



Public Health
England



**Public Perceptions and Experiences of
Community-Based End of Life Care Initiatives:
A Qualitative Research Report**

Prepared for Public Health England by Solutions Research

June 2016

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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1. Foreword

This report is intended for commissioners of end of life care services, to support new ways of commissioning through using public health approaches to build compassionate communities.

To date, there is little published research into the public's experience and appetite for this approach to end of life care in England. PHE therefore commissioned this qualitative research study to gain insight into the public's awareness, perceptions and experiences of community end of life care initiatives. The research focuses on subjective views and personal experience, to provide a snapshot of public opinion, in order to meet the need for in-depth research rather than quantitative (statistical) research.

As with all qualitative research, the findings are not scientific and cannot be considered fully representative of the wider population. The research does not provide detailed analysis on any particular intervention or provide comment on the quality of documented evidence. It is intended to build on the baseline assessment of existing public health approaches to end of life care across England commissioned in 2015, and further underpin the Public Health Approaches to End of Life Care Toolkit¹ published by Public Health England and the National Council for Palliative Care.

This work has focused on the user experience so has included interviews with people with a life limiting illness, informal carers/influencers and people who have been bereaved. The main findings of this research, which indicate strengths and barriers to this approach from a public perspective, are crucial to informing support required to build community capacity and ensuring that commissioner services are better placed to meet the identified gaps.

Solutions Strategy Research Facilitation Ltd (Solutions Research) has undertaken this qualitative research on behalf of PHE. Solutions Research is a commercial market research agency with experience and expertise across private, public and third sector organisations in the UK.

Dying and death do not happen in isolation from the rest of life. The circumstances of death differ among the population, and affect not just the person who is dying but also those close to them. The impact of a single death affects a wider network of carers, family, friends, employers and communities, and has a direct impact on population health.

¹http://www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf

Care for one another at times of crisis and loss is not a task only for health and social care services. The most protracted part of end of life care depends on care outside professional settings, and it is vital that family, friends and community are involved in developing holistic, community led responses.

The key elements of a public health approach, including community development and engagement, health promotion and education, are relatively new to end of life care, but have much to offer in creating compassionate communities and promoting the wellbeing of dying, caring, and bereaved people.

“This report (commissioned by PHE) is relevant to all of us. Sooner or later we will all encounter terminal illness and death among those close to us and one day need to face our own mortality. This report gives important insights into how both patients with a terminal illness and family members caring for them perceive the practical and emotional challenges.

“It particularly examines the role of community approaches to end of life and how this impacts on families’ caring experiences.

“Importantly, the report explains the role reversal experienced by adult children caring for their terminally ill parents. It eloquently describes the challenges faced by what is now referred to as the ‘sandwich generation’ – adults who care for their ageing parents and sometimes their own younger families too.

This report is an essential read for everyone both as individuals and for policy makers considering the role of community in the provision of end of life care”.

Professor Julia Verne BSc, MBBS, MSc, PhD, FFPH
Clinical lead, National End of Life Care Intelligence Network
Public Health England

2. Glossary of terms

This glossary defines and explains some of the words and terms used in this report.

Community approach to end of life

The public health approach to end of life care is concerned with social efforts led by a coalition of initiatives from governments, their state institutions, and communities, often in partnerships with health and other social care organisations, to improve health in the face of life-threatening/limiting illnesses, care giving and bereavement. These efforts occur through public education, improvement of social capital (trust, empathy and cooperation) and community development, enactment of laws, partnerships with health services and their professionals, and the creation of safe and sustainable social and physical environments.

Compassionate communities

Compassionate communities represent a major form of community development efforts that aims to accommodate death, dying, loss and care into our public health ideas, and to create supportive environments for those experiences. Educational institutions, workplaces, faith organisations, trade unions and other social organisations and settings reflect upon their own end of life care experiences in order to develop their own local policies and responses to these experiences. Compassionate communities can be outcomes of multiple processes, negotiations and partnerships, but mainly involve community practice efforts initiated by healthcare services, sometimes enacted by governments but implemented and decided upon by communities themselves. Compassionate communities involve policies created by communities themselves in order to actively involve citizens in their own end of life care concerns. In doing so they change social environments, cultures, conduct, and attitudes towards end of life experiences and care.

End of life care

Current end of life care is commonly direct service care with palliative care being the dominant provider. End of life care services prioritise certain needs to the exclusion of early care and certain life-threatening/limiting illnesses experienced in community settings (eg dementia care). Social problems associated with experiences of death, dying, loss and caring need to be considered within the contexts in which they arise. This means that end of life care needs community partners, initiatives and contributions.

Qualitative research

Qualitative research is defined as marketing and social research conducted whereby: the basic methodology involves techniques which seek to reach understanding through observation, dialogue and evocation, rather than measurement, and where the data collection process involves open-ended, non-directive techniques (not structured questionnaires), and where the data analysis output is descriptive and not statistical.

Palliative care

Palliative care offered as direct service provision in clinical sites by professionals accepts death as the outcome of terminal illness, and recognises the futility of clinical interventions aimed at cure.

Terminal illness

Terminal illness is a disease that cannot be cured or adequately treated and that is reasonably expected to result in the death of the patient within a short period of time. This term is more commonly used for progressive diseases such as cancer or advanced heart disease than for trauma.

3. Executive summary

Background

A public health approach to end of life focuses on community development and the partnerships between healthcare services and communities in recognition that death, dying, loss and care take place in everyday life within families and communities. However, to date, there has been little research into the general public's understanding and awareness of this approach to end of life care, or of the public's experience and appetite for it.

PHE commissioned Solutions Strategy Research Facilitation Ltd to help it respond to research needs relating to end of life care awareness and understanding among the general public.

The key objectives of the research were to understand the following:

- the awareness and knowledge of community end of life care across a number of key audiences
- their perceptions of community end of life care
- their experiences of end of life care and any community initiatives
- any improvements that could be made to community end of life care

Methodology and sample

The project was split into two phases. The scoping phase involved a rapid review of literature, interviews with key stakeholders and attendance at the launch of Dying Well Community Charter events.

The research phase involved qualitative fieldwork as follows:

- four quad groups with adult children influencers whose parents had been diagnosed with dementia or a terminal illness
- three paired depths with people with a terminal illness and their informal carer
- eight depth interviews and two paired depths with informal carers of people who had dementia or a terminal illness
- four quad groups and five paired depth interviews with bereaved informal carers whose friend or family member had died either with dementia or from a terminal illness
- nine depth interviews with informal carers of people who either had, or had died with dementia or a terminal illness

Key findings

Audience context

The end of life is undoubtedly a sensitive and complex time, with everyone's experience being different. An individual's journey through this stage is affected by many things including their age and whether they have a condition that is recognised as a terminal illness or a condition such as dementia, which is not necessarily perceived as terminal. Conversations about end of life therefore can seem out of context for people with dementia, as the focus is on living (well) with dementia, rather than on dying. Dementia can therefore feel qualitatively different to terminal illness, and any community-based end of life approach must take this into account.

Central to the public's perception of a public health approach to end of life is their response to the concept of community more generally and an individual's ability to identify with a community feels likely to have an impact on their willingness to engage in community end of life initiatives. The concept of 'my local community' varied widely among respondents and each definition was highly dependent on the individual. Some respondents reported feeling part of their local community, but others did not and those who do not may find it more challenging to see their local community as a natural resource, even if they may welcome broader support.

Carers of people with terminal illness

The relationship seen between terminally ill people and their informal carers is compassionate, caring and conscientious, but also pragmatic and accepting that the end of life is approaching. Terminally ill people rely heavily on their carers for holistic care and support at all levels, including practical help, some physical care and emotional support.

It could feel challenging for carers to pre-empt and anticipate the needs of the person they were caring for. For most, this was the first time they had gone through this and they typically managed and responded to the immediate day to day needs of the person, rather than reflecting on the process.

A key area of difficulty for carers is not just attending to their own needs, but even in recognising that they have needs beyond getting through each day. Their lives feel consumed by caring for their loved one and their concerns are focused on the other person's needs, not their own.

There is general recognition that conversations and relationships are helped if there is an opportunity for frank and honest discussion about the future and end of life planning, although this can be very hard to do.

Carers of people with dementia

Much of the above can also apply to those who care for people with dementia, but with some added challenges.

The condition can be challenging to manage and carers may have had no opportunity to talk to others and access help. The gradual progression of the disease means that adjustments are made on an ongoing basis and it can take some time to recognise how debilitated a person with dementia may have become over time. Examples suggest that carers want their loved one to live and manage on their own for as long as possible.

Dementia as an illness is less certain than a terminal diagnosis. It is unpredictable – the symptoms do not follow a set pattern, and it may last for years or even decades. Carers often do not conceptualise dementia as a ‘terminal illness’; the focus can consequently be less on death/dying and more on living with dementia. This can mean that it takes a long time for carers to recognise that they need help, and what type of help this should be.

A number of barriers to accessing support can also present when someone has dementia compared with caring for someone with terminal illness. The unpredictable nature of the illness can make it harder to put care in place as carers are unsure what will be needed on a given day. Additionally, the illness is invisible from the outside and there can be a stigma attached to the diagnosis, so patients sometimes isolate themselves by preference. The illness can also make people behave strangely, which can impact on their ability to carry out normal everyday interactions.

Other factors can also cause the carer extra stress. Change can be difficult for a person with dementia, who can be very dependent on routine and they can suffer from unpredictable mood swings, often happening very quickly.

The bereaved

After bereavement, carers demonstrated some emotional distance which can aid perspective, including the ability to reflect back over the whole end of life journey and experience.

They are consequently able to consider what support made the biggest difference to them and their loved one at different stages of the end of life journey and to recognise the importance of having difficult conversations before death.

They highlight the changing role of a carer after the death of a family member and how death not only represents the loss of a family member, but can represent the loss of an identity and purpose.

Conversations about end of life

Raising the topic of end of life and last wishes is acknowledged to be difficult across audiences, and the taboo surrounding discussing death is evident. There is however some recognition that there is value in addressing this taboo at a societal level, and also a sense that this is gradually changing.

For terminally ill people and their carers, the benefits of encouraging conversations about end of life earlier in their journey can be appreciated. However, in reality it feels highly challenging for either a carer or a person with a condition to raise the topic, so in practice it is often reported to be avoided.

Early conversations when the patient has insight and full capacity are seen as ideal, but these can seem premature and be painful to introduce, particularly when the patient has dementia which is not often conceptualised as terminal. However, although the topic feels easier to raise when a person is in the later stages of the condition, if their cognitive capacity has been compromised, then the conversation may be less meaningful. For people with dementia, timing is therefore seen to be particularly key.

Expectations of care

When respondents consider the different types of care for life-limiting and terminal conditions or dementia they tend to focus initially on support offered by or signposted by the medical profession. The NHS is positively seen as providing medical care, and is not usually expected to provide non-medical support (emotional support, practical support etc.) although signposting to these is expected from the NHS.

