

Merseyside and Cheshire Community Engagement Initiative

Interim Report for 2012

Background

In 2008's DH End of Life Care Strategy called death "the last great taboo in our society", and identified a "lack of openness and discussion about death and dying". It is to break this silence that the Dying Matters Coalition was first to say that talking about death doesn't bring death closer. It's about planning for life.

The North West Clinical Pathway Group (2008) identified as one of its 11 key recommendations

"A public campaign should be established to raise awareness about end of life care resulting in a more open conversation within society which also engages people's views about death and dying."

This recommendation was mirrored in the evaluation of the Merseyside and Cheshire Cancer Network(MCCN) Dying Matters Week in 2010

North West Multi - Professional Education and Training Levy (MPET) monies were identified to engage the public at the local level and build on the work of Dying Matters Coalition.

The next steps 2010/2011

In 2010 two meetings were held, which included Hospice Clinical Managers and End of Life Steering groups, to discuss how to develop and take this forward, regarding raising public awareness of issues related to End of Life such as advance care planning and death & dying.

The plan was to work with either the local Hospices or End of Life Care Locality Groups, with a named individual taking the lead in organising a number of community engagement events. Where both the Hospice and the End of Life Care Locality Group expressed an interest in taking the lead, the expectation is that there would be local discussion and consensus on who will lead, with one application made per area.

This approach had been given broad support across the Network, as it doesn't focus on just one period of time, such as the national dying matters week, but will be continued over weeks and months and will work beyond health services.

To support the Hospice/Locality Lead(s) the following was planned and delivered:

- Mary Matthiesen Director for Conversations for life held a workshop for all Hospice/Locality leads, explaining the concept of community engagement and how to go about identifying and engaging with up to 30 community leaders
- Mary, then held a one day event local to their area, with the Hospice/Locality lead and the community leaders which was followed up with a further half day session with the same group entitled “moving to action”, helped the group to plan what they did over the following weeks and months
- In addition to this facilitation each Hospice/Locality was given a small amount of monies to support their local action plan and there was also support from a media company, Mills Media, secured and funded through the Network to work in a bespoke way with each local team on community publications etc.
- In return MCCN asked that each Hospice/Locality Lead submit the plan they have for community engagement, with a progress report, including how funding has been committed part way through and at the end of the year

Progress to date

Since 2011, five areas have held community engagement events (Wirral, Southport, Aintree and Halton, Central and South Liverpool) in 2011 and Western Cheshire have planned their community engagement event for March 2012.

These events (appendix1) have been well received by the organisations involved The organisations are discussing the topic of death, dying and loss in their own communities and follow up meetings have occurred with them in autumn 2011 and planned also early 2012 to hear their progress and offer any help required

Feedback from leads re community engagement re death, dying and loss

Halton

- Presentations to local Women’s Institute
- (Local Involvement Networks) LINKS engagement and attended their meeting and talked about Advance Care Planning (ACP) –feedback 90% positive
- Involved with LINKS in a database to include Dying Matters materials
- Link with Council and Social Services
- Looking to have in 2012 a multi-cultural celebration to include Death, Dying and loss

Central and South Liverpool

- A Steering Group to oversee the project and to devise a 6 month Action plan -first meeting 2012
- The group want their own identity and name suggestions include “Live and Let Die group” or The “Do or Die group.” No definitive name has been chosen as yet
- Meetings are taking place with solicitors, funeral homes and others to design a Funeral Planning Party which will be open to the public and there is a

possible partnership opportunity with Sunflowers Cancer Support who are also looking to do something similar.

- Work is on-going with the media company to develop thought provoking posters to be displayed at key community hubs.
- A range of targeted and topical articles are also being developed.
- A survey has been devised which is designed to capture attitudes towards death and dying on an individual basis.
- The survey will soon be available to complete online via survey monkey in a partnership initiative with Wirral Voluntary Community Action.
- There is a potential of regional partnership opportunities as the draft survey has been sent to other members of the project across the Merseyside and Cheshire region
- Planning an Art Competition/Exhibition for March 2012 which will involve schools, youth groups, places of worship and community groups around the subject of death dying and loss.
- Meetings have begun to take place around organising a Cultural Open Day which will showcase how different cultures/religions celebrate/commemorate death and will inform, educate and hopefully entertain people.
- Initial meetings have taken place with the hope that the drama performance by a local youth group will take place between February and April 2012.
- A DVD will also be made and sent to community groups to use as a medium to start conversations
- Research has taken place to locate local Quiz nights in central and south Liverpool will soon be contacting the Quiz Masters to see if the Dying Matters quiz questions can be included in one of their quiz nights.
- Liverpool's community groups want a Directory of Services / signposting service to link people and groups together to raise the profile of existing services.

