions were initiated with another library in the extended city area. The Initial contact and discussions eventually led to a successful meeting, staff *"seemed to warm to the idea"*; leaflets were distributed, an area was agreed for a Café Conversation, a seed grant application was made and an area of the library is now dedicated to the area of death, dying, loss and care (Figure 9).

- b. Significant contact was made with a community organisation during phase 1 of the CCP, but other than being informed about and aware of the project no other action resulted. Contact was maintained in the second phase and it is only now, in year two, that the organisation has applied for a seed grant, nominated members for the Good Neighbour scheme and have begun to engage more proactively with the project, moving from information and awareness to partnership, action and empowerment.



FIGURE 9: BIBLIOTHERAPY RESOURCES IN LIMERICK CITY LIBRARY MADE AVAILABLE AS A RESULT OF A SUCCESSFUL SEED GRANT

- c. As a result of discussions with a Garda Inspector about the Project and its aims, the Community Development worker for Limerick City was invited to attend the morning briefing sessions at each of the Limerick City Garda stations to outline the project aims. Members of An Garda Síochána subsequently attended the CCP workshops on Grief and Loss.
- d. A well-known Limerick business woman, and Limerick Person of the Year 2012, Ms. Helen O'Donnell agreed in November 2012 to become the local Champion for the Compassionate Communities Project. She officiated, with the Mayor of Limerick, at the public launch of the CCP website and the communication leaflets in that month. As Compassionate Community Champion, she hosted the Café Conversation in her premises at the Hunt Café, and is leading the process of bringing together a group of prominent Limerick entrepreneurs under the flag 'Friends of the Compassionate Communities Project'.
- e. One of the first major task of the Friends of Compassionate Communities was the sponsoring by a local business and creation by staff from the University of Limerick of the Before I Die Wall, which provided a focus for members of the public and those attending the International Conference to reflect of their Before I Die' wishes (Figure 10).



FIGURE 10: BEFORE I DIE BOARD DEVELOPED BY CCP AND UL

In Newcastlewest, contact was made with approximately 45 statutory, voluntary, community business partners during phase two of the pilot period (Appendix A). A local community action group was established to guide the work of the project. It is anticipated that this local action group will continue to meet. Whilst some of the contacts resulted in no interest or no further communication, again the majority remained at the INFORM level where there was communication about the project and distribution of relevant information or leaflets. Interestingly, a number of organisations declined to participate citing that the topic was too sensitive or irrelevant for their members, suggesting that there is a need to develop a strong and compelling

case for at least engaging to the INFORM level in the topic area. Some examples of successful the fruits of the engagement in Newcastlewest include:

- a. The Ribbons of Remembrance service that engaged 300+ members of the public (Figure 11)
- b. The contribution of poems written by 25 teenagers from Desmond College Secondary School
- c. A public presentation by Christy Kenneally on death, dying, loss and care organized by the Compassionate Communities Action Group (28 attendees) (Figure 12)
- d. A film night hosted by the Newcastlewest Film Club, in association with the CCP featuring a dramatic presentation of the challenges of living with and dying from Alzheimer's Disease. (30 attendees)
- e. An art exhibition on the theme of death, dying, loss and care organized by the Newcastlewest Arts Group, chaired by Ms Vicki Nash, (50+ attendees) and featured at the 3rd International Public Health and Palliative Care Conference



FIGURE 11: RIBBONS OF REMEMBRANCE

A member of the public in NCW attended the first Compassionate Communities event in NCW following an advert in a local newspaper. He said he had an interest in the area and topic and attended most of the subsequent events. On reflection, he suggested that *"if we could just get 4 practical talks a year on this topic with a good attendance of 50 people at each one, we'd be making a real difference"*.

As outlined earlier, tools and resources were still being developed when the initial contacts were being made. The community development workers and attendees at the focus groups agreed that it was important to make contact with a clear aim and concrete things or opportunities for people / groups rather than just information giving. The tools e.g. leaflets, seed grants, training opportunities have now been developed and can be used for future networking. Contact with the 170 organisations and agencies led to 46 people from Limerick City and Newcastlewest attending training in grief and loss, 13 seed grant applications submitted for consideration and 19 people expressing an interest in Good Neighbour training. There was certainly a value in making the initial links and following up with stakeholder organisations. The project team now need to consider whether engaging directly with community agencies is the correct approach to this work, or whether it would be more efficient to plan a series of 6-12 major events in targeted areas throughout the Mid-West, together with a strong media / PR plan, aimed at the general public, with a view to establishing a committed membership base to drive



FIGURE 12: CHRISTY KENNEALLY TALK

change and action within the community. It might be useful in subsequent phases of work to utilize this approach and

determine if the impact and uptake from the contact reaches more people.

Café Conversations

Café conversations for organisation-specific participants and the general public on issues related to death, dying, loss and care were organised in conjunction with community partners in both pilot areas. In Newcastlewest 40 people attended a public meeting hosted by the Compassionate Communities Development Worker in October 2012. Local people participating in the evaluation commented that this was a good number in comparison to other local events. 11 people attended a subsequent Café Conversation in November 2012 and two other similar events drew a total of four and seven attendees respectively. It is clear when looking at the reach of community engagement in NCW that formalized events with a clear purpose such as Ribbons of Remembrance or public talks drew a larger audience. Café Conversations held in association with these events might prove more useful in the long term as an approach to engage people at a deeper level. One community development worker said *"Public meetings work well, but the Café Conversations are hard, they need to be themed so people have a real focus, the general approach doesn't really work, people need to be guided"*.

In Limerick City, Café Conversations were more successful. A total of seven Café Conversations were held with a total attendance of 72. The most successful one was held for teachers, where 20 attendees actively engaged in what was described by an attendee as *"a lovely gentle introduction"* to death, dying, loss and care. The public Café Conversation arranged for The Hunt Museum, scheduled to take place as a prelude to the International Conference had an attendance of only 8, despite the Before I Die Board causing a considerable stir with people visiting the venue at the same time as the Café Conversation. Again this highlights the importance of presenting the Café Conversations as something tangible, creating considerable awareness of the events through media and possibly running them after a public event. The community development worker assigned to the City also made use of existing meetings and events e.g. Masses, a Cycle Against Suicide and a community networking event to communicate the CCP message, which enabled large numbers of the public to be reached.

Matched Seed Grant Scheme

The aim of the seed grant scheme is to provide financial support to inspire and support community groups, organisations and individuals who wish to mark in some tangible way their response to the universal realities of death, dying, loss and care as lived and experienced by those living, working or studying within their communities. Applications for the second round of seed grant funding were encouraged from organisations in the pilot areas of Limerick City and Newcastlewest via the community development workers. This small grant scheme offers matched funding possibilities for initiatives associated with death, dying, loss and care. The decision to award a seed grant is made based on a review of applications by the project steering committee. Successful applications are required to spend their funds within a timeframe of approximately three months and provide matched funding in the form of direct contribution or contributions in kind. A total of 13 applications were received for the scheme and 11 seed grants were subsequently awarded.



The two applications where awards were not made, included one from a radio station outside of the pilot region – that proposed to produce a series of short radio programmes covering the practical details surrounding bereavement. On review of the application, it would appear that this may have been a missed opportunity, since even though the Organization was outside the catchment area, the programmes to be developed had the potential to impact on a national / international audience via the internet through live and downloadable podcasts. These projects may have been particularly useful

FIGURE 13: RESOURCE AREA FUNDED BY SEED GRANT SCHEME – BARNARDOS LIMERICK SOUTH

additions shared on the Compassionate Communities Website. It is recommended that this application is reconsidered for the next round of available funding. The second application that was not funded proposed to hold four workshops over a period of four months covering themes associated with the Think Ahead project. Whilst the intention of the application was relevant and within the aims of the project, an excessive amount of funding was requested (€1,000) and the proposal lacked appropriate detail for the scale of the award requested.

As Table 3 indicates, a total of €5,665 was awarded to eleven applicants to develop a range of projects, many of which were developed in partnership with the local community, relevant to the area of death, dying, loss and care. It is clear from engagement with these organisations, that had the seed grant scheme not been made available, these projects may never have reached fruition, or would have been delayed considerably.

Organisation	Purpose of Award	Amount Awarded	Project Complete	Numbers Reached
Dooradoyle Library	Development of a bibliotherapy collection of 41 books associated with death, dying, loss and care.	€500	Yes	Available to a membership of 8,000 in Limerick City and County.
Mary Immaculate College	Development of a 5 session mindfulness project to support staff and students who are having difficulty in coping with issues relating to death, dying and loss.	€500	Yes	12.
CARI (Children at Risk in Ireland)	Creation of a remembrance garden for staff and client reflection, in honour of a staff member who died and was cared for by Milford Care Centre	€690	Yes	Up to the point of opening, the garden had already impacted on the 75+ people involved in the project
Barnardos Northside	Purchase of books / workbooks associated with death, dying, loss and care for use with children and families as part of planned intervention by the service.	€500	Yes	50 families in this quarter have received intensive support and universal support has been given to 70+ children. All have access to these resources and they are also been used in structured work with children and families directly affected by life limiting illness.
St Munchin's Family Resource Centre	Supporting the monthly "Good Grief and Biscuits" coffee morning for people to attend who need support around grief and loss.	€200	Yes	8 people have attended the drop in sessions to date.
St Munchin's Family Resource Centre	Training of Community Ambassadors – a group of local people who will link with people from the experience when experiencing difficulty (including sickness, isolation and bereavement)	€500	Yes	6 community ambassadors have been trained.
Barnardos Southside	Provision of library resources relevant to death, dying, loss and care to support service users.	€500	Yes	250+ children and 50+ parents per quarter
Newcastlewest Film Club	Host public film event and Café Conversation.	€275	Yes	20 people attended the film night
Newcastlewest Arts Group	Development and exhibition of 15 pieces of visual art centred on the theme of "The Universal Realities of Death, Dying and Loss"	€500	Yes	Impossible to quantify. 20 people actively engaged in the project. 50+ attended opening night. Ongoing exhibition in NCW and Conference exhibition to 250 conference attendees and hotel patrons.
West Limerick Resources	Support development and delivery of two experiential workshops in Newcastlewest (1) How parents can support their children through bereavement (2) Rainbows volunteers activities to support children with a bereavement.	€500	Yes	7 people attended the parents workshop. 10 attended the Rainbows workshop and 5 have expressed an interest to facilitate Rainbows groups
Brothers of Charity (NCW)	Build a memory garden for service users and members of the community to sit and remember loved ones.	€1,000	Yes	Project at start-up phase

The range of organisations across Limerick and Newcastlewest engaging in this manner with the CCP and Milford Care Centre crosses many social boundaries - the general public, children and family services, higher education, the arts, older peoples service and those with intellectual disabilities, bringing the work of the project to some of the most vulnerable groups in society. Historically, as a member of the Project Advisory Committee commented *"these are groups that Milford Care Centre has never formally engaged with."* The projects developed are in the spirit of those discussed by Kellehear in his book "Compassionate Cities" and the true value of these, when we consider the matched funding in the form of direct labour, time, additional donation etc is considerably more than the €5,665 invested. The positive social impact of such engagement and investment is clear when projects reach completion (see Box 2 CARI Case Study) and the vast majority of the projects funded have produced sustainable outputs that will have an impact over many years beyond the completion of the work.