Currently however, community initiatives can feel poorly signposted and knowledge about and access to community-based support feels variable. At times a lack of support after assessment, diagnosis and medication can be referenced. Community-based initiatives feel less integrated than medical services, with no clear roadmap for accessing them and a lack of awareness of what is available. Despite this, some people had been signposted to support and others had proactively searched for and found local initiatives.

For those with dementia, community initiatives can feel particularly hard to access with little NHS signposting being reported and a limited knowledge of what is available.

Responses to the concept of community-based care and support

The idea of community-based end of life initiatives, as described in the research, is generally welcomed, although it can be challenging to envisage how these might be realised in different communities.

The case studies provided as stimulus material prove an interesting way to bring the topic to life and, when considered together, explain the concept well, showing the breadth of approaches available. Showing a variety of different approaches allows people to see how this could work in their own community, and most found something that 'could work for them'.

On discussion, there is a recognisable gap in terms of needs, with community provision being seen as a supplement for what healthcare does not (and is not expected to) provide.

However, the concept can also feel idealistic. The word 'community' is complex in terms of its meaning and if no sense of community exists, how a community could come together to provide this type of support can be questioned. Sustainability of the concept and specific initiatives is also raised as an issue with key important questions such as who is behind the strategic idea and who will drive forward and fund local initiatives being raised. Most would be looking for credible not-for-profit organisations with experience, to drive forward this type of community initiative.

Several barriers are identified to accessing initiatives. Acceptance of the situation and lack of awareness of availability are seen as critical, so signposting (ideally from the NHS) is seen as crucial. Logistical barriers can exist, as can emotional barriers such as pride and stigma around the idea of accepting outside help. For patients with dementia, trust, loss of dignity and barriers relating to the variability of the condition which impact on social interaction are raised.

Use of language to enhance the concept

The language used to describe community-based initiatives is important in first impressions of the service offered. However, as first presented, the idea of 'community-based support services for end of life' is not always well-understood and is not easy to visualise. The idea of 'community-based services' can lack a meaningful generic descriptor that ties the ideas and underlying concept of compassionate communities together as a theme. A complicating fact is that end of life and dementia are perceived differently and the phrase 'end of life' does not necessarily therefore signal the inclusion of dementia.

Encouraging engagement

Older people such as new retirees or empty nesters are seen as natural volunteers to help in community-based initiatives. People who have previously been bereaved or previously been a carer are also seen as potential volunteers. Within the sample, there were several examples of respondents who already volunteered (seen more in bereaved respondents), or who were interested in volunteering in future (seen more in current carers).

However, there are also barriers to participation both as a volunteer or as a participant including questions around how the broader strategic idea is being moved forward, who would set up these initiatives at a local level, and how they would be funded. Most would therefore look for credible, known organisations to spearhead and initially deliver initiatives, and the appeal of initiatives may differ according to who or what is perceived to be behind them.

In conclusion, despite a positive reaction, implementing the approach in a consistent and considered way across the country feels as if it will require investment of time, effort and funding support. This will take time to build on the current successes and change attitudes to end of life care – particularly when considering the fundamental attitude shift required to address the taboo and also encourage a sense of caring for your fellow citizens.

However, despite the barriers raised, the research identifies a genuine support for the notion, and for those who have accessed this type of support it is clear the difference it can make to the lives of the person and the carer.

4. Background

A public health approach to end of life care offers a successful model of community care. It builds partnerships between healthcare services and communities in recognition that death, dying, loss and care take place in everyday life within the family and community, at home or at work, in villages or other settings, activities and experiences.

Palliative care focuses on providing patients with relief from the symptoms, pain, physical stress, and mental stress of a serious illness, and seeks to optimise the quality of life for patients with life-limiting illnesses, their families and carers. Health promotion in palliative care describes the idea that end of life social and psychological needs are best addressed through health and death education, community development, personal reorientation, policy and environmental change.

Contemporary palliative care services are co-ordinated and provided by multidisciplinary teams that seek to support patient-centred care across levels of service, wherever possible in the environment of choice. It also engages caregivers, the bereaved and communities in their own care by working with those communities to identify issues associated with health and wellbeing at the end of life.

However, end of life care is more than palliative and hospice care. Age-related and other life-threatening illnesses present end of life care issues experienced at home among friends and relatives, and in community settings. The awareness of dying changes social roles and relationships. Social changes are also encouraged by physical, psychological and psychiatric morbidities. These social matters related to life-threatening illness experiences can only be addressed within the same networks and contexts that they arise. The design of a systematic end of life care approach therefore involves the creation of normal and routine community relationships that go beyond service-provision, and involve the family.

Public health activities to facilitate this community development approach involve engagement with a range of local resources including schools, workplaces and museums as well as traditional end of life care professionals to break down the social taboo around death and acknowledge that end of life care and support is the responsibility of us all.

In recognition of this, PHE has been working with the National Council of Palliative Care to support the adoption of a unified end of life care approach throughout the country. This has included the creation of the Dying Well Community Charter, which incorporates a pilot scheme in eight areas of the country; Lancaster District, Chester Local Authority Areas, North Somerset, Dorset, Hackney, Hull and the East Riding of Yorkshire, Birmingham and Liverpool. This team also produced the Public Approaches to End of

Life: A Toolkit with a leading academic. PHE are currently supporting the rollout of the toolkit by hosting a series of workshops offered to each of the 12 Strategic Clinical Networks across the country.

A number of end of life care community development activities and projects already exist across England and are meeting end of life care need. Despite this, to date there remains little published research into the general public's awareness of community initiatives and their appetite to access, engage and participate in these approaches. PHE has therefore commissioned Solutions Research to conduct this qualitative research to gain insight into the public's awareness, perceptions and experiences of community end of life care initiatives.

The findings of this research comment on the awareness and knowledge that the public has of community-based end of life care, the perceptions they have of the concept and its translation into practice. They also detail experiences of dying people, informal carers and the bereaved, across different life limiting illness and provide insights relevant to those involved in furthering this new approach to end of life care. This report also provides a number of recommendations across the health and care system to ensure that future improvements are well placed to meet the needs reported by the public in this research.

5. Methodology

5.1 Research objectives

This research was designed to enable PHE to assess the progress of the current implementation of community initiatives for end of life care, the extent to which existing provision met public need, and how the approach could be more successfully implemented.

As such, the objectives of this research were to understand:

- the awareness and knowledge of community end of life care across a number of key audiences
- their perceptions of community end of life care
- their experiences of end of life care and any community initiatives
- any improvements that could be made to community end of life care

5.2 Method and sample

This project involved two stages as follows.

5.2.1 Project scoping phase

A rapid review of literature was carried out prior to the qualitative research. This was designed to scope previous work in this field, define the topic areas for the qualitative research, and input into development of the topic guide and stimulus materials. The stimulus for the research comprised images and case studies on boards, each illustrating a different theme relating to end of life. These were used to help explain the concepts being discussed to respondents. The findings of this rapid literature review are included in Appendix 3.

Four in-depth interviews were undertaken with stakeholders involved in public health approaches to end of life care. These were carried out face to face and by telephone and lasted for approximately 30-45 minutes. These were included to brief the Solutions Research team about current initiatives in England, including the pilot scheme, to aid their understanding of the concept and its translation into practice.

These insights were used to help generate the stimulus materials as described above, and to inform the topic guide for the main body of the research. (The topic guide can be seen in Appendix 1.)

The Solutions Research team also attended two events hosted by the Dying Well Community Charter. The Dying Well Community Charter is a commitment by individuals, communities and organisations to work together towards some guiding principles that 'should apply for all of us and our communities as we are affected by dying and death' (for more details, see http://www.ncpc.org.uk/sites/default/files/Dying_Well_Community_Charter.pdf)

5.2.2 Qualitative research with key general public audiences

Following the project scoping phase, a phase of qualitative research was carried out across a range of general public audiences. The fieldwork was staged with a short break after approximately a third of the sample had been interviewed, to review the sample and topic guide. A mixed methodology was used, tailored to specific audiences of interest. In total, 69 people were interviewed which is a robust sample for a qualitative research project. It is not intended to be a representative sample and as such cannot be statistically analysed or grossed up.

The full sample and method were as follows.

- four quads (four-person groups) with **adult children 'influencers'**:
 - two quads with people who had a parent diagnosed with a form of dementia
 - two quads with people who had a parent diagnosed with other terminal illnesses (different terminal illnesses were included across the sample)

Small quad groups were used because a small group environment is more supportive. It enables respondents to bond well together, allowing them to discuss their shared and individual needs, their experiences, and their attitudes to end of life care approaches.

Adult children 'influencers' were people over the age of 40 who had one or both elderly parents diagnosed with a terminal illness or dementia, but who were not as yet in the very final stages of life.

- three paired depths with **people with a terminal illness approaching the end of life, and their informal carer**

Paired depths with a person with terminal illness and their carer were used to allow respondents greater levels of self-expression, in the presence of a friend/family member. Terminally ill respondents were offered the choice of being interviewed separately from their friend/family member to give them choice and flexibility about how they preferred to take part, but all three chose to be interviewed as a pair. One respondent had cancer, another had cancer and heart failure, and the third had chronic obstructive pulmonary disease (COPD) and advanced Parkinson's.

- eight one-to-one depth interviews and two paired depths with **informal carers**:
 - four one-to-one depth interviews with people caring for someone with a terminal illness
 - four one-to-one depth/paired depth interviews with people caring for someone with dementia
 - two paired depths with people who cared for someone in early stage dementia

This audience comprised of people (a mix of spouses and adult children) who informally cared for those with a more advanced terminal illness or dementia who were approaching the end of their lives. Given the sensitivities attached to talking to these respondents and the potential for upset, depth interviews were used. These gave respondents the privacy, time and space to express themselves and their personal experiences.

- four quads and five paired depth interviews with **bereaved informal carers**:
 - two quads with people whose friend/family member had died with dementia
 - two quads with people whose friend/family member had died from a terminal illness
 - three paired depths with people whose friend/family member had died with dementia
 - two paired depths with people whose friend/family member had died from a terminal illness

This audience comprised people who had informally cared for people with dementia or other terminal illnesses who died within the last two years. Quad groups were again used to allow respondents to benefit from the small group environment to share and discuss their opinions, contrasting their different experiences. Depths were also used to allow respondents to express views in a private setting. These sessions explored the whole journey from diagnosis, through death and bereavement, and the range of different approaches and services they experienced and could have benefited from.

- **ethnic minority communities**: Nine depths with informal carers (friend/family members) of people approaching the end of life, and the bereaved

One-to-one depth interviews were carried out with members of ethnic minority communities who either informally cared for, or had lost, a friend/family member to either terminal illness or dementia. The communities included were Indian Hindus, Indian Sikhs, Black Caribbean Christians and Pakistani/Bangladeshi Muslims.

5.2.3 The research recruitment process and ethics

Respondents were recruited to take part in the research by professional market research recruiters using a screening questionnaire which had been agreed with PHE. See Appendix 1.

