

‘PLACE OF DYING’ AND END OF LIFE SUMMARY OF SHALLOW DIVE STUDY

FINAL REPORT - January 2015

1. Introduction and background:

The management of **dying patients** was raised as a topic at the May 2014 meeting of the Healthwatch Cornwall Steering Group, where it was pointed out that the majority of people prefer to die at home but in reality the majority die in hospital.

The National Survey of Bereaved People (VOICES) undertaken by ONS in 2013 concluded that only half of people (50%) who express a preference to die at home, actually die at home.

The Royal College of Physicians recently completed a care of dying patients audit across the country. 90% of all main hospital trusts took part Royal Cornwall Hospital Trust did not participate in this study.

The following table summarises the data recorded for Kernow Clinical Commissioning Group (CCG) regarding where people die in Cornwall. Figures suggest that Cornwall compares favourably regarding the number of people who die at home. However data is not available as to the percentage of people who are making the choice to die at home.

Place of dying	% Cornwall	% England
Home	23.88%	21.54%
Hospital	44.88%	50.71%
Nursing Home	23.61%	19.59%
Hospice	4.89%	5.59%
Other	2.4%	2.12%

Source: ONS by Public Health England - data for 2010 - 2012

The Steering Group commissioned a short study that would aim to capture people’s experiences and views on the topic in order to inform a fuller discussion by the Group.

Objectives

- To undertake a ‘shallow dive’ insight gathering exercise to capture people’s **experiences and views** on end of life and specifically on the subject of place of dying.

- To conduct up to 16 in-depth interviews with recently bereaved people or families to explore their recollections and experiences of a loved one dying.
- To design and use a Topic Guide to support the conversations.

This short report summarises the experiences and insights shared during the study and the recommendations arising.

2. Recommendations:

1. With multi agency partners develop a clear information pack, or packs, on end of life pathway, planning, choices and support available.
2. Consider plain English and speaking in this pack and any forms used by care professionals. For instance in discussing end of life planning, use the word 'death'.
3. Share insights and experiences from report at a meeting with commissioners, with a view to consider gaps in services and potential issues in services such as the advantage of evening carers or assisted living technologies for care such as lifeline or other. Consider the problem of emergency services transporting people to hospital to die, instead of support being provided at home.
4. Identify the gaps in skills and confidence that front line workers from multiple providers face that prevent them offering support with end of life planning. Seek innovative ways of providing **training and building confidence**.
5. Find opportunities to encourage people to talk about end of life planning and dying. This could include continuing with the **Death Talk - Death Café** sessions around the County.

3. Study methods and approach:

Activmob methodology:

Activmob has been recognised for developing and deploying a successful product methodology called '**Insight 2 Action**', and has a proven track record of using the methodology on a number of projects in the past five years.

The approach has been recognised and awarded for its effectiveness in implementing social marketing techniques.

Insight2Action is a grounded theory based on an inductive approach. This involves a qualitative study; often called a ‘shallow dive’ to identify the key issues that can then set the topics for a future deeper study.

The full approach follows six **Steps** as follows:

Steps	Typical Activity
Preparation	Desk research, local mapping and familiarisation, preparation of engagement plan and Topic Guide
Shallow Dive	Informal conversations in formal and informal places to capture a base line picture of the topic or locality
Coding & Analysis	Concepts and themes begin to emerge from coding the insights. These generate hypothesis, which are statements on what defines the community or topic. A short insight report is produced summarising learning and making recommendations for further study.
Deep Dive & Testing	Conducted over a longer period of time and would normally include spending a significant amount of time with the target groups to test the hypothesis
Analysis & Theory	Data is coded with new information from the Deep Dive to test whether given the new insights from the Deep Dive, the earlier hypothesis still stand?
Study report	The final report documents the substantive theory that can only emerge from an inductive study - information drawn from the community itself. The report documents the evidence from both the Shallow and Deep Dives and the hypotheses that emerged and were subsequently tested.

The Approach for this study:

This study used the **first three steps** as highlighted in the table above.

Preparatory work:

In preparation for speaking to people for this study considerable care and thought needed to go into the design, content and language of the Topic Guide and the most appropriate channels for reaching people to speak to. A short briefing sheet was also produced to provide information to potential participants providing some information on the study, what would be involved and how people’s views would be recorded and held anonymously.

A small element of desk research was also undertaken to provide some background to the topic.

Shallow Dive - Engagement:

Using the Topic Guide (see appendix 1), informal conversations were held in a variety of locations and others via telephone interviews as preferred by the interviewee. Group conversations were also undertaken.

Experiences and insights were captured anonymously either during or after the conversations.

Coding and analysis

The data from all conversations were reviewed, coded and themed to provide the commentary and evidence in this paper. A presentation of the insights was prepared and presented at the Steering Group meeting in November 2014.

4. Who we spoke to:

In line with conducting a qualitative study, which needed to involve a **small number** of people several methods and channels were used to invite people to participate. These included:

- Healthwatch Cornwall general ‘call to action’ for people to participate and share their story via social media, newsletter and website.
- Contact made by Activmob with a number of organisations who work with people in a palliative care setting or work families and carers to encourage individuals to participate.
- Contact made with small informal groups where people naturally come together to invite them to participate.