Aintree

- Small Steering group set up comprising of Woodlands Hospice staff, Salvation Army and Hospice Fundraising to ensure all relevant have dying matters materials
- The steering group is made up of members from four community organisations- The Salvation Army, Association of Funeral Directors, Feel-Good Factory and Woodlands Hospice have invited and encouraged others to join.
- The steering group are currently considering ways of getting the Dying Matters message into various community venues, libraries, GP practises, churches nursing homes, housing associations etc.(in addition to our own organisations) and our next meeting is focusing on the literature that is already available. The group had originally thought that as a group they might design their own information pack but on reflection most people thought they should (initially at least) use the Dying Matters literature rather than re-invent the wheel.
- The plan is to invite Mary Matthiesen on to facilitate a further workshop in March 2012 in order to maintain momentum.

Wirral

- Steering group set up that will act as a resource and public voice to the Wirral End of Life Care Steering Group as one of its objectives
- First meeting will be held in January 2012, name and logos suggested; Dying to Know, Wirral Community Network
- Commencing in Jan 2012 Advance Care Planning (ACP) Training for volunteers in conjunction with Wirral Hospice St Johns
- Information on services available to Wirral via an online information hub called Wirral Well
- Wirral Well to have section specific to Dying to know and to link with Conversations for life

Southport

- Queenscourt Hospice in Dec 2011 sent to each organisation involved in the community engagement events a Xmas card reminding them of what they agreed, action plan and to get feedback as a result of this
- Involve the organisations in Dying Matters week in May 2012
- Invited Sixth Forms in the area to take part in poetry, drama completion with schools get the different organisations to judge
- Meeting in February 2012 to plan May 2012 Dying Matters Week
- Organisations to attach Dying Matters Leaflet to their payslips
- Newly opened Macmillan Information Centre keen to get involved in Dying Matters Week in May 2012

Western Cheshire

- Involved in deciding with key people the way forward for 2012 and date set for March 2012 for community engagement event

Local MCCN media support

Mills Media have offered support to this initiative from graphic design, logos, posters and video, media contacts and exhibition products, banners, run events, installation stands

Evaluation of the initiative

There are four aspects to the evaluation of this initiative

1. The feedback pre and post community engagement events from the organisations who attended **by November 2011 and February 2012**
2. The feedback from the community engagements leads across MCCN **by September 2011**
3. Evaluating the process with organisations for sustainability in 2011/2012 thereafter by focus interviews or survey **by May 2012**
4. Interim report for Palliative and End of Life Care Clinical Network Group **November 2011** and Final Report **April 2012**

Key Findings of the initiative to date:

1. If the lead has a community role already makes the work within the organisations easier e.g. contacts, networks, previous projects etc.
2. Helpful to have community leads and contacts prior to setting up a community engagement event
3. Requires time and at least two dedicated people to lead this forward e.g. small dedicated project team
4. Value of using an independent experienced community engagement facilitator for the community engagement events
5. Important to have representatives from end of life care at the community engagement events, to support the emotional issues and questions that can arise from this topic
6. Everyone saw the events as very helpful and had a greater understanding of this topic than before they attended the events.
7. Organisations met who would normally never have the opportunity to meet or have knowledge of each other's existence
8. Willingness from community organisations to get involved