This research project was carried out according to the Market Research Society's code of conduct and ethics. The code of conduct was applied to all areas of the project. It covered all aspects of recruitment, including the screening questionnaire, ensuring that respondents gave fully informed consent. Respondents were made aware of the purpose of the project in advance, at recruitment and in a confirmation letter. At the start of each research session, it was explained that their details and responses were fully anonymous and confidential, and that no personal details would be passed to PHE. It was further explained that they could refuse to answer any questions if they chose, and could terminate the interview at any point. Finally, the way that their responses would be used in the report was explained – that if quoted, their words would be attributed only as far as noting their respondent type (eg 'carer of person with terminal illness') and that no quotes or case studies would be used that might identify them from their personal circumstances.

This report has been submitted to the PHE Research Support and Governance Office for an internal review by the Research Ethics and Governance Group (REGG).

REGG stated: "The report outlines the project and states that it was conducted in compliance with the MRS Code of Conduct. From the information provided in the report there is no apparent cause for disquiet and, on this basis, publication is recommended."

Further details about the MRS's code of conduct and how it is applied in qualitative research can be seen in Appendix 2.

5.2.4 The research process

- research sessions began by discussing an individual's condition (or their friend/family member's condition), and their personal experiences
- the issues of community and other end of life care approaches were then raised – this was to explore their spontaneous awareness and knowledge of any initiatives in their area, and what they may have heard about in other areas
- following this, the concept of community-based end of life care, and a range of different approaches that have been used, were explained to respondents
- stimulus included case studies and concept boards developed for the research. These included:

- case studies of initiatives designed to support current or bereaved carers of people with a terminal diagnosis or life-limiting condition
- case studies designed to support current or bereaved carers of people with dementia
- case studies of initiatives to support people approaching end of life
- case studies of initiatives that encourage conversations and breaking the taboo surrounding discussing end of life
- these approaches were then reviewed in terms of potential suitability at particular points of the end of life journey, in their own local area, for their family/friends

Sessions were carried out in Liverpool, Birmingham, Leicester and London in July 2015, with approximately 2/3 of sessions undertaken in areas where the Dying Well Community Charter is being piloted (as per Background section). Other areas were chosen to ensure a good geographical spread, and a mix of urban and rural locations.

5.2.5 Approach to qualitative analysis

The qualitative analysis comprised a variety of approaches, including reviewing notes, transcripts and audio tapes. Primary analysis in the form of theme-discussion was undertaken from the first research sessions. Themes were then further developed throughout the fieldwork via progressive focusing and interim analysis discussions among the team.

For the formal analysis, each moderator reviewed their own interviews and groups, and created a set of analysis notes that were themed, and with any differences by audience type highlighted. The research team then held a formal analysis day where each moderator's detailed notes were discussed and compared and a final analysis conducted.

6. Research findings

6.1 Audience context

6.1.1 Respondents' sense of 'community': feeling part of a community

Public health approaches to end of life care are centred around community development and engagement to improve the care of people at the end of life within their local area. Central to the public's perception of this approach is their response to the concept of community more generally. Consequently, within the research, sessions focused on whether or not people tend to feel part of a community, as this could impact on their subsequent attitudes to 'community-based' approaches.

Some people reported feeling part of a community. The word 'community' resonated with them and they could immediately discuss who and what made up their community.

'Dad likes to go to the shop and he still can go to the shops, so that's how he gets his community – talking to people in the shop and talking to the neighbours.'
(Carer of person with terminal illness)

Their understanding encompassed reciprocity and sharing – their community provided mutual support and the feeling that the community would be there for them in times of crisis. Such people could include older people, people living in more rural locations, or people with strong local ties eg a local school or church, but this varied across audiences and individuals. Those who lived in small communities such as villages or supported housing complexes tended to easily identify a community to engage with.

'There's a lot going on in the village, and it's up to the individual if they want to join in. It used to be a small village but it's grown now, there's a village hall and a lot of society and clubs, you can trace a lot of families that have lived here in the village for a long time.' (Carer of person with dementia)

'A general perception of community has completely changed from when my mum and dad were younger, a community then was classed as what your local community was as opposed to now.' (Carer of person with dementia)

For the small sample of ethnic minority respondents, who were recruited on the basis of religion/culture (Indian Hindus, Indian Sikhs, Black Caribbean Christians and Pakistani/Bangladeshi Muslims), there were different definitions of community. Religious communities were particularly important to older respondents, and tended to be described as very close-knit, traditional and conservative and generally centred around

faith settings (temples, mosques, gurdwaras and churches). These were centres for both religious and social activities, which could act as community hubs. However, some older, first generation respondents described a tendency for such settings to be male-dominated in certain faith groups, eg mosques. Furthermore, some ethnic minority respondents reported a sense of social hierarchy within some communities, with people with status and influence (eg faith leaders) described as able to influence the behaviour of others and determine some boundaries and exclusions of the community group. Taken together, this may mean that communities centred around these settings or focused on such leaders may not be accessible by all people in all contexts.

Among other ethnic minority communities, participants reported that shared heritage and ethnic backgrounds, traditions and cultural values helped to define their sense of shared identity, such as language and food. Some respondents indicated that identification with this type of community was particularly heightened during the celebration of festivals like Diwali or Eid.

For many ethnic minority respondents, communities were seen as practical, real and accessible – a part of their daily lives. These were described as diverse networks, which included family, friends, work colleagues, neighbours and whomever they felt they could turn to for support and help. In some cases this may result in identification with more than community or support network: This idea was discussed among several of the younger respondents (NB: small sample).

'I turn to my neighbours and work colleagues are if I need help. I rely on people outside my community. My English neighbour has helped me more than anyone from my own community.' (Carer of person with dementia, Indian respondent)

6.1.2 Respondents' sense of 'community': those who did not feel part of a community

Other respondents reported feeling less part of a community. In the small research sample of ethnic minority respondents, these were all women and were mainly second generation respondents across all faith groups.

'I used to go to the mosque regularly before I got divorced and everyone talked to you and respected you. But everything started falling apart after I got divorced. I was being ignored. I stopped going to the mosque. Obviously my children lost out on the cultural side.' (Carer of person with dementia, Pakistani respondent)

Some respondents in the mainstream sample also reported little sense of belonging to a community. For some this was a result of a lack of any existing community - for example if they lived in an area without key focal points where people gather such as a local pub or library. Others were aware of an existing community, but were not open to embracing it and actively chose not to engage. This was sometimes noted where communities

were formed around different values to those held by the individual, or where an individual's personality did not lend itself to engagement in a community. For example, some very elderly respondents described themselves as feeling too 'set in their [individual] ways' to join a community.

'I am not a churchy person, I've never done the coffee mornings or the WI or anything. They're not my cup of tea. I don't get involved in that sort of thing.'
(Person with terminal illness)

An individual's ability to identify with a community is likely to have a direct impact on their perception and willingness to engage in community end of life initiatives. If respondents had little or no sense of community prior to their end of life journey, it was more challenging for them to see the community as a natural resource for support. This did not indicate that there was no appetite for support that was broader than that encompassed by the medical model, but that being anchored to a concept of community may make it more difficult for them to envisage.

6.2 The end of life context

6.2.1 The end of life context: complexity of the subject

The end of life is undoubtedly a sensitive and complex time, with everyone's experience being different. A complex combination of factors determines the extent to which people may be willing to engage with, and participate in, community initiatives relating to end of life care.

Such factors include the type of life-limiting condition (conditions with and without a terminal diagnosis) and stage in the end of life care journey (early diagnosis to last stages of life), the age of the person with the condition (needs typically vary by age), and the individual's experience of local community prior to end of life. These factors impact not only on the response of the individual, but their carers too – whose own individual needs will vary according to the factors outlined above. Regardless of their different experiences and needs, participants across the sample welcomed discussion of community end of life care initiatives and valued the opportunity to share experiences.

6.2.2 The end of life context: life-limiting conditions and terminal diagnoses

End of life could feel more or less pertinent depending on whether the person had a terminal condition such as cancer with a terminal diagnosis, or a condition that may ultimately prove fatal but was not officially terminal, such as COPD. For terminal illness, even if the time remaining was unclear, life could still feel defined by the condition. It could be easier to predict what people with conditions will go through - the parameters

were clearer, and the symptoms and physical deterioration trajectory tended to be better understood. For those with a terminal diagnosis, the idea of life ending therefore often felt concrete and could be more top of mind, whereas for those with conditions such as COPD or neurological issues, end of life could feel less top of mind. Cancer diagnoses seem to provide the most clearly defined end of life trajectory and pathway, which allowed carers to focus on physical care and comfort. Although a painful time, the focus helped carers to feel that they were doing their best.

When considering dementia, although it was understood as a long term condition, it was rarely perceived as terminal in the same way as other physical conditions are. Whereas a terminal illness has a known end-point, dementia was seen as life-limiting. Conversations about end of life therefore often seemed out of context - the focus for both people with dementia and carers was reported to be more about living (well) with dementia, rather than on dying from the condition.

'We were told 'You don't die of dementia, you die with dementia.' Something else takes you away and you happen to be a sufferer of dementia as well. It takes you to all sorts of difficult situations in the future.' (Carer of person with dementia)

Although carers and people with dementia reportedly understood that the condition would invariably lead to a slow decline and deterioration over many years, dementia was not often attributed as the actual cause of death. Dementia therefore seemed qualitatively different to conditions with a terminal diagnosis, or those that were life-limiting and understood to potentially lead to death (eg COPD) and any community-based end of life approach needs to take this into account.

'There's nothing I can do between now and then to alleviate the situation – if there was I would take action but there isn't, so I take it one day at a time.' (Carer of person with dementia)

'I don't think people look at it as somebody dying...If somebody says they've got cancer, people see it as how long have you got. When someone's got dementia, they don't look at that as a cause of death.' (Carer of person with dementia)

Similarly, when considering both terminal and life-limiting conditions compared with dementia, a person with a terminal or life-limiting condition's personality was more likely to remain.

Although the topic of end of life can be difficult to raise, it could therefore feel easier to time end of life conversations with a person with a terminal/life-limiting condition than with someone who had dementia.

6.3 Audience insights

6.3.1 Audience insights: caring for people with terminal conditions, their carers and the bereaved

Terminal illness encompasses a range of conditions, and associated differences in how these were perceived were seen across the sample. These differences could impact on attitudes towards end of life care, and relationships between people with conditions and their friend/family members. The relationship between informal carers (in this sample, often adult daughters) and a person with a terminal illness was observed to be compassionate, caring, and conscientious. Parents relied heavily on their daughters for holistic care and support – practical, physical and emotional. Many adult daughter carers additionally had busy lives and were juggling their own needs with those of their parents. Some lived a distance away and had full and part time jobs as well as children at home. However, despite these external pressures, their experiences were discussed as a treasured time, and were often seen as an opportunity to support friend/family members through end of life in a positive way.

Carers were seen to focus very heavily on their friend/family members' needs, to the extent that it felt challenging for carers to recognise that they, as a carer, had their own needs beyond getting through each day. Their lives could feel consumed by caring for their friend/family member, and when asked about needs, their concerns were overwhelmingly focused on the needs of the person with the condition rather their own. Some respondents reported guilt at the feeling that no matter how much they did, they felt that they could never do enough. Such feelings of guilt and of not doing enough were also seen in ethnic minority respondents.