The community development workers indicated that the seed grant scheme was an area of interest in their liaison with community groups but sometimes it was difficult for groups to see how the money could be utilised, particularly within the tight timeframes required for the pilot. Funding opportunities need to be well-advertised, through local press, community radio, via Parish and school networks and online resources e.g. Activelink with regular calls for funding and deadlines so that people can plan their projects and applications well in advance. Consideration might also be given to making funding available for projects that may impact in any area of the Mid-West, regardless of the address of the person

THE JOURNEY

In Newcastlewest the local arts group created a body of visual art exploring the themes of Death, Dying, Loss and Caring, together with a video record of the progress of the project. In addition 2 public art installations were created. A 'sculpture' using river rocks was built with an 'audience' looking on. "Before I Die" installation was used that encouraged people to write their thoughts were made available to the public in town Square over two weekends. Growth among the direct participants was noteworthy. At the beginning they found it hard to grasp the concept and indeed some were reluctant to engage in conversation, more so committee members than artists. As the project went on, it was very clear that everyone was willing to open up about the themes, contributed to all discussions and were much more comfortable about doing so. At the three exhibition venues: Red Door Gallery, NCW Parish Church and County Library the number of viewers were beyond expectation and there were some great conversations on the theme. The formal opening of the exhibition attracted one of the largest crowds ever for an opening in town. The cooperation of all participants was notable. Particular note should be made of the joining by Desmond College to include their "Dying to be a Poet" at every venue and on the dvd. Exhibiting in the Parish Church – a first for any art exhibition in town led to reaching a wide audience. Exhibiting in the Public Health and Palliative Care Conference was an honour. The donation of the Compassionate Heart sculpture to Milford Care Centre by John Sherlock and the painting "Bystander in 'The Taking of Christ'" to the Parish Church by Keith O'Rahilly will act as lasting mementoes of this project.

receiving the award. As the project momentum and communication mechanisms grow, it is envisaged that the scheme would operate without a need for the development workers to spend so much time supporting organisations to develop their ideas.

Experiential Workshops

Two sets of "How I Manage Grief and Loss" workshops each involving two ½ day sessions, were held at Milford Care Centre, facilitated by senior staff engaged in the CCP and the social work department. These workshops were aimed at people employed by community agencies who were engaged in supporting people in their community affected by death, dying, loss and care issues. A total of 20 people attended the November workshops (dropping to 15 on day two) and 26 attended the February 2013 workshop (dropping to 18 for the subsequent workshop in this set, held one week later). Participants attended from a range of organisations that would not have usually availed of learning and development opportunities offered by Milford Care Centre (see Appendix C for a list of participating organisations). Day One of the workshop included warm up activities, individual and group reflection on early experience of loss, completion of a River of Life's Losses and learning from loss. Day Two focused on understanding of grief, organizational responses to grief and factors that may make grief difficult for people. The workshops evaluated very positively (Figure 14). Overall, scores were slightly higher

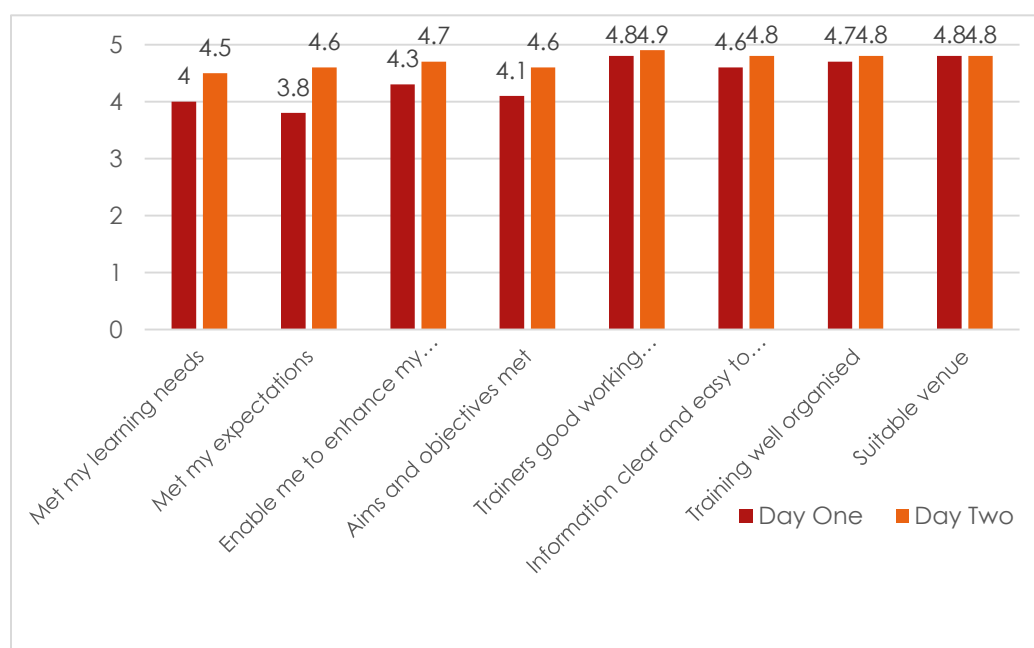


FIGURE 14: PARTICIPANT EVALUATION OF 'HOW I MANAGE GRIEF AND LOSS WORKSHOP' - COMPARISON DAY 1 AND 2

for day two which may be explained by participants confidence with the project and the trainers, a greater understanding of the purpose of the course and what to expect, or the more general and theoretical nature of day two. Some participants noted that the aims and objectives were not clear prior to them coming onto the workshop and clear definition of these in advertising for the course would be useful in the future - this may explain why scores for day one regarding the workshop "meeting participants expectations" is slightly lower (3.8/5.0), since some people did not know what to expect.

The vast majority of attendees were very satisfied with the course and did not suggest any areas where improvement could be made, complementing the facilitators for their gentle approach and appreciating the stories of others. Where improvements were suggested these included:

- More time for exercises

- A smaller group
- Reconsidering the use of incense
- A focus beyond grief to include issues such as loss due to separation
- Tea break needed!
- Ensure everyone can be heard
- Run course in pm so no need to go back to work afterwards
- More group discussion
- More information on services and helping others rather than self-awareness – as a professional
- Provide the aims and objectives before the event – ensure self-care after
- 100% experiential not the best for bringing back something tangible to work setting

Many of these suggestions arose from the first workshop and the second workshop was subsequently adapted accordingly (e.g. incense was not used, the course was held in the afternoon and more information provided as above).

Other areas of potential focus for workshops include:

- How to respond in the anger phase
- Dealing with grief and loss in children/adolescents
- How to deal with people returning to work after loss
- Self-care
- Dealing with relatives and conflict

One participant reflected "I had done training at Milford years ago, and I did the bereavement education project years ago. I came to these workshops thinking I knew it all, I had heard it all before. But I was shocked at how much I learned and benefited from being there. The trainers are expert facilitators, wonderful. I couldn't believe when I did my River and compared it with the one I did years ago, how much I had had to deal with. When you work with vulnerable families, you lose that rawness. Being on that course has made me realize how strong I am and how raw those people really feel".

Whilst the workshops were evaluated using a standard form post workshop, and participants generally reported high levels of satisfaction with the course, it would be very useful to formalize the aims and objectives of the workshop and evaluate the effectiveness of the project against these aims. For example, if one of the aims of the project were to improve the participants confidence speaking to people who are recently bereaved, in what ways could this confidence be assessed pre and post course? If an aim of the course were to reduce the fear of death and dying, several measures can be used to evaluate the effectiveness of the course as outlined in the Death Anxiety Handbook (Neimeyer, 1994). Evaluation in this manner enables the intervention of the workshop to be assessed with regard to effectiveness. This in turn adds to the evidence based in the field of health promoting palliative care and may reduce unnecessary duplication by others who seek to deliver education in this manner.

The role of the community development workers with regard to these workshops was to inform members of the community of their existence and to encourage participation. In hindsight, the community development workers have both acknowledged that they would like to have attended the workshops to continue their relationship with participants, and both have indicated that with some support and supervision, they would have been in a position to provide the training. A train the trainer approach to the delivery of such workshops is highly recommended to enable the skill base to be shared and broadened in this area. Such an approach is the key to sustainability.

Community Education Programmes

Death Education in Schools

In pilot Phase 1, the CCP explored the idea of initiating a programme to provide support for children in the Primary School sector, in dealing with the experience of death, dying, loss and care. Some resistance was met and it was thus considered that further consideration should be given on how best to achieve the appropriate aims.

A member of the CCP Project Steering Committee and one of the development workers met with the Principal and Chaplain of the school that was originally involved. It was decided that a Focus Group should be held, bringing together representation from a cross-section of schools in the area. This meeting was held and four teachers attended. Though the number of attendees was small, the feed-back was interesting for the project. The group unanimously thought that the optimum way to approach the Death Education project was to visit schools individually and explore their needs. The term Death Education was perceived to be too stark. The teachers agreed the information and support in the form of suitable literature and books for children would be well received. It was suggested that Grief and Loss workshops with specific reference to the teaching profession would be beneficial to colleagues.

Although the concept of visiting individual schools is time consuming, this approach has been commenced. The Development worker has visited a number of Primary Schools in the Limerick City area and the reaction has been mixed. One such visit was the catalyst to a Café Conversation, attended by all staff working in the school and in another school, the Principal requested advice from CCP/MCC regarding how to cope with the death of a pupil. Whereas in another site, the Principal, after much discussion, felt that the topic was too sensitive at the time as some members of staff were unwell and living with life-limiting illnesses.