Examples of evaluation results from the community engagement events

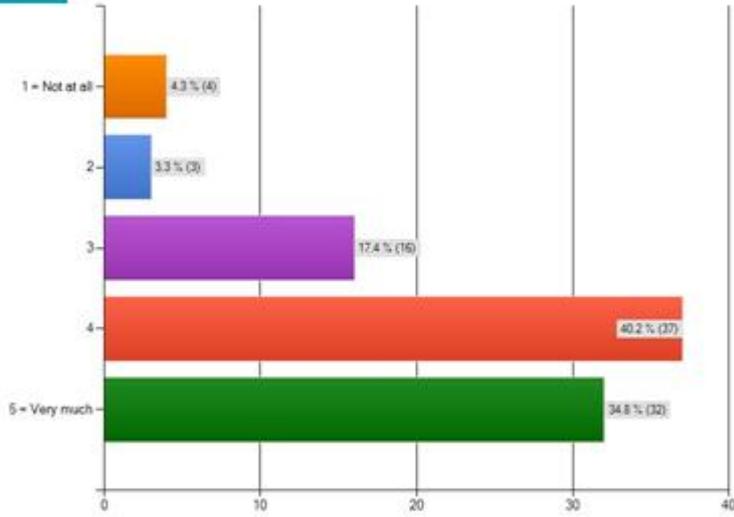


MCCN Communities Convened

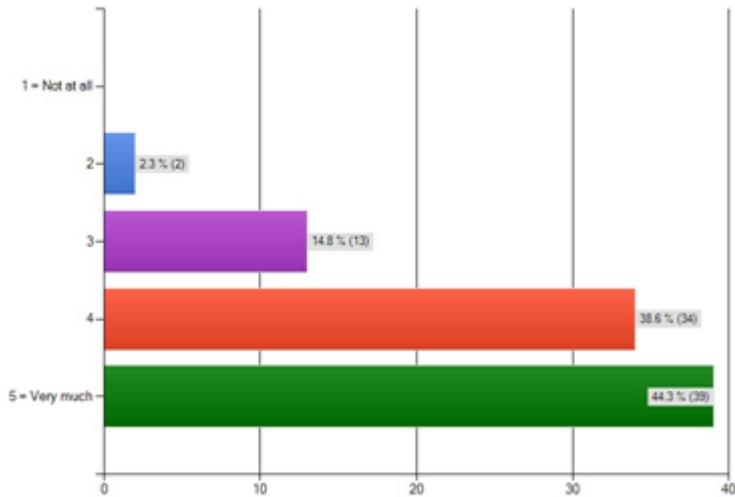
Lead Organisation	Registered Community Leaders*	Day of Event Attendees	Completed Evaluations
Halton Haven Hospice	57	44	21
Marie Curie Hospice, Liverpool	35	20	15
Woodlands Hospice	33	26	21
VCA Wirral	24	21	20
Queenscourt Hospice Southport	31	24	19
Total	180	135	96



Q5. Do you think these sessions will alter your conversations with others?



Q6. How likely are you to implement your new knowledge / skill (s) and speak to others following the session?



Sustainability of community engagement across Merseyside and Cheshire Clinical Networks (MCCN)

- It is important to be able to embed this initiative within current groups for it to be sustained
- At present the leads are looking with organisations as to how this can be achieved.
- Links with Local Involvement networks(LINKS) and Community Voluntary Services(CVS) where viewed as useful by the group
- National Council for Palliative Care(NCPC) Dying matters Coalition, link in with as an ongoing resource
- Link in with National End of Life Care Programme Lead Clare Henry to update on work (appendix 2)
- Important to link in with locality groups as to work of this initiative to date and ongoing support
- To keep meeting to share ideas

Summary

It is still early stages in this initiative, but the signs to date are very positive and this is due to the enthusiasm of the community engagement leads across Merseyside and Cheshire Clinical Networks and all the community organisations involved.

Next Steps

- Publicise the work of the initiative in National End of Life Care Newsletter and National Council for Palliative Care *Inside Palliative Care* in 2012
- MCCN to support the leads and continue to evaluate progress by May 2012
- Link the leads and the organisations involved in the initiative to date to Dying Matters Week in May 2012
- Meeting in February 2012 to plan May 2012 Dying Matters Week
- Build on sustainability plans

Appendix 1 –Sample of a Community Engagement Event agenda

RAISING AWARENESS IN RELATION TO DYING, DEATH AND LOSS A PARTNERSHIP PROJECT: MEETING 2

12.00pm - 4.30pm

Tuesday 5th July 2011

Karalius Suite, Stobart Stadium, Widnes, WA8 7DZ

Purpose: Moving from Momentum to Implementation

“Through community engagement, we will raise awareness that death and loss are a natural part of the human condition, and thereby leading to a greater ability to speak more openly about them and with those affected.”

Goals:

- To recap our 2nd June meeting.
- To identify key areas for short-term and long-term focus.
- To begin to link areas of interest with tangible implantation steps.

12.00-12.30	Light Lunch, TEA / COFFEE
12.30-1.30: PART 1	Recap Summary of 2nd June Meeting
Welcome	Bernie Thomas - End of Life Care Facilitator Halton/St Helens
Introductions & Vision	Bernie Thomas - End of Life Care Facilitator Halton/St Helens
Overview of the Day	Mary Matthiesen
Recap of 2nd June Meeting	Mary Matthiesen
	<ul style="list-style-type: none">• Draft Raising Awareness Messages• Defined Opportunities of Raising Awareness• Draft Community Engagement Plan/Goals
1.30-1.45	TEA / COFFEE
1.45-3.30: PART 2	“HOW DO WE USE WHAT WE’VE GOT TO GET WHERE WE’RE GOING?” Beginning to Define Tangible Forms Self-Selected Table and Group Discussions
3.30-4.30	GROUP FEEDBACK AND NEXT STEP

Please could you register your interest in attending this EVENT, giving your name, contact number and email address by contacting Debbie Ryan as follows:

Appendix 2

Overview of Death, dying and loss initiatives across England

National Work across the country is happening around death, dying and loss
Locally the leads are utilizing the services of Mills Media either collectively or individually as appropriate

Research

In the North East a piece of research on this project to create a compassionate community approach to death and dying is underway completes December 2011

Teesside is the first area in the country to implement the plan to use public health approaches to transform end of life services.

The Compassionate Communities project was developed following the North East's 25 year public health strategy Better Health, Fairer Health, published in 2008.

Strategic – A 3 year Macmillan funded work with St Luke's Hospice and public health commenced in 2011 and the aim of which was to develop a new and innovative **End of Life Public Health Service** to support a change in public knowledge, attitude and behaviour towards dying, death and bereavement and through this make living and dying well the norm

Grass roots

MCCN Community Engagement Initiative on death, dying and loss is being delivered within the local communities within the present community organisations established.

Each three approaches of research, strategic and grass roots complement each other