'I would rather suffer myself than let my mother down. She has done so much for us and I feel I will betray her if I don't look after her myself.' (Carer of person with dementia, Black Caribbean respondent)

'I love her, but I've got children and I've got a job and when I come over sometimes, I'm doing ironing and putting washing away and I'm doing jobs, and I want to be a friend.' (Carer of person with terminal illness)

6.3.2 Audience insights: caring for those with dementia

Dementia was widely acknowledged to pose challenges for both individual and carers. It was seen as a complex condition with specific needs and requirements for both the people with dementia, and their carers. Many research respondents had not previously had an opportunity to share their experiences with others, and the research sessions often led to emotive discussions which were appreciated by other respondents.

'Mum keeps thinking her memory is going, mentioning she should go to the doctors, and I'm thinking, you have been through so many clinics and so many checks and yet you think this is an emerging issue.' (Carer of person with dementia)

The needs and challenges of the condition were also seen to vary according to the stage of the condition with the impact on the carer becoming more challenging as the condition progressed and the person with dementia progressively became less in touch with reality.

In the early stages, carers reported noting distressing signs such as memory lapses and a dawning realisation that these were something more than normal cognitive decline. However, although carers recalled initially being fearful of a dementia diagnosis, there was also less reported impact on day-to-day life, and the relationship between the carer and the person with dementia was still adult to adult.

Once the condition was established, carers typically focused on maintaining the status quo for as long as possible, often making big changes to make life appear normal for the person with dementia. This was reported to be an increasing drain on their day to day life and time.

'There's a lot of things she doesn't want me to be doing in terms of looking after her, it's a massive big deal every time something needs doing. I find it difficult. She doesn't acknowledge most of the time that she's got any problems.' (Adult child influencer, parent with dementia)

When dementia reaches its advanced stage, carers reported more challenging situations. The reduced mental capacity of the person with dementia meant that they could often be unaware of any issues or of any impact of their behaviour on others and the role of the carer became that of adult – child. Many carers reported that this type of dependent relationship could dominate their lives.

'My mum is a complete prisoner and is unable to leave my dad alone for a minute unless I am there ...the joke is my dad is blissfully happy.' (Adult child influencer, parent with dementia)

The gradual progression of the condition did however mean that both people with dementia and carers made adjustments over time.

'I can't believe how much has changed in a year. A year ago I wouldn't have thought I could cope with how it is now at all. I would have been completely horrified and terrified. I sort of convinced myself that what you see [in other sufferers] wouldn't happen to Mum. Looking back, I was very naïve about how bad

it gets. But it happens gradually so you just get used to it and learn to cope.’ (Adult child influencer, parent with dementia)

A person with dementia’s sudden mood swings and changes in personality were often described as the hardest aspects to deal with. Their mood could swing from passive to aggressive without warning, and high levels of volatility in moods, behaviours and emotions were described. Some carers described their friend/family members additionally becoming introverted, highly anxious and isolated, and seeking to avoid contact with others.

‘It can be hard to accept what they have become...they become someone you don’t recognise and then they don’t recognise you.’ (Carer of person with dementia)

‘In a way it is a double bereavement, you lose them twice, the person you know and love and then the death.’ (Bereaved, cared for someone with dementia)

The complexity and variability of dementia impacted on the care needs of each individual. It could be challenging for carers to identify consistent solutions and care options, as a person with dementia’s needs could be so changeable and unpredictable, often varying from day to day. This made it harder to plan, and meant that a high degree of flexibility was required in any approach. This could itself feel challenging – the unpredictability added constant stress, and unforeseen issues and situations often arose, and comprised a constant worry and cause of anxiety for the carer.

Other aspects of care also felt difficult for carers. Care could be stressful, particularly when the person with dementia was argumentative, aggressive, rude, and abusive or repeated themselves frequently. Time-management could be challenging, as people with dementia could require persuading to do simple tasks, and often could not be rushed. Personal care added another challenge – intimate care could be embarrassing for both people with dementia and carers, and stressful for adult children to manage. Financial management was also identified as a challenge, particularly keeping the person with dementia’s finances secure. People with dementia could be overly trusting, lacking reason and judgement, and so being highly vulnerable to fraud and ‘con men’, or could become paranoid and mistrustful of their own family’s financial motivations.

Caring for a friend/family member with dementia was often described as a relentless role with little respite, particularly if their friend/family member was suspicious or mistrustful of other people. This was more often the case if the carer was a spouse, or an adult child who lived with the person with dementia – such carers often reported feeling unable to leave a person with dementia alone even for short periods, so could start to feel like a prisoner in their own home. Carers routinely become used to

overlooking their own needs, and within the sample, few had talked to others about their experiences while their friend/family member was alive and needing care.

'You give up your time and your life, only to have them throw tantrums at you and...the incontinence, it is always something. It is a living hell. Looking back, it almost cost me my marriage and my own sanity. But you do it for love, for the person they were, even if they no longer love you.' (Bereaved, cared for someone with dementia)

Nevertheless, all of the carers in the sample were keen to maintain their friend/family member at home for as long as possible – moving them to a care home was seen as a last resort.

6.3.3 Audience Insights: Changing Attitudes to Dementia in Ethnic Minority Communities

Some older ethnic minority respondents reported existing taboos and misperceptions around dementia that could prevent it being discussed, diagnosed and treated in particular community. Some Muslim respondents reported that dementia was sometimes believed to be contagious. This meant that it was rarely acknowledged or its presence admitted outside the immediate family. Sometimes the person with dementia was reported to be kept out of sight beyond the immediate family. However, such taboos and misperceptions were widely acknowledged to be changing, even among more traditional communities. The second generation in particular reported changing attitudes, such that dementia is becoming a much more acceptable topic for discussion. Among the second generation, there is no longer any shame or stigma surrounding asking for help or talking about the topic – there is both an increased awareness of the condition, and a noted growing prevalence in certain communities. Some compared the topic to talking about cancer – i.e. uncomfortable but acceptable. Respondents theorised that it has become more acceptable because of the increased awareness through mainstream and ethnic media. They did however acknowledge that change can be slow, and theorised that there needs to be a complete cultural change in the mindset of some of the first generation within the community.

'If you look at 10 years back it was unthinkable for Asian families to put their elderly parents in homes, but the attitude has changed now. It was a taboo in the community, but now their thinking has changed. We are still a little backward as compared to even the Indian community back home. We are still holding on to cultural values that we had 30 years back when we came to this country.' (Carer of person with dementia, Indian respondent)

6.3.4 Audience insights: the bereaved

Bereaved respondents, many of whom had some emotional distance from their previous caring role, were able to provide insights over the whole end of life journey. As such they were able to provide judgements about the types of support that had or would have been most useful at particular stages throughout the end of life care journey.

Respondents in this sample could appreciate the benefits of community initiatives supplementing medical support. As will be discussed later with reference to reactions to the stimulus materials presented, no single benefit was perceived as key – these varied between individuals and situations. However, some of the most common key benefits articulated included respite and emotional support for carers, practical help for their friend/family member and (for some, depending on the individual) social events within the community.

Many of these respondents particularly valued the scope for support for the bereaved that community end of life initiatives could provide. They highlighted the changing role of a carer after the death of a friend/family member and how death not only represents the loss of a friend/family member, but can also represent the loss of an identity and purpose. Some indicated that appropriately tailored support can enable bereaved carers to renegotiate their relationship with their life.

'I think it's just as important to have something for the carers as well, because I know that after I lost Dad, I had no idea what to do with myself, what do I do with my day now?' (Bereaved, cared for someone with dementia)

6.3.5 Inequalities across audiences

The key inequality noted across audiences was that, as discussed, people with a terminal illness or life-limiting condition appeared to have a clearer care pathway than those with dementia, with better signposting to other resources. This could sometimes lead to carers of those with dementia feeling unsupported.

Ethnic minority and cultural inequalities were noted, and were discussed in context in section 6.1.

Few other inequalities were noted. Geographical inequalities could be seen in that some local service provisions were described as excellent (eg Hackney) while others were perceived to be lacking. However, it is difficult to interpret this more broadly as this is a relatively small qualitative study.

Because the research focused on C2DE respondents, it was not possible to fully examine socioeconomic inequalities. Although there was some sense from the small number of BC1 respondents that they felt more equipped to find out about local

resources and perhaps fight for them, even some BC1 (dementia carers) reported difficulties accessing care or support.

Similarly, no gender inequalities were noted. Although carers/influencers, particularly adult children, were more typically women, there were a number of men in the sample who provided devoted care for a close friend/family member. They were highly engaged in the care process and no major differences were noted.

6.4 Audience insights: needs

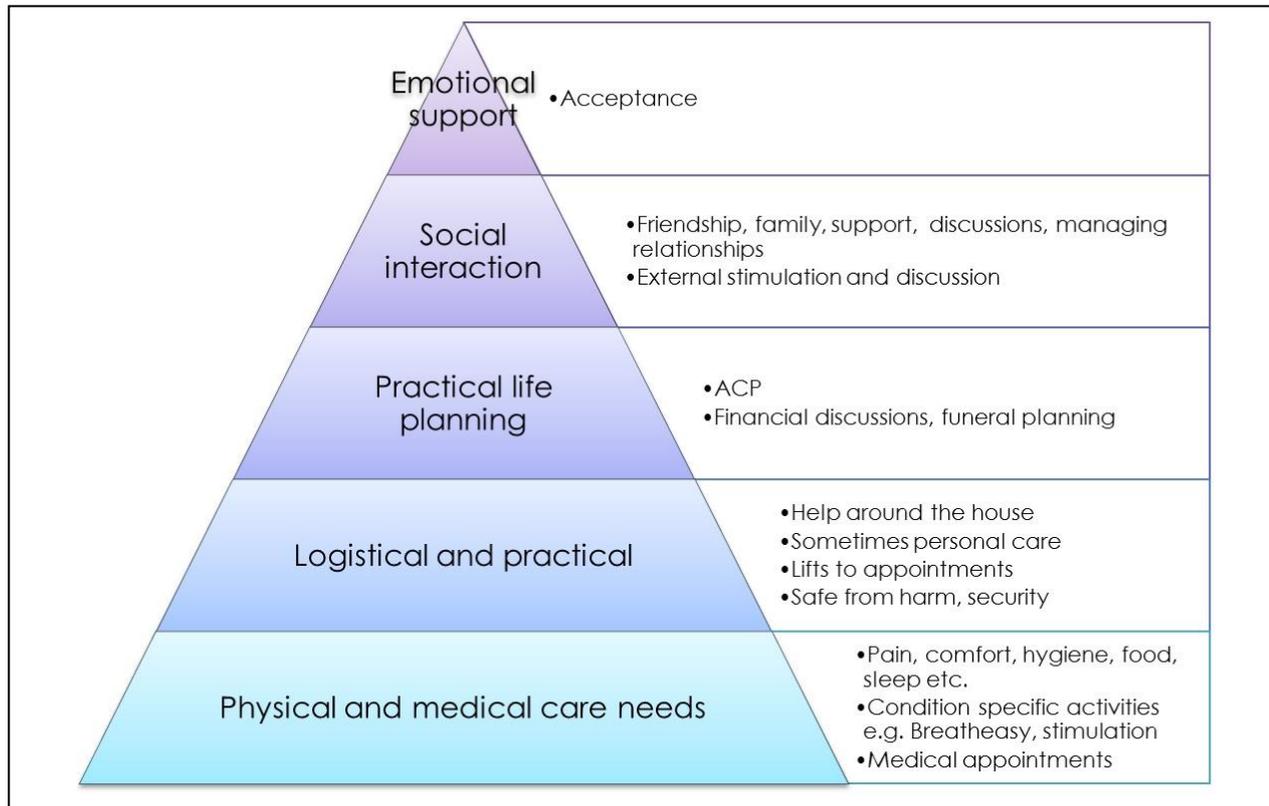
6.4.1 Overview

Carers, adult child influencers, and people with a terminal diagnosis collectively discussed the needs of people with terminal diagnoses, life-limiting conditions or dementia. Adult child influencers, who were caring for someone not yet approaching end of life, were least able to comment, as they had not yet gone through an end of life journey with their friend/family member.