A tutorial session with a group of staff and students from Mary Immaculate College on CCP was also conducted regarding the relevance of issues associated with death, dying, loss and care in the classroom. The College are very interested in the area and it is proposed that a working group will be brought together in late 2013.

Community Education Programme

The first project plan for the CCP identified a potential need to develop a community education programme focusing on death, dying, loss and care that would ideally have academic accreditation at undergraduate level. The development of such a project did not take place in Phase Two of the pilot project due to a lack of resources / personnel changes. A suggestion was made by a staff member who previously worked for the organization that a seed grant could be awarded to enable the project to be developed. However, a decision was made to examine the potential for the education project to be funded separately from the seed grant scheme, from resources assigned to the CCP. The timeframe for the development of the project, associated evaluation, recruitment and delivery of the education project was very tight and will therefore remain a priority for the next phase of the project.

Such a programme is recommended for development, since there is a gap in such education in Ireland. The project could integrate the experiential, scholarly, social, individual, emotional, and intellectual dimensions of death and dying in a practical way, possibly using *The Last Dance* (deSpelder, 2011) as a core text. The course, running for between 8 and 12 weeks (one evening per week) would be open to anyone with an interest in thanatology - the study of death and dying. Modules could include:

- Attitudes toward death, dying, loss and care
- Social, cultural and historical influences on death and dying
- Mortality and society
- Death and dying in healthcare
- End-of-Life issues and decisions

- Facing death - Living with life threatening illness
- Last Rites: Funerals and body disposition
- Death in the lives of children and adolescents
- Death in the lives of adults
- Beyond death / After life
- The Path Ahead: Personal and social choices

In addition to attending the weekly class, participants would be required to complete an assignment and weekly learning tasks. Access to a computer and the internet would be required. Following evaluation of the project, an application could be made for accreditation as a CPD module in an academic institution. Such a course has the potential to be self-funding or profit making for Milford Care Centre following its establishment and consideration to delivering the programme in any subsequent phases of the Compassionate Project should be considered.

A course of this nature, whilst partly experiential, is quite academic and formal. It would also be important to consider providing training to the general public in talking to people about issues associated with death, dying, loss and care, since communication is a core theme within the CCP's proposed triple call to action. Such a short training project could be delivered within the community as a short evening or weekend course and could be developed around The Think Ahead Form or utilise other models internationally such as Conversations for Life (<http://www.conversationsforlife.co.uk/>). The Conversations for Life project inspires and engages the public, staff and communities to overcome the taboo of talking about death and dying based on the stories of real people. They report that public and staff workshops and community facilitation increase the confidence, conversations, and connections needed so more people can access information and resources and live their last days in the place of their choice. This project is tried and tested and was the first public health supported community-wide (public and staff) awareness initiative in the UK in collaboration with NHS Cumbria in 2009/2010. Conversations for Life have delivered staff development days to thousands of health and social care staff, medical & nursing students, care homes, GPs, community nurses and those working with patients living with chronic conditions (cardiac, renal, dementia) and have enabled seven communities and more than 200 community organisations (healthcare, hospice, aging, youth, government, voluntary, and service organisations) to launch their own community-led awareness initiatives. Consideration to using or adapting this model should be given priority in future phases of the development of the CCP and opportunities to secure external funding to support this development should be considered.

Evaluation of Strand Two – Summary

It is clear from the evaluation that the community development workers spent a considerable proportion of their time networking and developing links within their assigned geographical areas. Most of this work focused on forging links with voluntary, statutory and community organisations, who had varying degrees of interest in the Compassionate Communities concept. Where the concept was embraced and understood, engagement with the project progressed through a trajectory from information sharing to empowerment through participation in training, applying for seed grants and/or nominating people as potential Good Neighbours. In Newcastlewest in particular, the networking led to the development of some new, potentially sustainable initiatives that had reach to and an impact on the general public, thus raising awareness of the project and discussion regarding death, dying, loss and care within the community. Whilst the project plan had decided to focus on the town of Newcastlewest, this decision, in hindsight, did not reflect the reality of the community of Newcastlewest which includes an extensive hinterland. The application of this within the project plan sometimes acted as a barrier to engagement with the natural 'community'.

In Limerick City, maximizing opportunities to speak to existing groups resulted in new contacts for the community development worker and Café Conversations, particularly those held in organisations were successful. Such

engagement takes time and commitment and is considered more effective when there is a clearly defined aim to the contact e.g. promotion of resources or opportunities offered. It is clear that from the contacts made with 140 + organisations that the key outcomes were attendance at training, receipt of seed grant applications and the development of specific local initiatives, e.g. the Before I Die Wall. The time spent in direct contact at the startup phase of community development is considered well spent since it is important to ensure that people who may never have engaged with the project, do so or at least have an understanding regarding its aim and objectives and can therefore make an informed choice regarding participation. Once a critical mass of people have been identified and events are well attended, identification of a core group of committed individuals to drive the project further locally in a sustainable manner with the support of the project team might then become the focus of attention for the community development worker. This process was starting to emerge in Newcastle West and in the City through the concept of community champions and local action groups. It is important to recognize that where the engagement has been successful, particularly through the seed grant projects and training opportunities that the compassionate communities' message is spreading. Milford Care Centre is engaging with organisations through the project, that it would never normally reach through the direct provision of specialist palliative care and education. This in turn presents opportunities for Milford Care Centre to engage in social/ public education through structured communication between these areas and the project team, to maximise the reach and impact of training and education to the widest possible audiences.

Connection with the general public must remain a key focus for the CCP in future phases and there is an opportunity to link with other national initiatives e.g. Think Ahead, Final Journeys or UK concepts such as Conversations for Life. The Café Conversation technique appeared to have a limited impact in this phase of the project. Interestingly, a similar concept "The Death Café" is gaining considerable momentum in the UK and US, generally taking a city based approach to engaging the general public in conversation around death, dying, loss and care often using a thematic approach (Underwood, 2013). A similar model of Café Style Conversation, utilizing monthly themes is a key feature of public engagement in dementia as part of the ASI / Genio project.

Linking with schools is important and whilst the reaction has been mixed to concept of death education in schools, it is clear that the programme is making steady progress to engage with the education sector and providers in the local area. It is important to ensure that future efforts in the area of death education in schools are evidence based, consider the use of programmes developed elsewhere to reduce duplication and are collaboratively developed in association with other stakeholders working in this area e.g. The Irish Childhood Bereavement Network and TCD (a PhD student (qualified teacher from the Mid-West) is developing education programmes in this area).

Whilst low numbers at the Café Conversations may have been a result of limited advertising or marketing, it may also reflect Irish society's reluctance to engage in such conversation. Two of the key reasons cited for groups and agencies not to engage in the CCP during this phase, in any way, centered on a fear / reluctance to talk about death, dying, loss and care and the lack of recognition that this topic has relevance to those engaged with various community groups. The main aim of the CCP is *"To enrich and support society to live compassionately with death, dying, loss and care"* and it is clear that there is considerable work required to raise awareness of the importance of this field and encourage people to become confident in talking about these issues, before they can ever be expected to do things differently. This in turn supports the need to focus on enabling thought and conversation as described in the projects Triple Call to Action.

Strand Three: Community Mentors/Social Model of Care

Strand Three of the project was designed to develop, roll out and test a social model of care within the project's pilot areas. Specifically the project plan outlined that the team would:

- **Identify and agree a model for the Community Mentor (CM) Project as part of an agreed model of Social Care, in association with community partners in Limerick City and Newcastlewest.**
- **Recruit and train Voluntary Community Mentors.**
- **Advertise, implement and evaluate the Community Mentor Project / Social Model of Care .**

A model for the Community Mentor Project has been identified, agreed and refined in association with community partners. Mentors will be recruited and trained in Q4 of 2013 and the initiative will then be operational.

The agreed social model of care by the team is referred to as "*The Good Neighbour Project*" and has developed from an initial model proposed during the CCP conceptualisation phase. The initial model was based on the 'Home Hospice' concept from Australia that enabled people at the end of life, to receive social support and hands on care from members of the community. The model was adapted to reflect the different levels of service available in the Mid-West region, where a specialist palliative care multidisciplinary Hospice at Home service is available. The focus of the Good Neighbour project is therefore not to provide hands on physical care, but to work in partnership with community based organisations, groups and individuals to make available additional social supports to those living with advanced illness.

The model centres on the identification of volunteer Good Neighbours from the local community. The role of the Good Neighbours is to facilitate the person / family affected by advanced illness at home to mobilise their social networks to support them through the provision of social care – to seek out and enlist the 'good neighbour' capacity within local communities. Helpful tasks performed may include seemingly small things like walking the dog, doing the shopping, collecting a prescription, filling a coal bucket, lighting the fire or sitting with the person while the carer takes a break, but together these can help relieve some of the burden, loneliness and isolation often experienced both by the person who is ill and those caring. Providing any kind of personal care is not part of the Good Neighbour role. While the first port of call is a person's/family's existing social network, if this is insufficient, assistance may be sought from other voluntary sources, and only then the direct provision of the support by the Volunteer Good Neighbour. The role of the Good Neighbour is as follows:

- The Good Neighbour is a volunteer.
- Initial contact with the Good Neighbour may be made by a health / social care professional with the person's / family's permission, the patient or a family member.
- The Good Neighbour responds by accepting an invitation into a family's home.
- The Good Neighbour meets with the patient and their family to identify the different social-care tasks that will assist the person being cared for at home.
- The Good Neighbour identifies with the patient and their family the social network of family, friends and neighbours in their community.
- The Good Neighbour, on behalf of the patient / family, makes contact with identified members of the social network to elicit their willingness and ability to assist with specified social tasks and agrees a roster / timetable.
- The Good Neighbour identifies, with the patient / family, a coordinator of informal care to help sustain the support. This could be the main carer, another family member or someone else in the social network.
- The Good Neighbour role is short-term, facilitating the start of a process that should be self-sustaining.
- In circumstances where a social network is not available to assist with social care the Good Neighbour will liaise with community and voluntary organisations to elicit their assistance.
- If the required support is not available through existing community resources the Good Neighbour may undertake to provide the social support directly.

- A Good Neighbour should maintain close links with the Compassionate Communities Project Co-ordinator(s), Milford Care Centre.
- A Good Neighbour should attend regular educational and debriefing sessions as advised.