Unlike any other study, we quickly discovered that **everyone, whether a professional, front line worker or individual had a story or experience to tell.** These informal conversations added richness and enabled some of the early insights to be tested.

One on One interviews	7 women (25 - 80 +)	3 men (45 - 70)
Group discussions	15 women (30 plus)	10 men (30 plus)
Informal conversations	15 all ages	10 all ages
Totals	47	33

5. Insights and Experiences:

The following section of this report details the insights and experiences shared with us during this study. The sub headings reflect the **key themes** that emerged from the analysis of the conversations.

End of Life General Insights:

Big Picture:

When talking to people about their experiences of someone close to them dying or speaking to others about their own thoughts and planning for end of life it became very clear that the element of where someone dies must be considered as part of a much bigger picture of end of life.

Many factors impact on where people die. People’s choices on ‘where’ are influenced by things such as the illness they are suffering, where they live, support they have, and the way they may die and pain management.

Timing:

Throughout this study the importance of **timing** and in particular knowing the right time to have a conversation about place of death was paramount.

‘they didn’t speak to my sister until there was nothing else they could do for her - then she wanted to talk and was very clear about what she wanted and why - she said she wanted to die in hospital because that is where she would feel safe’

The meaning of home:

As we gained a deeper understanding from people a range of views emerged as to what each of us mean by ‘home’. Traditionally someone choosing to die at home we would interpret as the house / home you live in. However a variety of other aspects of what home means were mentioned including; the people, animals, garden, smells, temperature and things. Examples were shared where some of these aspects of home were brought to the person in their final days.

The meaning of home for people who are homeless or sofa surfing was raised as something that should be explored further.

Others had very specific reasons for choosing to die at home:

“I want to die at home because I built this house”

Health inequalities:

Choices people have regarding end of life including where you want to die highlight some serious health inequalities for some people. A number of examples emerged of barriers to choices around end of life. These included:

Where you live and the type of home you have. Some people do not have a home; others live in unsuitable housing for dying at home, lack of carers available, transport and proximity to hospitals.

Mental Health - and some other conditions where people may not have capacity reduce people’s choices.

Young People:

While this study did not speak to young people or children, everyone who participated felt instinctively that certain additional considerations needed to be in place. People felt that it was **more important** for young people and children to die at home.

“It has to be different for children and young people”

People also suggested that as parents, going through the pain of caring for a child they would find a way of keeping them at home. Suggestions were made that the practicalities of caring for a child could be easier to manage:

“Physically we could manage looking after our young son at home, we could move him to keep him comfortable and clean ourselves”

End of life a Pathway

“Dying is the only thing we are certain of ... but there is no clear pathway or journey to prepare us - it always seems to be a surprise”

From analysing the experiences and insights from those who participated, a form of **pathway of key stages** emerged. In an additional step to the study, we were able

to share this 'pathway' with a number of people to test our analysis. Everyone involved in this testing confirmed that the 'pathway' made sense.

Stage 1 - BEFORE YOU KNOW:

This was identified as the stage when someone may have a life limiting illness or living with a long term condition fairly well.

People suggested that at this stage, the focus is on treatments, options, pain and tests and no one talks about choices, expectations and preparing for end of life. Concerns other than place of dying are beginning to be important such as how the condition or illness could impact on family.

At this stage people in general are unprepared and have no information on '*what might happen and how it might happen*' - the only experience people could draw on was what may have happened to someone else when they died.

"My Dad died in a full ward in hospital, with people dying and horrible, horrible noises and suffering.... I don't want that for me or any of my family"

Stage 2 - TRIGGERS:

The majority of the conversations revealed a common stage where something happens or changes that triggers us to think about choices and planning for end of life and in particular where we want to be cared for at the end of our life.

Typical triggers mentioned include a step change in a condition or a worsening in symptoms and / or pain and the realisation that these would not improve again. Others highlighted the point when they noticed that their family or carers were struggling to manage.

"I won't be seeing any improvement now - physically its downhill and I need help"

"I don't want to be a burden. I can see my family are struggling to cope"

"Dignity and self-respect"

People highlighted that in their experience, professionals are not tending to have conversations around end of life at this stage and yet it was suggested that this could be the right time.

With regard to children and young people it was suggested that these triggers did not really apply in these circumstances. People generally felt again that it is different and even with these triggers you would want to continue '*tying*' looking for alternative treatments. It would not be the right time to start thinking about end of life.

Stage 3 - Panic and Chaos:

Once there is a realisation that a person is in need of much more care or palliative care as they may be approaching their end of life a whole chain of activity takes place. The term panic and chaos is suggested as this is how people describe this time where the appropriate care is being put in place especially with a view to people **remaining at home** where possible.

Arranging for someone to be discharged from hospital to either their home or nursing care is a job that requires a great deal of paperwork, phone calls and

conversations across a multitude of agencies. There are clear protocols to follow with professional staff dedicated to the activity. Sometimes getting suitable arrangements in place can take longer than planned which can lead to people remaining in hospital longer or dying in hospital.