It could feel challenging for carers to pre-empt and anticipate the needs of the person they were caring for. For most, this was the first time they had gone through this, and they typically managed and responded to the *immediate* day to day needs of the person, rather than reflecting on the process. The journey felt like a very reactive process, which made it challenging to be proactive and plan ahead. Some were only able to look back and reflect upon the points with which they may have needed help after the end of life journey was over.

‘There’s nothing I can do between now and then to alleviate the situation – if there was I would take action but there isn’t, so I take it one day at a time.’ (Carer of a person with dementia)

Carers identified different needs that on analysis could be developed into a hierarchy, reflecting very basic and practical needs, through to more emotional needs. These are illustrated in the diagram below.



At the bottom of the pyramid, typically representing key areas of focus, are the basic needs of the individual being cared for. These consumed the most time and energy and were often most highly prioritised. These needs were reported to encompass physical and medical care such as pain relief, comfort, hygiene, food and sleep. Condition-specific requirements were also seen as important fundamental needs, as were logistics such as attending medical appointments.

Other practical and logistical needs were also seen as important and fundamental to care, such as help around the house, personal care, transport and security.

At the next level, issues around Advance Care Planning, funeral planning and other financial plans were identified. At the highest level were more social needs such as friendship, family, managing relationships and external stimulation, as well as emotional support. The focus on meeting basic needs often meant that needs further up the pyramid such as access to emotional support or social interaction, could feel less likely to be prioritised.

People with dementia were identified as having additional needs. These included support needs, such as practical help to cope with day to day life such as a familiar environment, being cared for by someone known and trusted, who had a good understanding of the person and their condition. Consistency in care and other routines was also identified as important, eg reminders about keeping safe, back-up and safety systems, and personal care routines including washing, eating and drinking. Condition-

specific needs were also identified – these were largely focused around stimulation, and included both mental stimulation to keep the mind as active as possible (eg memory triggers, singing, music and mental exercises), and physical activities to keep the person with dementia as active and fit as possible.

'I find it quite hard to persuade her to go somewhere different, that's really upsetting for her as she doesn't know why we're doing it. Also I worry that she'll be ok, that someone else is going to look after her properly when I'm not there. And to leave her when she doesn't want to be left. I can't leave her on her own at all, I wouldn't be sure what she was doing.' (Carer of person with dementia)

6.4.2 Carers' needs (spouses, adult child influencers and the bereaved)

Further barriers were identified for carers accessing support for themselves. As previously discussed, these typically centred upon the carer mindset of *'It's not about me'*. Some carers had not previously considered that they themselves could need or access support, as their main focus was typically solely upon supporting their friend/family member. Carers often thought only of the person with the condition's needs, or how some of the practical aspects of the care they provided could be supported – eg *'someone else to get the shopping'*. Some also expressed the belief that the carer should *'do it myself'* or share needs within the family rather than looking for external help, and seeking external help could sometimes, for some, lead to feeling guilty or a sense of failure. (It was unclear whether such feelings would have prevented individuals from accessing support if it was properly signposted and readily available, as many had not had the opportunity to access any community based support.)

'For me, just to have someone else, another adult that would truly understand what she's going through and what her needs are, to be able to come and give me a break on a daily basis and I know that I could trust that person that would be a massive thing for me.' (Carer of person with dementia)

Carers' needs were therefore often both overlooked and poorly recognised - many struggled to meet the conflicting demands of both their own, and the person they were caring for needs. Many carers expressed how glad they were to support friend/family members, while others admitted that they found the burden of care and the associated challenges of subsequent dependency very stressful and frustrating. This was particularly true if the individual was unpleasant, aggressive or abusive, and carers commonly voiced feelings of guilt and conflict. Many carers felt deprived of any support and the research session was sometimes the first time that they had shared experiences with others in similar situations.

People caring for a person with dementia reported having additional needs, and discussions revealed a lack of confidence and knowledge about how best to manage

the individual and the condition. Many likened it to parenting, but with no clear rules or strategies for coping. Carers identified several potential areas where they felt support would be welcomed, namely advice about how to manage the mood-swings and aggression that can manifest in people with dementia. A common question was whether it was more effective to challenge difficult behaviours or to acquiesce, and the best ways to encourage compliance and good behaviour. More broadly, other needs included how much to share with others about the condition, and information about the value and importance of social activities, as this was not always fully appreciated.

Some bereaved people highlighted additional needs. For some, there was a gap in the provision of information on how to recognise when death was imminent – examples were given of doctors not preparing people well for this, and of people missing the point of death because they were unprepared for it.

Other reported unmet needs included uncertainty about the process that their friend/family member's body goes through, and whether or not they could be part of that (eg laying out). For others, reported needs focused around the legal and logistical issues related to death eg certification, funeral directors – more support was called for at this stage to help navigate through the process. After bereavement, respondents also frequently expressed a need for emotional support and the need to talk and grieve. In addition, a need identified by many (and surprising to many) was the gap in their lives in terms of time after their caring duties were over.

'When I was caring for Dad I knew I would miss the old him when he went, but it was awful near the end so I thought I would at least enjoy having my own free time again. I was surprised at what a gulf there was, and how unoccupied my days felt. I actually had to go to counselling over it, and I've since taken up volunteering.'
(Bereaved, cared for someone with dementia)

6.4.3 Awareness of, and accessing, care services and community initiatives

When respondents considered different types of care for either life-limiting illness or dementia, they tended to focus first on the care signposted by the medical profession. This could include primary or secondary care from the NHS, social care or other 'formal' 'community' care-provision such as dedicated charities, hospices, or local council services. Support from condition-specific support groups was also mentioned, and support from an individual's network, i.e. friends, family and neighbours, was a common theme. Community-based support was not however typically top of mind.

In contrast community initiatives felt more poorly signposted, and the term 'community based services' often failed to resonate. NHS signposting to community-based services felt patchy to respondents, even for those with a terminal illness. Some people reported excellent awareness and signposting through their GP or the NHS while others came

across community-based support services online, or though being proactive and contacting charities (or other organisations) themselves.

'Nobody told us anything about any help at all, we contacted Age Concern off our own backs.' (Carer of person with dementia)

Community-based services therefore felt less integrated than medical services, with no clear roadmap for accessing them. When the notion of community-based services for end of life care was introduced and explained, research respondents could see a need for such services but they were largely unaware of what was available in their local area. For those with dementia, community initiatives felt particularly hard to obtain with almost no NHS signposting being reported – so there was a limited knowledge of what was available.

'I had no idea anything might be available so I didn't even know to look. To be honest I would have expected the GP to know about it.' (Carer of person with dementia)

Consequently, accessing community-based support felt sporadic. Across the sample, many referenced a lack of support after assessment, diagnosis and medication (if required). For dementia in particular, there was a perceived gulf in terms of other support and resources and little follow-up – there were mostly only annual reviews to assess any changes or decline.

'They did absolutely nothing, it was a case of 'she has dementia, now get on with it'. I've had to fight tooth and nail for everything.' (Adult child influencer of parent with dementia)

Some people proactively searched for support and found local initiatives; some asked relevant charities and others went online to search (eg forums, online support groups, Google).

'I went on the Brain Tumours Support group on Facebook which gave me a lot of support, I used to speak to people doing exactly the same thing and it made me feel less alone.' (Bereaved, cared for someone with terminal illness)

Ethnic minority respondents reported consistent responses to those of the mainstream audiences. There was no awareness of any community based support, only of NHS and Social Services. Some respondents had accessed social care via the local authority but did not know what else was available, and were therefore unaware of what to ask for. Most relied on doctors and hospitals to signpost them to services and in some cases the hospitals had made referrals to social services.

Few differences were noted in the types of community initiatives accessed between pilot and non-pilot areas. Examples of community initiatives reported by research respondents included an 'extra care' village (communal retirement village with care staff), an Alzheimer's carer course, befriending (volunteering to go to a person's home and socialise with them), carers' meetings, singing for the elderly, exercise groups, ethnic minority-specific groups (eg Black Caribbean Alzheimer's group) and memory clinics.

6.5 Conversations about end of life

6.5.1 Overview

Respondents recognised the difficulties of talking about end of life and the taboo surrounding death in most cultures. Although some thought that this taboo was easing, others (particularly older participants) questioned the need to break the taboo at all, as they did not agree with the idea of normalising death and dying. On consideration, some respondents across audiences did feel able to discuss the concept and could appreciate the value of a 'good death'. In addition, helping children to understand death, particularly breaking the taboo earlier in life and having policies to support bereaved children, were all also seen as having value, although it was agreed that they would need to be sensitively handled.

'I would agree with breaking the taboo about conversations' about death, I think you should be able to discuss it openly, I think that it would benefit everybody.'
(Bereaved, cared for someone with terminal illness)

6.5.2 Conversations about end of life with the terminally ill/life-limiting conditions

The idea of encouraging conversations early was welcomed by some carers and the bereaved. Starting the conversation earlier suggested a sense of better control, making it easier to deal with the practicalities of death (eg wills and other finances) before death was imminent. The key advantage perceived were that it would lead to friend/family members being better prepared.

'You have to go through that process of acceptance, and once you have, you need to have the chat about last wishes.' (Bereaved, carer of person with terminal illness)

Ways to broach the conversation about death and last wishes were however still reported to be difficult. Although some had openly discussed the wishes of the dying person before they passed away or became too ill for such conversations, others reported that it had been too difficult, and regretted not having raised the topic while their friend/family member was still alive. Discussions about the topic were reported to

require both the carer and the person with the condition to accept the situation, i.e. that the ill person was going to die. For some carers, such acceptance represented 'giving in', which was seen as a key barrier and very difficult to do.

The bereaved respondents in particular recognised that it was easier to have a discussion about last wishes when death was not imminent, and that when a person is facing actual end of life, it could be too late to attempt to start breaking taboos. It was felt to be particularly difficult to raise the subject when a person has a serious condition that is not always seen as 'terminal' such as dementia or a long term health condition, eg COPD.