The Compassionate Communities Project, through the development workers for Limerick and Newcastlewest, put out a call to community based organisations to nominate a member as a volunteer Good Neighbour to take the lead role of behalf of the organisation in the initial trialing of the of the Good Neighbour Scheme. Potential Good Neighbours apply to become MCC volunteers by completing an application form and having an individual follow-up discussion with members of the Compassionate Communities Operations Group to establish that there is a 'fit' between the person and the Good Neighbours scheme as outlined. As with all MCC volunteers, Good Neighbours must have Garda clearance which will be organised by MCC.

A good neighbour should be a person who:

- Has maturity, common sense and the ability to be discrete and sensitive.
- Has a good understanding of confidentiality.
- Is confident and out-going, relates well to others and communicates effectively.
- Is respectful and non-judgmental at all times.
- Has a good sense of humour.
- Is a good organiser,
- Has a good sense of personal boundaries and a clear understanding of purpose of the role.
- Has been nominated by a sponsoring organisation, e.g. Lions Club or other local voluntary organisation, and will also become a Milford Care Centre volunteer, or may be a concerned community individual who becomes a Milford Care Centre volunteer.

A working group has been developed to oversee the development of the Good Neighbour Scheme with Clinical Nurse Specialist representation from the Hospice at Home Team and the HSE via the Deputy Director of Public Health Nursing. The project plan highlighted that the Good Neighbour Scheme would be in place by Summer 2013. Considerable work has occurred to develop and agree the concept and this took time to ensure that all key internal and external stakeholders bought into the initiative and were supportive of it in principle. It became clear that community organisations who would be the link between the majority of potential good neighbours and Milford Care Centre were not clear regarding the purpose of the scheme or what it entailed. It was then agreed to bring people together for two days orientation and training where the CCP vision for the scheme could be communicated to the relevant organizations and these organisations would also have the opportunity to shape the scheme and provide feedback on the proposed model.

Community organisations and groups were invited by the community development workers to nominate people to attend two days of training. A total of 19 people were nominated and attended training in February / March 2013 (6 from Newcastlewest and 13 from Limerick City). The community development workers noted that there was a certain amount of fear amongst organisations that their volunteers were maybe being "poached" or were already at their capacity in terms of what they were required to do. However, where organisations did send people, they usually sent more than one on the training which was useful from the potential of mutual support following their return to their base. Training was delivered by senior members of the CCP project team. The community development workers would like to have been in attendance at the training so that they could support the participants after the training and hear more of the concerns and/or experiences of participants. It would also have been useful from a train the trainer perspective to have the community development workers in attendance and possibly co-facilitating the workshops to enhance sustainability, support and roll-out.

Day One of the training project focused on explaining the aim of Compassionate Communities and the concept of the good neighbour scheme. As highlighted in Figure 15 there was a statistically significant difference in each indicator after training with the exception of *"I am interested in finding out more about the Good Neighbour*

Project" which was already very high before training commenced. The training was highly evaluated and it is clear that participants found the course interesting and the potential of the Good Neighbour Scheme exciting

"I have learned so much in such a short few hours, I hope this project takes off and is a great success and I'm proud to have been involved in this pilot workshop"

"Today was very clear and has provided information and clarity around exactly what is expected of a good neighbour, but sadly it has reminded me of how a member of a community can very easily get lost and forgotten".

Day Two of the project centred on communication skills and the logistics of how the Good Neighbour will work with the person and their family and the broader community. A total of 16 people attended the second day of training and again the workshop evaluated very positively with significant improvement in participants perceived understanding and skills associated with the project (Figure 16). The workshops were considered practical and useful in both personal and professional settings:

"I just loved it so much, it will help me so much more in my life. I am very happy that I did this course".

"I am so grateful to X and X for being so good at their jobs and giving me a good understanding. Thanks a million, will use some of the information at my place of work."

Participants were given the opportunity to shape the Good Neighbour model and a number of useful suggestions emerged from the training that have subsequently been considered by the project team and incorporated e.g. the need for Garda clearance.

Following the training programme, the development of the Good Neighbour project is now awaiting implementation, roll out and evaluation at the time of this report. There has been a delay in implementation, in part due to the focus of coordinating the 3rd International Public Health and Palliative Care Conference in Limerick by the project team, and also due to the time taken to secure insurance for the Good Neighbours and to negotiate with and inform key stakeholders about the initiative. From the participant's perspective, the delay has been frustrating and somewhat disappointing *"I think the momentum might get lost"* commented one keen trainee at the focus group in Limerick City in July. *"They said they would call people and let them know if they have been chosen...maybe they did but I didn't hear anything."* The community development workers are also disappointed that the delay has occurred and there is an urgency to now reconnect with the people who expressed an interest and take the project to the next phase of implementation and evaluation.

At the time of writing, all of the participants have been contacted and all of the sponsoring organisations are being followed up with. Arrangements have now been agreed regarding insurance for good neighbours and a selection process is due to commence in September 2013. An information leaflet and application form have been developed and Limerick PCTs have been briefed regarding the scheme. The delay due to the conference has also been positive in that it provided the opportunity for the team to consider other models of social support, reflect on the nature of the volunteer and people's natural capacity to care as well as the legal and safety issues associated with a scheme such as this. The project team have expressed a commitment to achieving the implementation of the Good Neighbour Scheme in Autumn 2013, subject to an extension of project funds. A model for the evaluation of the scheme must now be developed, prior to the roll out of the scheme, to add to the emerging evidence regarding the reach, impact, effectiveness and sustainability of such an approach in end of life care.