Family and carers are left not knowing what to do, not aware of what is available or what to expect or how sort things out for the best. Often families are at a loss to know what the person actually wants because the conversations are likely not to have been had. Family living away and complex relationships can lead to fraught times. For people living on their own, this can be a very distressful time to make appropriate arrangements.

Amongst this period of chaos, the person who is needing the arrangements to be put in place is likely to have limited energy and a desire to start handing their over their affairs to others. The last thing they want to spend time on is completing forms and paperwork.

In general it is at this point that some professionals will be having conversations with patients about their future care. The NHS use a recently updated booklet called **Planning for your Future Care - A Guide**.

*“People have a lack of energy to deal with these things and assume what they have requested will happen... they don’t want to be filling in paperwork”
(Professional)*

Stage 4 - Care at Home:

Cornwall has two hospices and a number of teams providing community based palliative care via the Palliative Care Nursing Team. There is a very clear set of criteria for people to be referred to these services. The Palliative Care Nursing Teams achieve a much higher percentage of people dying at home if these are their wishes than those not on their caseload. Families spoke very highly of these services and suggested ‘*you would need to be very lucky*’ to receive their support.

People spoken to regarding the reality of caring for a loved one at home highlighted the following points:

Dying at home requires you have a strong family and **network** of friends to cover 24/7 care. Others suggested that your family would need to become experts in understanding the system and support available.

“... plus you have to work hard to build good relationships with professionals to be there when you need them’ and ‘you need a routine and checklists to cope”

There are a great number of **challenges** to be dealt with when supporting someone to die at home. People spoke of the reality of caring of someone who is dying, the fear and responsibility of making sure ‘*you are you doing the right thing*’. Being able to deal with rapid changes and for other dealing with the guilt of how you may have dealt with things on occasions.

“I feel guilty that I used to shout at Dad because he wouldn’t take his tablets or eat”

For the people and families involved in this study, they felt that whilst caring for someone at home during their last weeks or days, the default position for additional support was hospital rather than their GP.

Reasons for people not dying at home:

Through conversations with people both individually and in groups a number of key factors were identified as to why people, who either had expressed a wish to die at home or family believed this is what they would have wanted died elsewhere.

Lack of end of life pathway and information

People are not aware of a pathway through which information on support and choices are clearly accessible that they could use to help plan. There is almost a 'romantic view' amongst people and families that '*it will be alright*' and assumptions are made about what will be available at the time.

People do change their minds through reasons such as fear, pain and dignity. People want to die at home as long as they can see that their family and carers can cope.

Information and a clear pathway for end of life should support this and be a responsive and flexible system.

Support for dying at home

People (including professionals) said that there is not enough nursing and carer support across the county. In particular staff and families struggle to find carers who can support someone to be at home with a lack of night sitters being available at short notice.

Others suggested that for a person and their family to be at home overnight without any support is a very long time and called for establishing an early evening round by nurses to settle people down for the night. It was suggested that this could potentially reduce the number of carers who would contact emergency services during the night.

The complexity of ensuring everything is in place for someone to be cared for at home can mean families either managing without appropriate equipment or support or people remaining in hospital and dying.

Evenings and out of hours

Many people's experience at the start of this study suggested that the 'system' and in particular out of hours is taking people to hospital from home when they are dying in line with emergency services role to preserve life. Several people recounted experiences of their loved ones being treated at home and in the ambulance and dying in A&E due to the paperwork not being fully in place. This included Expected Death Forms and Do Not Resuscitate.

"I have the forms somewhere, but I know it will be alright"

Isolation and Inequalities

A lack of family and social networks, rural locations, poverty and poor housing can all reduce people's choices over where they die.

Finally there were suggestions made by some that receiving a late diagnosis or even a misdiagnosis could affect someone's choices.

6. Cornwall -Local Policies and Strategies:

The following information is currently available to local people about end of life and planning.

Royal Cornwall Hospital Trust have a strategy that is underpinned by the following statements:

- Support end of life care out of hospital settings to reduce unnecessary admissions and support people dying in the setting of their choice.
- Comprehensive guidelines for professionals
- Develop a more generalist palliative care service working closely with local hospices and Macmillan services.
- A flow chart outlining emergency discharge from hospital for someone to return home has been produced and shows how services are working together.

Kernow CCG has the following commitment regarding patients living with dementia:

- End of life planning / care pathways prevent unnecessary admission to acute care and enhance the delivery of palliative care for this client group in the care home setting.

NHS Community Health Services are a resource for health care professionals in all community care settings in Cornwall to access expert support for patients facing a life threatening condition irrespective of diagnosis, in particular for:

- Management and monitoring of persistent symptoms.
- Management of complex emotional/psychological issues.
- Management of complex social/family issues.
- End of life care.
- Advice on the above aspects of palliative care
- Health professional palliative care education and training

There is a clear referral pathway for GPs or healthcare professionals to use.

The team provide their patients with the Planning for your Future Care and will aim to use their Preferred Priorities for Care (PCC) document to conduct a conversation with patients. This is a non legal binding document to represent someone's future hopes and wishes.

Appendices:

A - Activmob Topic Guide (used for conversations)

B - Presentation of Insights