6.5.3 Conversations about end of life with people with dementia

In considering discussions about end of life with people with dementia, timing was seen to be key. When reflecting back, it was seen as useful to have early conversations about last wishes, and conversations about advanced care planning and end of life care wishes. However, in reality it felt highly challenging for either a carer or a person with a condition to raise the topic, so in practice it was often reported to be avoided. Early conversations when the patient has insight and full capacity were seen as ideal, but these could seem premature and be painful to introduce. Conversely, although the topic felt easier to raise when a person was in the later stages of the condition, if their cognitive capacity, trust or personality were, by that point, compromised, the conversation may be less meaningful.

'When can you have that conversation, they could live with it for ten years and be physically healthy.' (Carer of parent with dementia)

6.5.4 Triggers and barriers to end of life conversations

Respondents reported a variety of factors that had enabled conversations about end of life and last wishes. Sometimes the person with the condition had raised the topic, and although carers may not have initially been receptive, this was generally seen as a positive route into the conversation. Acceptance on the part of the carers was also key, and a focus on practical arrangements (funeral and financial planning etc.) was also seen to ease the emotional impact of such conversations.

'Dad wanted to talk me through his funeral plans. At first I didn't want to hear it, I was in denial and didn't want to think about his death, but looking back on it, it was a good thing to do. I knew I was carrying out his wishes for his funeral, and that helped a bit.' (Bereaved, cared for someone with terminal illness)

Some also recognised that people outside the family can help with these discussions and that the emotional distance can make it less of an emotive discussion – for

example, by sharing the news that end of life is approaching in an appropriate way and providing support in helping with practicalities such as financial planning, wills and advice. Some respondents reported that a trusted healthcare professional had initiated conversations.

'We've talked about what music mum wants at the funeral, and about her will. We don't talk about the fact she is going to die per se – I don't think I could manage that conversation. But I can take notes about music and money.' (Carer of person with terminal illness)

There were however some strong barriers that could inhibit discussions. While all respondents acknowledged the importance of raising the subject early, it could still be very difficult. Denial was key – for example, denial about the condition, the diagnosis, and the prognosis could have a huge impact on discussions, as could fear of dying. From a carer's perspective, not wanting to cause further pain or upset at an already difficult time, as well as concern over how to raise the topic, were mentioned as challenging barriers. The implications of raising the topic were sometimes seen to suggest abandoning hope that the person with the condition would recover.

6.5.5 Ethnic minority perspective on end of life conversations

For some ethnic minority respondents, particularly in South Asian communities, discussing and dealing with terminal illness was described as a taboo subject which could be perceived as disrespectful by the family. Some felt that it may also be seen as 'tempting fate' to discuss last wishes.

'Even if I want to discuss things I won't because what if something happens? I will never forgive myself.' (Carer of person with dementia, Pakistani respondent)

This could result in a moral dilemma for carers who wanted to respect their friend/family member's wishes but could find no way to broach the topic.

'I need to feel it is morally right for me to have such a conversation with my parents. It is not just about them, it is about me too. I have to live with it and the question always arises whether I am doing the right thing.' (Carer of person with dementia, Indian respondent)

Some second generation respondents however felt more open, willing and ready to have such conversations. They felt there was a need for general awareness-raising and education in the community for people to challenge myths and help change attitudes.

'We Hindus relate death to life. If you have lived your life with religion then you expect your death with religion and what happens after death. It will be more

socially acceptable if someone with some religious knowledge talks about it.'
(Bereaved, cared for someone with terminal illness, Indian respondent)

Older respondents felt that GPs and religious/spiritual leaders were better-placed to have conversations about end of life. Such conversations were often seen as more acceptable if – assuming the patient had a good relationship with their GP - they were initiated by the GP. It was seen as important that such conversations were undertaken by someone with an understanding of the individual's culture and religious beliefs and traditions around death and dying.

6.6. Responses to the concept of local community initiatives

6.6.1 Overall responses

The concept of community-based support was introduced and explained to respondents (listed within the topic guide; see Appendix 1). The idea of community-based support was generally welcomed. However, at times respondents found it challenging to envisage what this might look like in their own communities, and case studies – in the form of stimulus materials provided in research sessions - were needed to bring the concept to life.

Respondents saw a recognisable gap in terms of needs, and community provision was seen as a supplement for what healthcare does not (and is not expected to) provide. This was commonly seen as an acceptable and welcomed role for communities and volunteers today. For many, the overall concept evoked an idea of 'traditional times', when communities and people supported one another.

'For support and being able to help do other things, I think it's definitely a great need.' (Carer of person with terminal illness)

However, the concept could also feel idealistic, particularly to mainstream audiences. As discussed earlier in this report, the concept of 'community' was complex in terms of its meaning to an individual, and for those who did not feel part of a local community the concept of community care and support initiatives was hard to envisage. Consequently, several respondents questioned how a community could come together to provide support, if no sense of community currently existed. For such respondents it therefore felt easier to see the idea working in practice for those who were already part of, and engaged in, a local community but was not seen as applicable to all. At worst, there could be accusations of this being compared to the 'Big Society' which was not seen to have worked, and respondents could question exactly who or what would be behind such initiatives and what funding and longevity could be expected. Some noted that projects would need credibility and passionate leadership in order to drive forward and be successful.

The phrase 'community driven' was problematic, with different people having different associations with the term. Some respondents assumed that projects that are 'community driven' would be small, poorly funded or poorly supported. Funding in particular was often raised spontaneously and quickly within the discussion, and many respondents questioned who would pay for initiatives. These issues raised further concerns about how community initiatives would be set up and sustained, and whether anyone would want to be part of an initiative with little perceived security.

'You don't want to be starting initiatives and projects for them to wither on the vine because they're on very shaky funding.' (Carer of person with dementia)

When respondents considered the idea more broadly however, providing support and services in the community – for example, a national charity such as Age Concern organising local events - felt more appealing than these being devised and driven by the local community (i.e. by the people within the community).

The views of the ethnic minority respondents were similar to those of the mainstream audiences. The concept of local community initiatives was seen as a good idea which would work for both men and traditional women (who may feel more comfortable going to faith settings), non-English speakers and the elderly. Community initiatives were seen as accessible and relevant, so were seen to meet people's religious and cultural needs. It was also thought that having specific initiatives within ethnic minority communities would boost people's confidence in attending – for example, by having no language or cultural barriers.

'I am confident and can go to any group in any setting. But I know many women from my community don't have the confidence to go to mainstream groups. It is not about the language, but it is about the confidence to join in mixed groups or with people from different cultures.' (Bereaved, cared for someone with dementia, Pakistani respondent)

'This is a good idea for people who might really need the support, but who wouldn't go out seeking it because of language and cultural barriers.' (Carer of person with dementia, Pakistani respondent)

Further barriers to community initiatives were identified by ethnic minority respondents. A lack of trust and confidence in community-based initiatives was evident among a few older South Asian respondents, some of whom felt that community groups would fail to deliver a credible, quality service. Particular concerns raised included whether confidentiality would be maintained, and whether they would be judged by other members of their community.

'Community groups are good to deliver services like advice on benefits and filling forms, but something like this requires real expertise. I don't think many Asians will feel confident approaching them for services. It will be hard to change people's attitudes and mindsets.' (Adult child influencer, Indian respondent)

'It has to be in a neutral place where I feel safe to go and don't feel that my community is watching me. I want to feel secure that the person I am talking to will not gossip and my story then is spread in the community.' (Bereaved, Pakistani respondent)

'I would be scared to go to a community group for such matter because I will be worried about my in-laws finding out.' (Carer of someone with dementia, Pakistani respondent)

Muslim women additionally reported that they may not feel comfortable about going alone to mosques or other community based settings. Concerns about how the elderly or housebound would access the services were also raised.

'I won't feel comfortable going to a mosque to access the service. First of all people will wonder what I am doing there and secondly there are only men there. Most women won't go.' (Carer of someone with dementia, Pakistani respondent)

6.7 Reactions to case studies and themed stimulus boards

6.7.1 Overview of reactions

Respondents were shown a series of themed boards, showing case studies about how different communities had implemented community-based services. 3-4 themes were shown to respondents depending on the audience.

These stimulus materials were seen as an interesting way to bring the topic to life and, taken together, they explained the concept well. They demonstrated that there was no single blueprint for what a community-based approach should look like, but when combined they showed the breadth of approaches available. The range of approaches allowed respondents to start to see how the idea could work in their own community. There was interest in each theme, depending upon such factors as a respondent's age, attitude, personality and local community, and most people found an idea that they could engage with and thought would work in their own situation and community.

'I'm more impressed with the variety so you know that there are people out there that want to help. I can't really see anything on there that would be beneficial to the situation that I'm in.' (Carer of person with dementia)

6.7.2 Case studies covering breaking taboos and encouraging conversations about end of life

As a theme, this encouraged discussion and debate around the types of conversations respondents had had with their friend/family members, and the most effective and appropriate stage at which to have them. The case studies represented both breaking broader taboos around normalising death and dying, and encouraging conversations about wishes surrounding end of life. Both of these were acknowledged by respondents to be important, but also challenging, as many people are fundamentally frightened of dying. The topic could therefore evoke their own mortality, with the older generation in particular still feeling that discussions about death are taboo.

In terms of the individual case studies listed on the stimulus board, some were more positively received than others. The idea of Death Cafés, for example, could evoke a strong negative response. The term 'Death Café' was often disliked as a name as it was thought to sound morbid, and made people feel uncomfortable. Both the logo and branding reaffirmed initial thoughts and the skull and crossbones were seen as unappealing. There was also confusion surrounding the concept - for example, who this type of event was for, how it would be facilitated and what would be discussed.

'This one turns me off completely, the one talking about Death, the Death café.'
(Carer of person with terminal illness)

However, a number of respondents reacted more positively to the idea of Death Cafés. Those who liked the concept (rather than the name) thought it could be a way of positively normalising death and dying for the wider general public. Some also thought it could be beneficial in a therapeutic way - a chance to emotionally connect with others who had had similar experiences.

'If they changed the name then it may be something we would go to, I can see it has some value.' (Carer of person with terminal illness)

Some of the other case studies shown were more positively received. The Natural Death Centre² often evoked a positive response as a useful, practical resource for carers. Its key benefits were seen to be providing advice, information and education about death, dying and the practicalities attached to these, alongside potential tools to support carers. The Bucket Project³ was also praised for offering resources, and one of its tag-lines of 'this event won't kill you' sometimes raised a wry smile – challenging death and fears in a direct way with light humour.

²<http://www.naturaldeath.org.uk>

³<http://thebucketprojectliverpool.blogspot.co.uk>

Similarly, the Schools Hospice project⁴ was also often praised, and the benefits to both the child and older person were appreciated. Children were perceived to benefit from learning from and respecting the older generation, with the possibility of additionally reducing fears about death and/or hospices. Older people in the hospice were perceived to benefit from the stimulation of time with children.

The idea of using arts projects to break taboos and normalise death and dying received mixed responses across the sample. Some welcomed these types of projects as a way to open people's minds to discussing death and dying, and as a way of breaking a taboo. These were identified as useful more broadly in society rather than as a way to directly help and support someone on an end of life journey. Some respondents additionally raised the value of films eg *Still Alice*, a recent film depicting early onset dementia, in helping to raise awareness and understanding of the condition. However, for other respondents, the idea of arts projects did not engage.