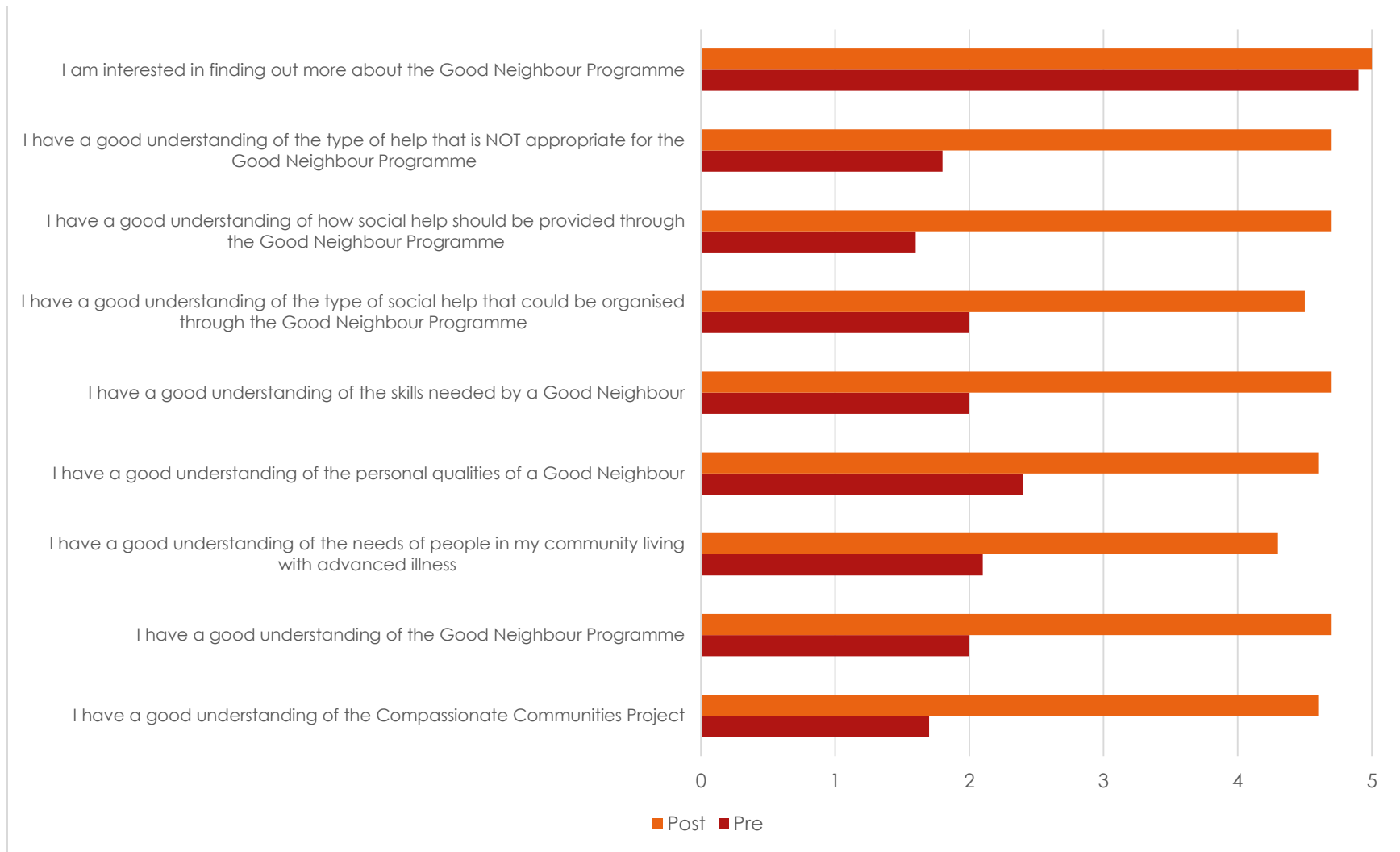


FIGURE 15: EVALUATION OF THE GOOD NEIGHBOUR TRAINING WORKSHOP DAY 1 - COMPARISON OF PRE AND POST

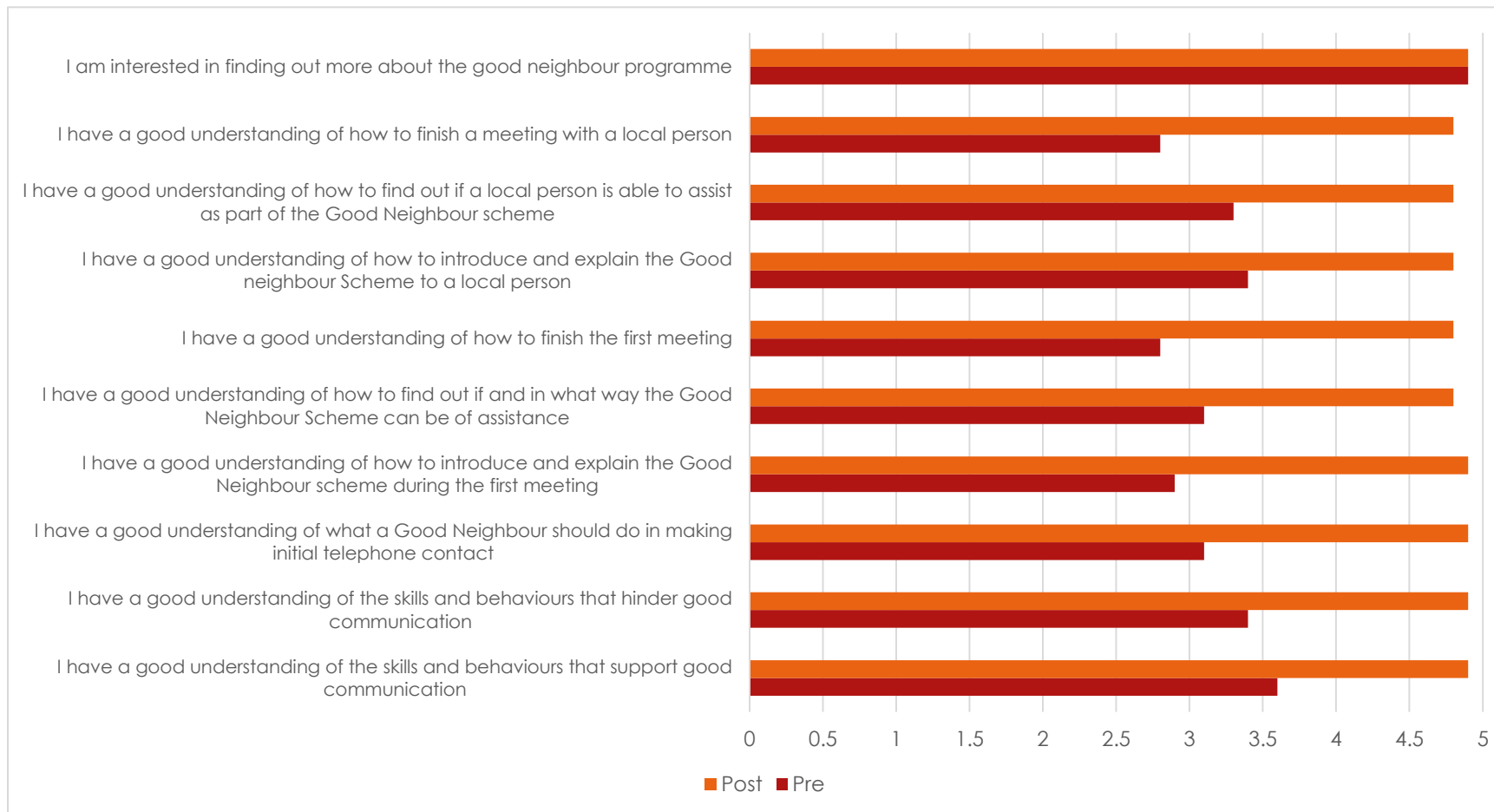


FIGURE 16 EVALUATION OF THE GOOD NEIGHBOUR TRAINING DAY 2 COMPARISON OF PRE AND POST

The 3rd International Public Health and Palliative Care Conference

In April 2013, Milford Care Centre, in association with The University of Limerick and The Irish Hospice Foundation hosted the 3rd International Public Health and Palliative Care Conference, which brought over 250 delegates from across the globe, to Limerick. At the conference the concept of an International Association of Public Health and Palliative Care was explored and an interim council was established. The Conference took considerable time and energy to host, and utilised the resources of the Compassionate Communities team, in addition to the many other departments that assisted with the event from all areas of Milford Care Centre.

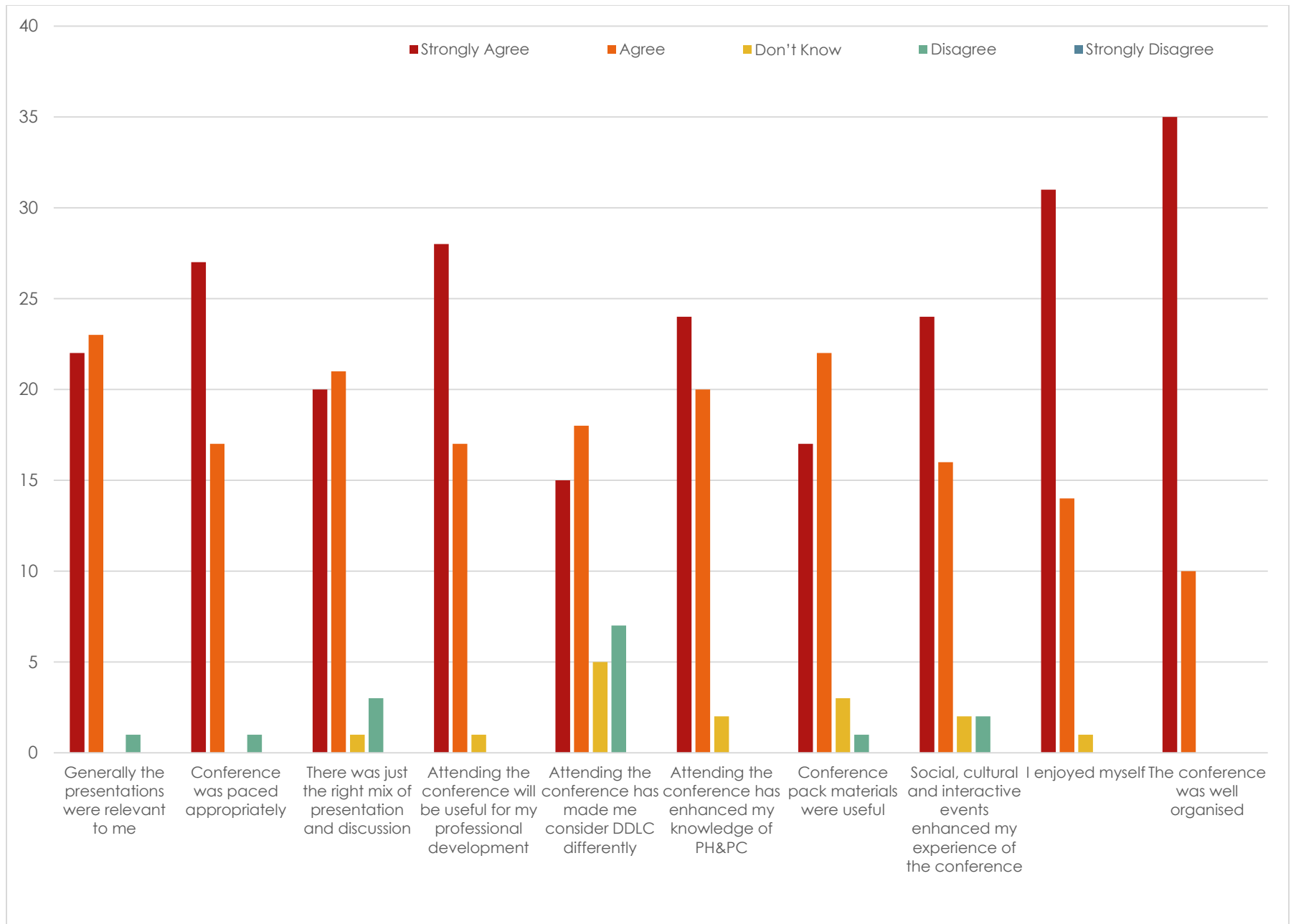
A total of 46 participant evaluation forms were returned. Figure 17 highlights the main feedback from the event and as outlined by the bar chart, satisfaction with the event was very high, across all domains.

The event offered an opportunity to show the series of Let's Talk films for the first time, and these were positively referred to by participants in the evaluation, who reflected on their simple, yet powerful messages.

"The DVDs were profound and very moving and got the message across in a beautiful way".

Participants enjoyed the opportunity to network, to hear from speakers such as Professor Allan Kellehear, Dr Bruce Rumbold, Nigel Hartley, Susan Newton, Dr Suresh Kumar, Paul Cronin, Dr Frank Brennan and Dr Kathleen McLoughlin, amongst others and found the mix between conceptual frameworks and practice to be useful. A small number of practical suggestions were offered to be considered for future conference organising committees to enhance participant experience at future events. The third day of the Conference was open to the general public, and whilst some delegates on the third day were from the public, numbers were quite low. This may have been a result, in part, to limited advertising to the public as a result of concern regarding too many attendees, since Day 3 was actually fully booked with delegates attending the whole event. In reality, many delegates did not actually attend Day 3 as anticipated and space was available for the public.

Events held alongside the conference e.g. exhibitions, storytelling by Dr Brennan and the Before I Die Board, were open to the public and to hotel visitors and awareness of the event was also promoted via local media and subsequent conference coverage on E-Hospice (www.E-Hospice.com) and via the EAPC blog (McLoughlin, 2013). The next conference will be held in the UK in 2015 and the Conference Chairperson has agreed to work with the organising committee to share the learning from the Limerick event.



Discussion

Milford Care Centre's innovative Compassionate Communities pilot project has continued to work positively toward its aim *"To enrich and support society to live compassionately with death, dying, loss and care and to demonstrate and evaluate the process of developing a compassionate community model in an Irish context"* in year two. A considerable amount has been achieved in the past twelve months, including:

- Funding and recruitment of 2 x part time Compassionate Communities community development workers.
- Development of the project identity and marketing via social media, and website (35,343 visits, 49,535 pages viewed, from people in 120 different countries) printed media, radio and direct contact with key stakeholders.
- Development and wide dissemination of a series of five communication leaflets to individuals and organisations in the pilot regions. They are also accessible to people throughout Ireland and across the world.
- Production of a series of short films, developed to complement the leaflets (these will shortly be launched and freely available as a world-wide resource).
- The Compassionate Communities Project took part in one of two regional pilots of the Think Ahead initiative, led by The Irish Hospice Foundation. Forms were disseminated throughout the pilot regions between September and December 2012. (The second pilot was in County Louth).
- Approximately 180 organisations/groups (see Appendix A) have engaged with the project in the last 12 months at varying levels of intensity. Many of these organisations work with the most vulnerable people living in the pilot areas and are organisations outside Milford Care Centre's usual sphere of contact and influence.
- Almost 100 people have engaged in Café Conversations specific to death, dying, loss and care.
- Eleven seed grants have been awarded to support community led projects in the field of death, dying, loss and care. Collectively, these projects have the potential to reach thousands of people within the pilot regions.
- 46 people attended training in grief and loss from a wide range of statutory, voluntary and community organisations.
- A working group to oversee the development of the Volunteer Good Neighbour scheme has been established, comprising representatives from Public Health Nursing, Palliative Care Clinical Nurse Specialists and the CCP team.
- 19 people have expressed an interest in the Good Neighbour scheme and attended the initial orientation and training. Volunteer recruitment is commencing.
- A local action group for death, dying, loss and care has been established and is led by community representatives in Newcastlewest.
- In Limerick City Ms. Helen O'Donnell, a prominent business person has taken on the role of Compassionate Communities Champion and has committed to coordinating Friends of Compassionate Communities.
- The 3rd International Public Health and Palliative Care Conference was hosted in Limerick in April 2013 bringing 250 delegates from across the world to share their thoughts and work with regard to a public health approach to palliative care.
- As a result of Milford's strategic leadership in this area, the strategic plan for palliative care services for the Mid-West specifically makes reference to Health Promoting Palliative Care and the CCP (Milford Care Centre / HSE, 2013) and the area is a key dimension of the work packages of the All Ireland Institute for Hospice and Palliative Care.

There were areas of the project plan where planned targets were not met precisely, specifically regarding the roll out of the Good Neighbour Scheme and the development of a PR / Marketing Strategy – however there has been significant progress achieved with regard to achieving media impact without such a strategy and a bank

of 19 potential good neighbours have been sourced and training has commenced. It is envisaged, that subject to further funding for the project, the Good Neighbour Scheme would be ready to commence in Q4 and evidence from the UK suggests that such a scheme may have considerable impact with regard to assisting people to be able to be cared for at home at the end of life with reduced isolation and concern regarding practical matters. The delay with regard to the Good Neighbour Scheme can be explained, at least in part by the project team's response to emerging innovative areas of work, including participation in the Irish Hospice Foundation's Think Ahead pilot and the hosting of the 3rd International Public Health and Palliative Care Conference which took considerable time and effort on the part of the project team.

Each Strand of the project has been evaluated and recommendations have been made within the context of this document regarding potential development in further cycles of the project. These are summarized below. What follows is a discussion regarding some of the more global issues arising for the project with regard to reach and sustainability.

Project Reach and Sustainability

Community development and community engagement requires passion and commitment. To date the CCP has been led by two committed members of staff, with a social work background and the former Head of Education, Research and Professional Development (who has since left the organisation but has a strong interest in the area and is supporting the work personally and professionally) and on a day to day basis the work is carried out by two dedicated part time community development workers (one of whom has since resigned). The delivery of a project by a small, core group of people has advantages with regard to achieving consensus easily and enables decisions to be made quickly. However there are disadvantages with regard to sustainability for those leading the project, the pressures and demands of other areas of work and the risk of burn out within this small staff pool. Consideration was given to broadening the steering committee for this project to include the Head of Mission Development and a Psychologist from UL, with an interest in community development, however these changes did not occur during the pilot phase. This expansion is now required to ensure that the project is both sustainable and inclusive.

It is clear that at a senior level within the organization, Milford Care Centre supports and endorses the concept of health promoting palliative care and the development of Compassionate Communities, since funding has been allocated to the concept over the last two years and senior staff have been assigned to manage and support the work of the project. The project team has availed of the expertise as required from the core clinical areas as resources have been developed. The CCP would now benefit considerably from a commitment to the provision of three years funding to enable staff to focus on the work of the project and not as heavily on the evaluation and justification of their existence. A three year focus would potentially increase the commitment to partnership of other organisations, increase the likelihood of a planned approach to addressing the identified needs of the community and provide job security for staff to excel and develop within their roles. The funding provided is also required to cover ongoing CPD for the community development workers to attend networking events relevant to their role in the UK. Opportunities for funding should be explored from agencies such as The Irish Hospice Foundation, AllHPC and The Community Foundation of Ireland, Avelink and The Wheel should be joined to ensure that potential funding opportunities are not missed.

Milford Care Centre, as an organisation is also a community and it is important for the organisation to consider the degree to which staff working there are aware of the Compassionate Communities project and are themselves open and willing to discuss death, dying, loss and care. Whilst some interventions with staff have been tested e.g. Café Conversations / Bill's Table, there is no clear plan for the implementation of the project within the community of Milford Care Centre specifically. The community development workers noted that they did not spend any considerable time working with staff internally and the standards for HPPC in specialist palliative care units have not yet been implemented within the organization (Kellehear, [Bateman and Rumbold, 2003](#)). Experience from organising the 3rd International Conference and research conducted in the field has highlighted a lack of understanding amongst staff regarding the approach and also some fear associated with

open discussion regarding death, dying, loss and care. This is significant, given the nature of the work at Milford Care Centre and evidence that where staff are more comfortable regarding their own mortality, they are more likely to initiate conversations with patients and their families regarding end of life care preferences (McLoughlin, 2012). For those staff that have engaged with the project through the conference or through membership of working groups, there is anecdotal evidence to suggest that understanding and knowledge regarding the project has grown and conversations regarding death, dying, loss and care are taking place within the organisation and at a personal level within the staff members own community / family.

Consideration needs to be given to the staffing skill mix within the project team. In 2012 considerable time and effort was made to recruit two part time community development workers with complementary skills bases. In reality, the community development workers acknowledge that they were in fact quite similar, with strong skills and preferences for the community development, direct contact with people aspect of the role. Marketing, technology, use of media, design were areas that were not as strong within their repertoire of skills and yet these are vital skills needed within this project. These skills can be bought in, can be channeled from the community within which the project is based or can be sustainably embedded into the project through the recruitment of a dedicated project manager who may also have a role in evaluating the project and delivering educational components associated with the project.

Community development and community engagement can take considerable time as highlighted in the introduction and is recognized to occur at different levels. Most of the work to date has been focused on the informing or awareness raising level of engagement. This has involved the community development workers personally contacting and meeting representatives from key organizations, and has resulted in positive developments with regard to attendance at training, seed grant applications and other local initiatives. Such an approach is labour intensive and many contacts did not go beyond the sharing of facts about the project. The activities of the project demonstrate a clear tiered approach to participation (Figure 18) that corresponds with levels of engagement from a community development perspective. A PR / Marketing strategy focused on each level, which considers the recommendations for website, social media, leaflet and film development should support the on the ground work and maximize the reach of the project within the pilot areas.

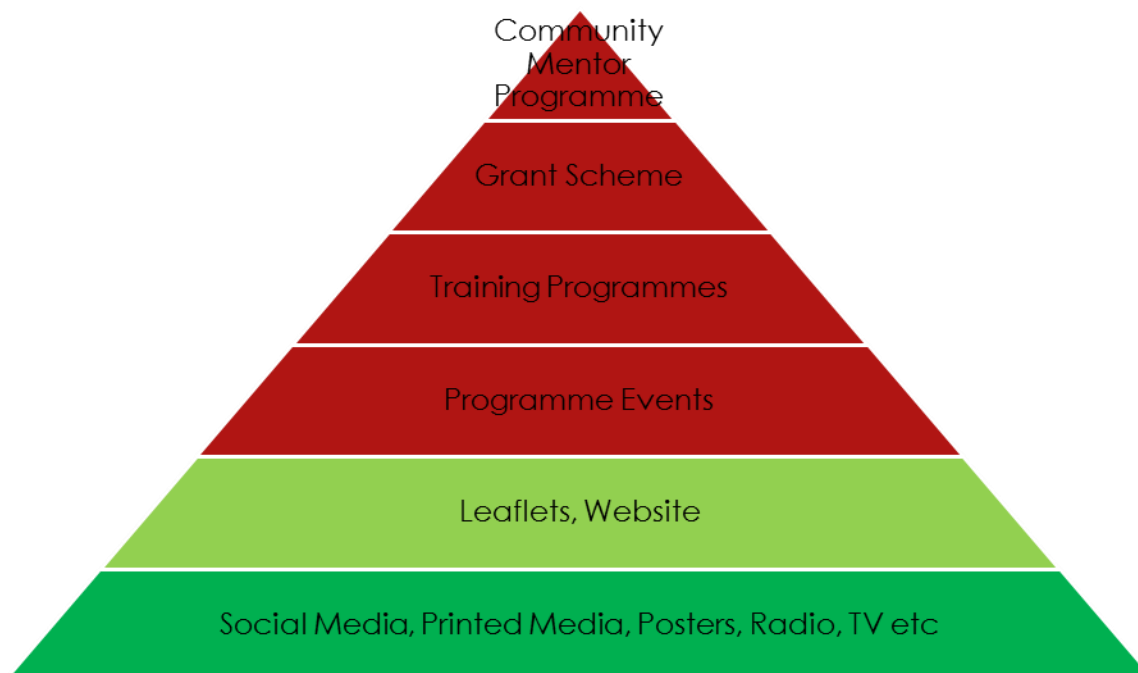


FIGURE18: TIERED APPROACH TO ENGAGEMENT

There are many structures and organisations in both regions, but particularly in Limerick City with a social inclusion focus. This is a reflection of the multi-faceted nature of social disadvantage as well as the diversity of needs at local level in Limerick City. It is also a reflection of the role and value of community development principles in addressing social exclusion, which recognise that people and communities who are experiencing social disadvantage are best placed to identify the causes and factors of that disadvantage and to develop appropriate responses. It is therefore important to continue to work in partnership with these groups to ensure that supports in respect of death, dying, loss and care are made accessible, that barriers to engagement with palliative care are reduced and that identified needs are responded to as they emerge.

Death, dying, loss and care is a complex area. Health promoting palliative care is difficult to define. It can be difficult to measure and evaluate outcomes and impact associated with new, developing concepts. However, through the pilot phases, the CCP is refining its approach and strategically, the CCP could benefit from direct alignment to a theoretical model that would underpin the rationale behind the strands of work undertaken. Kellehear's work, refers to an adaptation of the Ottawa Charter (Table 1) that could be utilised to frame the work streams with Milford Care Centre taking "*a population approach*" to issues relating to death, dying, loss and care that:

- Focuses on the health of the population
- Addresses the determinants of health and social wellbeing and their interaction
- Bases decisions on evidence
- Increases upstream investments
- Applies multiple strategies
- Collaborates across sectors and levels
- Employs mechanisms for public involvement (Nova Scotia Health Promotion and Protection, 2007)

Such an approach can centre on whole populations or sub-populations.