'It's not for me, but in a way I wish this kind of thing had been around 10 years ago, before I actually needed it, so to speak. I mean, if I had seen this when mum was still years away from her diagnosis, it might have been useful because we could have started talking about death outside of her actually dying, if you see what I mean. So I think it's a good idea, but for the general public, not those who are going through it – it's too late by that point.' (Carer of person with terminal illness)

6.7.3 Case studies covering support for carers and bereaved people

As noted earlier in this report, there was a clear need for emotional support for carers and the bereaved. Practical support was also considered necessary – which included factors such as respite for carers, support with transport for their friend/family member (to social activities as well as medical appointments), help around their own home or their friend/family member's home, and information about the particular condition.

The case studies shown on the 'Carer Support' board therefore resonated strongly with both carers and bereaved ex-carers, even if they had not previously considered their own needs due to their focus on the needs of their friend/family member.

Overall, the concept was generally welcomed, particularly the provision of a safe environment for discussion and emotional release.

'For me, the key thing is that we're not alone, people do it and people do an awful lot more than what we do... we want to do what we can, but it's nice to know that

⁴<http://www.stchristophers.org.uk/public-education/schools-project>

other people have got even bigger problems and are coping and still caring as well.’ (Carer of person with dementia)

Practical benefits were also noted by respondents. These included allowing time for other routine tasks that may have been neglected due to the extensive time-burden of care, or simply being given the opportunity to have some time apart from the person they care for (this was especially noted in carers of people with more advanced dementia). Other benefits included the provision of practical advice and information about death, dying, funerals, finances etc.

‘Just having a support group where we’re talking to people who have experienced it or are still experiencing it. I know that’s not for everybody but for me...getting out the house for a couple of hours really is a massive thing that people take for granted.’ (Carer of person with dementia)

Although few people in the sample had actually accessed community-based support as a carer, those who had recognised its value in terms of emotional, practical and educational support. Some anecdotes cited by respondents included a carer support group in London and a Dementia Carers course provided by the Alzheimer's Society⁵. Occasional barriers were however also raised for example, a respondent who attended a dementia group felt that he could not talk freely as he had no option but to take his friend/family member with him and felt unable to discuss her condition in their presence.

Some of the themes also extended to bereaved respondents. As previously discussed, many bereaved respondents reported a gap in their lives after their friend/family member died. The concept of peer support groups therefore extended to bereaved respondents, and was seen both as providing a place to talk about emotions, and as a place to talk about their friend/family member without embarrassment. Some bereaved respondents considered that peer to peer support earlier in the process could help support carers through the dying and bereavement process. It was further suggested that information about support activities could be given to the bereaved after the point of death.

Some ideas were developed further on discussion. The idea of a peer to peer support theme was appreciated, particularly the idea of bereaved people ‘passing on the knowledge’ to carers. Such knowledge might include ways to recognise when end of life is approaching (eg excessive sleeping), particular condition-specific issues, and emotional and practical support from the perspective of someone who had been through a similar journey. Some respondents also suggested linking carers with other carers who look after someone with the same condition, as they can understand one another’s

⁵<http://www.alzheimers.org.uk/training>

situation and can also discuss practical issues such as medication. Some would additionally appreciate online or telephone support for emergency moments of need.

6.7.4 Case studies of support for people with a terminal diagnosis or life-limiting condition

Most carers saw the needs of their friend/family members as of primary importance, but they often felt that they were personally meeting all of their friend/family member's needs. It could therefore be challenging for people with conditions to articulate gaps in needs. When considering the case studies on the stimulus boards, respondents reported feeling inspired by the wide range of initiatives. Upon exploration of individual case studies, most were seen as worthwhile and of value.

'I think it's brilliant that so much is going on out there, to be honest I didn't even know a lot of it existed.' (Carer of person with dementia)

Different types of benefits were noted when considering the case studies. Some of these centred on practical ways to improve the person with the condition's quality of life or to provide stimulation for people with dementia – examples of these included Alzheimer's Society's 'Singing for The Brain'⁶, Men in Sheds⁷ and COPD breathing classes. These benefits included social support for people with the condition, providing a better quality of life and, in some cases, potentially providing an extension of life.

Social and emotional benefits were also identified. External stimulus for a person with a condition – for example, being given the opportunity to talk to people outside the family – was reported to be a good conversational outlet for a person with a terminal diagnosis or life-limiting condition. Such involvement felt less emotionally draining for the carer, and could help to enliven and motivate people with conditions. Any support that came from outside the immediate family unit was also seen as less emotional in difficult times, and could be of particular benefit. Furthermore, encouraging normality in the face of illness, and engaging in normal activities, could help to remind people with conditions of the pleasures of normality.

When considering individual case studies, Singing for the Brain was felt to be a very worthwhile initiative in terms of stimulation and socialisation. Men in Sheds was also warmly welcomed by respondents. The name immediately resonated and felt warm, and was seen as a regular and normal physical activity that was appropriate for some elderly men to help prevent social isolation and loneliness.

⁶http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=760

⁷<http://www.ageuk.org.uk/notts/our-services/men-in-sheds/>

Befriending was also well received, although for a few this came with some reservations. The case study detailing 'Compassionate Neighbours'⁸ was seen as providing an opportunity for external stimulation in the home. This generated positive responses, particularly from those caring for someone with terminal illness. Those caring for someone with dementia however were more reserved about the idea, because the nature of the condition meant that people with dementia may not necessarily welcome or trust a stranger in their home. For this idea to work for people with dementia, it was seen as important to have the same befriender for a significant period of time for the purposes of building trust. Understanding the motivations of the befriender was also seen as key, particularly by respondents caring for a very vulnerable or susceptible friend/family member.

For religious ethnic minority respondents, and a small number of church-going mainstream respondents, case studies involving support for people with conditions in a religious context felt appropriate and motivating. Temples and mosques were considered to be acceptable settings, because any conversations about death would be in the context of religion.

The idea of 'Compassionate Community Champions'⁹ was also particularly liked by the South Asian respondents of the small ethnic minority sample included in this research. This idea was seen to provide an opportunity for respondents to give something back to their community. Most South Asian families reported a strong sense of duty towards their elders and the community, so the idea was seen as culturally relevant. The service was perceived to be flexible and accessible, as champions from the same ethnic and cultural background as the person they were visiting, could go to people's homes. Conversely, the option of speaking to champions from other ethnic backgrounds would make some younger South Asian women (second generation) feel more secure about not being judged. Champions could be trained in how to approach subjects within the religious context and could provide both practical advice and emotional support.

6.8 Barriers to accessing or participating in community-based support

Some barriers were identified across audiences and conditions. Some of these were generic, and some were more condition-specific.

6.8.1 Generic barriers to accessing or participating in community-based support

Acceptance of the situation and the approaching end of life was seen as a key barrier to accessing community initiatives – if either the person at the end of life or their carer

⁸<http://www.stjh.org.uk/neighbours>

⁹<http://www.compassionatecommunities.org.uk/get-involved/community-champions>

were in denial, they would be unlikely to seek out or even welcome services targeted at those going through an end of life journey.

Lack of awareness of the availability of such services was also identified as a barrier to access. Carers tended to focus strongly on practical and medical care and on the day to day needs of the person with the condition so carers may not have been thinking of longer-term, broader support options. An understandable focus on practical day-to-day activities which consumed most of their time also meant that many did not consider their own emotional needs for care and support. Having the mental energy to proactively seek out other support was reported to be challenging.

Logistical issues were also considered to be generic barriers to participating in community initiatives focused on end of life care. Factors such as competing commitments and time constraints, physical difficulties with moving and transporting participants and financial constraints, were all frequently raised as barriers.

6.8.2 Specific barriers to accessing or participating in community-based support

Some concerns were raised by respondents around stigma, embarrassment and pride. Some people with life-limiting conditions did not wish to admit that they needed help outside of their immediate family and others felt embarrassed about the diagnosis (particularly dementia) so may actively resist outside help. A number of carers additionally considered that their friend/family member's needs were being fully met by them and other friend/family members and therefore did not think that any more help or support was needed.

If a diagnosis was made in very old age (80+), some respondents reported that the person in question could feel set in their ways and have less interest in meeting new people or trying new activities. The carers of very elderly people reported a life that was strongly based in routines (even before diagnosis), so worried that they would not enjoy new activities which were seen as being out of their comfort zone.

'I think for Mum, because she's so set in her ways that you'll only get through to her is through my Dad.' (Carer of person with terminal illness)

Concerns about trust and of the motivations of people volunteering in-home support were raised by respondents across the sample, particularly those caring for people with dementia. Some carers questioned who they could trust to come in and care for their friend/family member, and reported fears of them being taken advantage of given their vulnerability, or of the person with dementia simply being unhappy with a new person coming into their home. In such circumstances, carers considered that knowing that a volunteer is trained and supported by a recognised charity could help to provide assurances. However, others reported that they would prefer in-home help from

someone they know, such as a friend or neighbour (although they sometimes preferred not to directly request help).

Some aspects of in-home need were identified as inappropriate for community support outside of the immediate family. These could vary between individuals and conditions, but typically encompassed situations where the person was most vulnerable. These included anything where the person with the condition may lose dignity, particularly bathroom-assistance, and with the discussion of personal financial details.

Many ethnic minority respondents reported a preference for discussing issues around end of life or dementia in a one-to-one setting, and expressed discomfort with the idea of sharing their feelings and experiences in a group. Additional cultural barriers were reported among South Asian respondents – in particular, daughters-in-laws may not be permitted to participate in group activities, or to talk to someone outside the family. It was therefore considered that emotional support and counselling for carers or other friend/family members would be more suitable in a 'neutral setting' eg a healthcare setting, library or school.

6.8.3 Additional barriers to accessing or participating in community-based support for people with dementia

The nature of dementia often created further additional barriers to engaging in community initiatives. A person with dementia's need for routine was reported as a possible barrier, as was the possible potential for mood-swings and anti-social behaviour.

Emotional barriers were also reported, particularly when considering attending dementia-specific groups. These could include social stigma, whereby people with dementia or their friend/family may not wish the diagnosis to be public, or lack of awareness and insight by the person with dementia, which may cause them to be confused or upset by attendance at dementia specific activities. In addition, some carers of those in earlier stage dementia also feared that seeing other people in a group who had more advanced dementia would negatively impact their friend/family member in terms of considering their own likely future deterioration.

Additionally, many carers demonstrated a lack of understanding of the importance of brain stimulation for people with dementia. Consequently the motivation of carers to attend groups and activities focused on stimulation for people with dementia may be low.

6.9 Use of language to enhance the concept of 'community initiatives'

The language used to describe community-based services and support was important in respondents' first impressions of the services offered. As already highlighted, the terminology 'community based end of life care' was not always clearly understood, and even the word 'community' felt like a generic term with different meanings for different respondents.

A complicating factor was that end of life and dementia were perceived very differently, so 'end of life' did not often signal the inclusion of dementia to respondents.