Recommendations

Following reflection on the findings of the evaluation and discussion with the CCP team, the following recommendations should be considered by Milford Care Centre and the project team for future action:

Project Governance, Funding, Staffing and Support

- Milford Care Centre commits to a 3-5 year funding model for the CCP.
- The Project Advisory Committee is expanded to include national / local stakeholders, with a range of skills and experience, meeting quarterly. The committee should include Professor Allan Kellehear and Dr Kathleen McLoughlin and invitations should be extended to senior representatives from the HSE's Population Health department, from a UL Department with expertise in business and marketing and from the Community Development sector. The Advisory Steering Committee should include both the external members and the CCP Project team (i.e. the MCC staff members) working with an inclusive and consultative structure.
- The Project Advisory Committee should explore mechanisms to obtain additional supplementary funding for the project over a three year period and consider involvement in development funding / research bids to agencies such as the AIHPC, the Irish Hospice Foundation, the Health Research Board and the Community Foundation of Ireland.
- The community development worker who resigned earlier in the year should be replaced and in doing so, consideration given to potential benefits of recruiting a project co-ordinator vs. recruitment of an additional 0.5 WTE Community Development Worker to increase the potential skill set available to the project team.
- A partnership approach between the CCP Project team and MCC's learning and development service should be developed and implemented in the delivery of the educational elements. The administrative

components associated with advertising, and evaluating the educational strands of the project are transferred to Milford Care Centre's learning and development service.

- The findings of this evaluation are disseminated widely at both national and international conferences and submitted to a peer reviewed academic journal to be considered for publication.

Focus of Work

- The three strand model adopted by the CCP provides a comprehensive framework for guiding the work of the project team and for the delivery of a varied range of Health Promoting Palliative Care initiatives within the designated project area. It is vitally important each of the three strands is given **equal weight** and that each is fully developed.
- The strands of the project are explicitly and directly aligned to the Ottawa Charter.
- The three strands of work from this phase of the pilot are adapted as recommended within this report and are continued with an extended focus as follows:
 - **Whole Population Approach**
 - Extend the project tools, resources and supports to the whole of the Mid-West.
 - Develop a PR / Marketing Strategy centred on the tiered products associated with the CCP and the Triple Call to Action, that includes a social media campaign
 - Revise the website and leaflets during their next update with the areas for improvement outlined in this report given due consideration.
 - Launch and roll out the series of short films.
 - **Engaging and Supporting Communities**
 - Extend the focus of engagement and support across the Mid-West, focusing on the development and organization, in association with community partners, of six major public events across the region within the first 12 months.
 - Engage the public / healthcare professionals with the CCP through linkages with other relevant national / international initiatives e.g. Think Ahead, What Matters to Me Training, Changing Minds, Conversations for Life.
 - Review educational inputs to ensure relevance across the life span and for groups working with death dying, loss and care in the broadest sense e.g. Vets, solicitors, funeral directors, florists etc.
 - Develop, deliver and evaluate the community death education programme.
 - Continue the links with teacher education and schools in the project area re: the development of training workshops for teachers and policy development within schools, linking with relevant national initiatives as appropriate.
 - Measure the impact of training workshops (based on the aims and objectives of the workshops), ideally using valid and reliable pre-existing measures.
 - Continue the seed grant scheme and make it available to applicants who commit to a project that impacts in the Mid-West. Ensure the scheme is widely advertised.
 - Consider the development of Milford Care Centre as a Compassionate Community, examining the use of the potential use of the standards for HPPC in specialist palliative care.
 - **Good Neighbour Scheme**
 - Devise / adopt an evaluation plan for the Good Neighbour Scheme.
 - Implement the Good Neighbour Scheme in Limerick City and Newcastle West for 12-18 months.
 - Depending on the evaluation, consider roll out across the Mid-West.
 - Consider the model proposed by [Abel \(2013\)](#) with regard to the phased development of personal community networks.

References

- Abel J, Walter T, Carey L, Rosenberg J, Noonan K, Horsfall D, Leonard R, Rumbold. B, Morris D. (2013). 'Circles of Care: Should community development redefine the practice of palliative care?' *BMJ Supportive & Palliative Care*. doi:10.1136/bmjspcare-2012-000359.
- Brereton, M. (2012). 'Report on the evaluation of Milford Care Centre's Compassionate Communities Project'. Milford Care Centre.
- Budd, J. and McCron. R. (1982). 'The role of the mass media in health education. Centre for mass communication research.' London: Health Education Council.
- Clarke, D. (2002). Between hope and acceptance: the medicalisation of dying. *British Medical Journal*, 324, 905.
- Conversations for Life (2013). <http://www.conversationsforlife.co.uk/>
- Conway, S. (2008) 'Public health and palliative care: principles into practice?' *Critical Public Health*, 18 (3), p 405-415.
- CSO (2006) Population statistics www.cso.ie
- CSO (2011) Population statistics www.cso.ie
- CSO (2012) Population statistics www.cso.ie
- Culhane, H. (2004) 'Groupwork with bereaved children'. *Bereavement Care*, 23 (2), p. 22-24.
- Donnelly, S. (1999). Folklore associated with dying in the west of Ireland. *Palliative Medicine*, 13(1), p.57-62.
- Donnelly, S. (2007). *Going Home*. A documentary produced by Sinead Donnelly, Ireland.
- Donnelly, S. (2010). 'Relatives' experience of the moment of death in a tertiary referral hospital.' *Mortality: Promoting the interdisciplinary study of death and dying*, 15, 1, p 81-100.
- Glasgow, R. E., Vogt, T. M. and Boles, S. M. (1999). 'Evaluating the public health impact of health promotion interventions: the RE-AIM framework'. *American Journal of Public Health*, 89, 9, p 1322-1327.
- Glasgow et al (2007) 'Applying the RE-AIM framework to assess the public health impact of policy change' *Annals of Behavioural Medicine*, 34 (2), p 105-114
- Horsfall D, Noonan K, Leonard R. Bringing our dying home: How caring for someone at end of life builds social capital and develops compassionate communities. *Health Sociology Review*. 2012;21(4):373-82.
- Horsfall D, Leonard R, Noonan K, Rosenberg J. Working together – apart: exploring the relationships between formal and informal care networks for people dying at home. *Progress in Palliative Care*. 2013. Doi10:1179/1743291X12Y.0000000047
- Irish Hospice Foundation – Final Journeys see www.hospicefoundation.ie
- Irish Hospice Foundation – Irish Childhood Bereavement Network see www.hospicefoundation.ie
- Irish Hospice Foundation – Think Ahead www.thinkahead.ie
- Irish Hospice Foundation – What Matters to Me see www.hospicefoundation.ie
- Kellehear, A. (1984). Are we a 'death denying' society? A sociological review. *Social Science and Medicine*, 18(9), 713-23.

- Kellehear, A. (1999). *Health Promoting Palliative Care*. Melbourne: OUP.
- Kellehear, A. (2004). Third-wave public health? Compassion, community and end of life care. *International Journal of Applied Psychoanalytic Studies*, 1 (4), 313-323.
- Kellehear, A. (2005). *Compassionate Cities: Public Health and End-of-Life Care*. London:Routledge.
- Kellehear, A., Bateman, G., and Rumbold, B. (2003). *Practice guidelines for health promoting palliative care*. Australia: La Trobe University.
- Kellehear, A. and O'Connor, D. (2008). 'Health-promoting palliative care: A practice example.' *Critical Public Health*, 18 (1) p. 111-115.
- Kellehear, A. and Young, B. (2007). Chapter in *Resilience in Palliative Care: Achievement in Adversity* (2007). Edited by Barbara Monroe, David Olivier
- Kumar, S. (2007). 'Kerala, India: A Regional Community-Based Palliative Care Model' *Journal of Pain and Symptom Management*, 22, (5), p. 623–627.
- Lewis, H. (2006). New trends in Community Development. University of Ulster. http://www.incore.ulst.ac.uk/policy/ilip/New_Trends_Com_Dev.pdf
- McLoughlin, K. (2012). *Identifying and changing attitudes toward palliative care: an exploratory study*. PhD thesis, National University of Ireland Maynooth.
- McLoughlin, K. (2013). Death of a Goldfish: Social Experience or Medical Event? EAPC Blog <http://eapcnet.wordpress.com/2013/06/17/death-of-a-goldfish-social-experience-or-medical-event/>
- McLoughlin, K., Rhatigan, J. and Richardson, M. (2010). Compassionate Communities Project Plan Development. Milford Care Centre, Ireland.
- Meecham, S. (2006). Prejudice undermines health promotion. *Nursing Standard*. 20 (27). P. 32-33.
- Miller, S. C. and Ryndes, T. (2005). Quality of life at the End of Life: The Public health Perspective. *Public Health and Aging*. Summer 2005. 41-47.
- Murray-Hall (2013). An Overview of Compassionate Communities in England. <http://www.amazon.com/An-Overview-Compassionate-Communities-England/dp/0954010132>
- NALA (2013) www.nala.ie
- Neimeyer, R. A., and van Burnt (1995) in Neimeyer, R. (1994). *Death Anxiety Handbook* (Ed). Taylor and Francis; Washington.
- Patton, D. Q. (2011). *Developmental Evaluation: Applying Complexity Concepts to Enhance Innovation and Use*. New York, NY: The Guilford Press.
- Paul Partnership (2010). *Strategic Plan 2011-2013*.
- Rao, J. K., Alongi, J., Anderson, L. A., Jenkins, L. Stokes, G. A. and Kane M. (2005) 'Development of Public Health Priorities for End-of-Life Initiatives,' *American Journal of Preventive Medicine*, 29, (5), p. 453-460.
- Richardson, J. (2002). Health promotion in palliative care: the patient's perception of therapeutic interaction with the palliative care nurse in the primary care setting. *Journal of Advanced Nursing*, 40: 432-440.
- Rosenberg, J.P. (2007). *A study of the integration of health promotion principles and practice in palliative care organisations*. Melbourne: QUT IHBI.

Scott, J. F. (1992). Palliative care education in Canada: Attacking fear, promoting health. *Journal of Palliative Care* 8(1), 47-53.

Underwood, J. (2013) <http://deathcafe.com/>

Wallack, L. and Dorfman, L. (1995). Putting Policy Into Health Communication. Available at [http://books.google.ie/books?hl=en&lr=&id=lf043QWsPwC&oi=fnd&pg=PA389&dq=Wallack+and+Dorfman+\(1995\)&ots=rrvNyUxqhi&sig=X2SVsklHBb2sWhk2XLR72Y2zXJU&redir_esc=y#v=onepage&q=Wallack%20and%20Dorfman%20\(1995\)&f=false](http://books.google.ie/books?hl=en&lr=&id=lf043QWsPwC&oi=fnd&pg=PA389&dq=Wallack+and+Dorfman+(1995)&ots=rrvNyUxqhi&sig=X2SVsklHBb2sWhk2XLR72Y2zXJU&redir_esc=y#v=onepage&q=Wallack%20and%20Dorfman%20(1995)&f=false)

World Health Organisation (1978). *The Declaration of Alma-Ata*. Geneva: WHO.

World Health Organisation (1986). *The Ottawa Charter for Health Promotion*. Geneva: WHO.

World Health Organisation (2002). *WHO Definition of palliative care*. Retrieved on 1st January 2011 from: <http://www.who.int/cancer/palliative/definition/en/>

Zimmermann, C. (2004). 'The denial of death thesis: a discourse analysis of the palliative care literature.' *Social Science and Medicine*, 59, 1769-1780.

Zimmermann, C. (2007). 'Death denial: obstacle or instrument for palliative care? An analysis of literature.' *Sociology of Health and Illness*, 29(2), 297-314.

Appendix A: List of Organisations Contacted: Limerick City

Type of Contact		
Community Area Based – St Munchins	St Munchin's FRC St Munchins Community Enterprise Centre Kileely resource Centre	These area-based community-owned and managed organisations provide a range of local services, supports, and facilities for individuals and groups. Most also develop and manage community enterprises which provide services and employment opportunities to local residents. They are managed by local volunteer Boards of Managements
Community Area Based - Southill	Southill Area Centre Southill Family Resource Centre Southill Community Dev Project 4 parks Forum (Umbrella Group) Southill Family Support Initiative Southill Clasp O'Malley Keyes Pk. Estate Management and Residents group	
Community Area Based - Moyross	Northstar Family Support Project Community Companions Sunflower Project	
Community Area Based – St Mary's	St Mary's Aid St Mary's Park FRC St Mary's Adult Ed.	
Community Area Based – Our Lady of Lourdes	Our Lady of Lourdes Community Services Group Bedford Row Family Project Caherdavin Community Centre	
Community Agencies / Services	LES Northside LES Le Cheile Paul Partnership Limerick Citizens Information Service Limerick Volunteers Network RAPID Limerick Youth Centre Limerick Social Services Sophia Housing Probation Services PALLS CSMT Ceim ar Cheim Doras Luimni IWA	There are 2 Family Resource Centres in Limerick City – St. Munchin's FRC based on the north side of the city, and Southill FRC based on the south side of the city. Working to community development principles, they aim to combat disadvantage by providing supports to families experiencing or at risk of social exclusion.
Bereavement / Suicide Services	Console Suicide Prevention Office Samaritans Regional Suicide Bereavement Healing Project Break the Cycle of Suicide	

Children's Services	CARI Barnardos (Southside) Barnardos (Northside)	
Health Services	End of Life Coordinator - MWRH A/Director of Public Health Nursing Children's Outreach Nurse, Life-limiting conditions Assistant Directors of Public Health Nursing St Camillus Hospital St Joseph's Hospital	
Health Centres	Ballynanty Health Centre Ballycummin Health Centre Bishop St. Health Centre Dooradoyle Health Centre King's Island Primary Care Centre Limerick City Health Centre Milford Castletroy Health Centre Moyross Health Centre Roxtown Health Centre Galvone Primary Care Team	
Pharmacies Throughout the City		
Travelling Community	Clare Programme for Healthcare for Travellers Irish Travellers Movement	
Emergency Services	Garda Defence Forces Fire Services	
Voluntary Services	SVP ICA/Farm Families Macra Limerick Local Heroes Lions Club	
Media	Limerick Leader I Love Limerick Live 95FM Irish Times, Health Section	
Churches (incl Parish Newsletters)	Christ the King Corpus Christi St John's St Mary's St Nicholas' Our Lady of the Rosary Pastoral Centre Christchurch - Methodist/Presbyterian Augustinian Church Church of Ireland St Munchin's Parish	
Sporting Organisations	GAA IRFU	
Libraries	Watchhouse Cross Library City Library County Library	

Residential Care Services for Older People	TLC Homecare and Healthcare Ltd. H.I.S.C. Sancta Maria Roseville Nursing Home St. Anthony's	
Bereavement / Cancer Support Groups	Raheen Bereavement Support Group Caherdavin Monaleen Cancer Support Group	
Retail Industry	Analog Devices Chamber of Commerce	
Individuals	13	
Politicians	1	
Education	Mary Immaculate College University of Limerick LIT Corpus Christi Primary School Southill Junior School Southill School Completion Programme Our Lady Queen of Peace N.S. Monaleen N.S Scoil Mhathair De Milford Grange N.S Caherdavin GNS St John's Girls NS St Patrick's NS Ard Scoil Mhuire Presentation Convent Crescent College Scoil Carmel Laurel Hill Secondary School Laurel Hill Colaiste St Clements Secondary School Castletroy College St Nesson's Community College St Munchin's Secondary School	

List of Organisations Contacted – Newcastlewest

Organisation	
STATUTORY	<p>Limerick County Arts Office Citizen Information Cara Medical Centre Dr. Loughnane Jasmine Unit-St Ita's Library Local Fine Gael TD Desmond College Secondary School Assistant Director of Public Health Nursing- NCW area SMI-Secondary School Mental Health Services Hospice at Home Team-NCW Health Promotion Officer-HSE Brothers Of Charity Well Woman Clinic Primary health care Clinic</p>
NON- STATUTORY/COMMUNITY	<p>West Limerick Resources Weekly Observer Desmond Complex Local Parish Foroige Limerick West FM Limerick Leader Irish Cancer Society-Volunteer Transport Scheme AbbeyFeale Heritage Project- Radio course Community Substance Misuse Team CSMT Limerick Live 95FM</p>
VOLUNTARY	<p>Chamber of Commerce Business Association Pallas Foods Ned Lynch's Pub Dooley's Pharmacy Marguerites Cafe Chamber of Commerce Business Association Pallas Foods Ned Lynch's Pub Dooley's Pharmacy</p>
LOCAL BUSINESSES	<p>Chamber of Commerce Business Association Pallas Foods Ned Lynch's Pub Dooley's Pharmacy Marguerites Cafe</p>

Appendix C: Website References to Compassionate Communities

<http://limericklocalheroes.com/limerick-is-first-irish-city-to-introduce-compassionate-communities-initiative>

<http://limericklocalheroes.com/cc>

<http://www.aiihpc.org/contact/59/useful-links/>

<http://www.mylocalnews.ie/articles/567/7/community-notes-1/compassionate-communities-ncw-film-club-45074/>

<http://www.limerickcity.ie/Library/WatchHouseCrossCommunityLibrary/CompassionateCommunities/>

<http://www.ilovelimerick.ie/tag/compassionate-communities/>

<http://research.pallcareni.net/sites/default/files/Marie%20Richardson%20compassionate%20communities.pdf>

<http://www.endoflife.ie/news/updates.aspx?article=c7bad497-697e-44e1-a7c1-9ebdbd269c98>

http://www.limerickdiocese.org/index.php?mact=Calendar,cntnt01,default,0&cntnt01event_id=544&cntnt01display=event&cntnt01lang=en_GB&cntnt01returnid=58&whatcat=%20%20%20%20%20%20Parish%20Ministry

https://www.facebook.com/permalink.php?id=274106285392&story_fbid=478365695551025

<http://kildimonews.blogspot.ie/2013/06/kildimo-community-notes-we-june-8-2013.html>

<http://spcare.bmj.com/content/early/2012/07/26/bmjspcare-2012-000311.full.pdf>

<http://www.healthuc.com/health-care/compassionate-communities-project-to-be-officially-launched-in-limerick-local-heroes-hub.html>

<http://www.limerickleader.ie/news/june-1-1-5134769>

<http://www.live95fm.ie/news/compassionate-communities-come-to-newcastle-west/83>

<http://ipu.ie/more-news/1347-limerick-pharmacists-urge-public-to-take-part-in-think-ahead-initiative.html>

<http://ipu.ie/more-news.html?start=36>

<http://thelimerickvibe.com/>

http://www.cari.ie/index.php/news_publications/detail/cari-commemorate-colleague-through-a-remembrance-area-in-the-garden-at-cari

<http://vimeo.com/54275894>

<http://ncwfilmclub.wordpress.com/2013/05/12/award-winning-film-amour-on-tuesday-21st-may-7-30pm-desmond-complex/>

<http://www.wlr.ie/supporting-children-through-bereavement/>

http://ec.europa.eu/education/adult/doc/confageing/keegan_en.pdf

<http://www.stmunchinsfric.ie/2012/07/a-community-response-to-loss-grief/>

<http://www.killeedy.com/news/38/Weekly%20Parish%20Notes%20June>

<http://www.rathkealeonline.ie/latestnews/Issue%20166.pdf>

<http://nmbi.newsweaver.ie/Newsletter/6btaq8okfne?a=1&p=30979465&t=19308765>

<http://www.hse.ie/2011annualreport/files/assets/seo/page79.html>

<http://www.moyvane.com/knockanurenates.php?notesid=315>

<http://bjsw.oxfordjournals.org/content/early/2013/05/29/bjsw.bct087.full>

<https://twitter.com/LmkLocalHeroes/status/271201588952043521>

Appendix D: List of Organisations Attending Training

Corpus Christi Moyross
Southill Area Centre
NCW Lions Club
Southill CDP
Jasmine Unit NCW
St Munchins FRC
St Marys
CASP / CSMT
West Limerick PHCP
BOC NCW
St Johns Hospital
Garda Siochana
Dept of Defence
Action Group NCW
HSE / IHF
MWRH
CARI Foundation
West Limerick Resource Centre
Brothers of Charity
Travellers Health Project
SVP
Foroige
Ballingarry Bereavement Support Group
St Anthony's Nursing Home
Nenagh Bereavement Support Group
Console
Christ Church, Limerick
LES
West Link
ICA
IFA
Roxtown Health Centre
IWA
Barnardos