However, positive terminology and descriptions of the benefits of attendance were generally well-received, as were references to compassion and caring, which had emotional appeal. However, other terminology could be misunderstood – eg 'Care in the community' was widely interpreted to mean either social care or mental health care.

For dementia-based support, there was an argument that the word 'dementia' should not be overly prominent as it may actually prevent attendance, as some people with dementia may be unaware of (or have forgotten) their own diagnosis.

Finally, the concept of a 'carer' was not well-understood in some ethnic minority communities.

'People will only be interested in the service if they understand what it is. They will only benefit from this service if they know what it could offer. For example, many people in the Asian community don't see themselves as carers, so they will not respond to the idea of a carers forum even though it would help them.' (Bereaved, cared for someone with dementia, Indian respondent)

6.10 Involvement and engagement in community initiatives

As previously discussed, information about locally available community-based support was seen as sporadic. Although a small number of respondents had looked online to find out about local services, they would prefer to be signposted to relevant activities or support along their journey by the medical profession. Ideally this would involve a face to face interaction with a healthcare professional who would talk them through all the available options.

'I think I'd like to hear about this stuff from the GP, leaflets are pointless for me, I wouldn't bother reading them.' (Bereaved, cared for someone with dementia)

It felt important to explain the benefits of community initiatives to the carer. This was seen to both encourage them to access the support and to effectively give them permission to attend. Elaborating on why their friend/family member would benefit may help to alleviate any feelings of guilt, particularly in relation to their own participation.

As previously discussed, some key questions were raised by respondents regarding funding and sustainability, which impacted on the likelihood of participation. Their key concerns centred around who would be driving this whole broad concept at a strategic level, who was driving the initiatives at a local level, where funding for these would come from, and how initiatives would be sustained over a long period of time. There was a sense that to really drive these initiatives through and make them fully integrated and beneficial, there would need to be significant attitudinal change about death and dying, a change in attitudes to 'community' and how people treat and support one another formally and informally within that community, as well as structural development and formality, all of which would take time.

For some respondents, the appeal of initiatives differed according to who or what was perceived to be behind them. Most respondents suggested that they would look for credible, known organisations to spearhead and initially deliver initiatives to ensure its sustainability.

The vulnerability of friend/family members was a key concern, particularly for those with dementia, where carers could be very suspicious about volunteers and their motivations. Ideally, respondents reported that they would prefer not-for-profit organisations, and some respondents commented that they might be more skeptical if initiatives were being run by a commercial enterprise.

Charities were considered to be well placed to drive community initiatives – as they were perceived as trusted, safe and credible organisations with extensive knowledge and no hidden agendas, which are run by well trained, professional staff. A number of charities were spontaneously mentioned that were seen to fit well with specific conditions – eg Age UK, Alzheimer's Society, MIND, and Macmillan. Hospices were also trusted as safe, credible institutions with well trained staff, but some respondents were concerned about their 'image' which was perceived to be strongly connected to death and dying. Religious institutions could be polarising dependent on personal beliefs, but, were recognised as established non-profit communities with structure and stature which may be well-placed to offer initiatives to particular communities.

6.11 Encouraging involvement and volunteers

There was general recognition among the sample that volunteering in an end of life or dementia specific initiative can be challenging as it involves engagement with an emotionally sensitive topic. Some respondents who were going through an end of life care journey with a friend/family member considered that they were likely to need time to grieve before they could support others, but could see themselves helping with initiatives in the future.

Understanding the cycle of reciprocity and how to recognise those who may be more receptive to volunteering could be key in terms of developing ideas – some people may be more receptive to being engaged, but others may need encouragement. Two particular audiences were identified by respondents as well suited to the possibility of volunteering in community initiatives. These included newly retired people who had more time available and may be at a life-stage of wanting to ‘give back’, people who have been bereaved and now feel able to support others.

Ethnic minority respondents noted the need for wider awareness raising about death and dying within ethnic minority communities to encourage volunteers. They noted that awareness-raising and education would need to be approached sensitively, with some relationship-building and trust established before a person could talk about death and dying. It was suggested that general awareness-raising to enable discussions in a socially and culturally acceptable way could be accomplished through community events (Hindu melas, shopping centres, temples). Testimonials from community members and examples of initiatives specific to a community were also suggested as ways to help raise awareness, understanding and trust among communities which were less likely to publically discuss death and dying. It was also proposed that ethnic minority media channels could also be utilised, along with GPs, ethnic minority celebrities and other leaders of influence (including religious leaders) within particular community to encourage involvement.

7. Conclusions

7.1 Overview

The research has demonstrated that there are many different levels of needs with regard to end of life care and community initiatives, which vary across conditions, individuals, families etc. Furthermore, carers and people with conditions are not necessarily aligned - both have different needs, many of which are not fully recognised or acknowledged. The current focus on palliative care as the main element of end of life care is acknowledged by many, with examples of good support accessed. For dementia carers in particular, the research highlights the gulf that can exist in current care provision. For some, there remains a substantial gap between the point of diagnosis and the ongoing support that may be required over the subsequent years until end of life is reached. Most would welcome support beyond direct service care and non-medical services.

7.2 Awareness and experiences of community initiatives

The research showed variable awareness of and uptake of community initiatives in each area. Even in areas where the Dying Well Community Charter is being piloted, there was low awareness among research respondents who lived in these areas of any community initiatives. Some respondents had found an initiative by chance, or had been referred or recommended by either a hospice or healthcare professional who thought they would benefit from the service. There were also a small number of examples of grassroots initiatives or informal support in their communities which further highlighted the varied nature of community end of life care initiatives experienced across the sample.

7.3 Perceptions of and appetite for community initiatives

The idea of public health approaches to end of life care that bring together communities and healthcare/voluntary services was welcomed. This was seen as a concept that could make a valuable contribution to the lives of those with life-limiting conditions and their carers. However, it could be hard to understand what the concept actually meant, and it could sound idealistic. While the case studies brought the idea to life and demonstrated the difference that such initiatives could make, they also highlighted some of the key issues and challenges surrounding the concept, its delivery and implementation.

A key reason why community approaches could make such a difference is that they appeared to match areas of currently unfulfilled needs, but could still go further. Such needs included:

- emotional support for both carers and people with conditions
- social interaction for the person with the condition (possibly alongside some respite for the carer)
- practical life-planning for both carers and people with conditions
- logistical and practical support for both carers and people with conditions
- condition-specific needs impacting on quality of life for people with conditions

7.4 Involvement and participation in community initiatives

Some barriers were raised to participation in community initiatives. These included the need to signpost initiatives, recognising needs, acceptance of the need, logistical barriers, interest in the type of activity and trust/vulnerability. Questions about funding and sustainability were also raised, and the need for a credible organisation to be involved.

Newly retired people and people who had been bereaved having previously cared for a friend/family member, were seen as ideal people to approach to volunteer in initiatives.

7.5 Dementia

Dementia was often considered distinct from other terminal conditions, particularly in its early stages where it was not considered as a terminal condition. This research highlights the importance of recognising the specific needs surrounding dementia, and how these needs impact on the way in which people with dementia and their carers access and engage with end of life care and support. The key insights that are most likely to impact on uptake of community services from the dementia specific sample of this research include:

- the challenging nature of the condition and its impact on individual and carers
- the variable nature and impact the condition has upon personality which makes it harder to plan consistent care
- the emotional, practical and psychological strain on carers which can dramatically impact on the quality of life for carers, whose needs are rarely addressed
- moving to advanced stage dementia can impact on the relationship between people with dementia and carers, with a shift for the person with the condition from adult to childlike
- less clear care pathways and poorer service-provision for dementia compared to other conditions, and lack of general understanding of the condition among the public, make it more challenging for carers of people with dementia to access community support

7.6 Language and terminology

Responses from participants in this research demonstrate that community end of life care initiatives clearly have the potential to help address unmet needs of both carers and people with conditions. However, the language and terminology used to describe these can be challenging, and it can be difficult to readily identify a meaningful way to express the generic idea that brings to life community approaches, demonstrates their key roles and values, and – most importantly – clearly differentiates the concept from other health service provision. There could, for example, be confusion between services provided in the community such as social care, and extended services offered by hospices and health charities.

The term 'Compassionate Communities' could work to communicate a different kind of service and relationship. This phrase also semiotically evoked the sense of positive care and reciprocity that lies at the heart of the concept. The word 'community' can however be loaded, and have different meanings to different people, sometimes with negative connotations. Responses to specific ideas such as 'Death Cafes' effectively illustrates the impact of naming-language and likely receptiveness to specific initiatives.

8. Recommendations

The research suggests several potential improvements to end of life care, involving different audiences. Overall, the findings demonstrate that the majority of participants welcome community approaches to end of life care as a way of meeting emotional and social needs, and that local players, commissioners and authorities should consider community approaches in their future local implementation of end of life care.

Despite a positive reaction, implementing the approach in a consistent and considered way across the country is likely to require the investment of time, effort and funding. It will take time to build on the current successes, and to change attitudes to end of life care, particularly when considering the fundamental attitude shift required to address the taboo and also to encourage a sense of caring for others and community support. Key concerns centre around how this concept is developed and supported at a broader strategic level, implemented at a local level and funded.

In evolving the idea and thinking how best to progress its implementation, there are a number of important considerations.

8.1 Recommendations for developing the concept:

- recognise current challenges in the language and terminology used to express the concept. 'Public health approaches to end of life care' is not a phrase well-understood by members of the public and should be simplified and clarified. It would be beneficial to develop a single generic term that best expresses the core concept and will help ensure the concept meaning and relevance to as wide an audience as possible
- consider ways to integrate community-based approaches with existing models of care, including those provided by third sector charities, as individuals look for credible established organisations with adequate funding to deliver these initiatives
- invest in creating a coherent strategy in which the complex concept and disparate ideas and examples can be unified in a way that will help to join initiatives across the country to raise awareness and access
- continue to include emphasis on breaking down barriers and taboo around death and dying, which serves as a barrier to accessing, engagement and involvement in community end of life care initiatives

8.2 Joining up healthcare and community initiatives:

- focus on raising awareness of existing community initiatives and emphasise the benefits of these initiatives to guide and encourage public engagement
- join up local community initiatives with local healthcare services to ensure information sharing, signposting and a continuity of care. For example, this could include community initiatives aligning with GP surgeries, local hospitals, health charities etc
- recognise that informal carers are a key player and target carers with information about initiatives that may support both them and the person they care for
- align this end of life community approach with wider initiatives in healthcare around community approaches – such as Dementia Friendly Communities

8.3 For those setting up initiatives:

- be explicit about the benefits of the approach, including why it is distinct and how it complements and adds value to the health model of care. This should include references to education, increased awareness, support at all stages along the journey etc
- consider how best to structure and set up initiatives to ensure credibility, stability and longevity. Respondents in this research discussed their willingness to access and volunteer only in those initiatives which had sustainability
- develop initiatives with the involvement of well-recognised and trusted partners such as hospices, key charities etc. to help add gravitas, build trust and gain traction in the initial development phase
- identify key leaders in communities and engage receptive individuals who may have previously benefited from such initiatives and could go on to be trained as peer mentors and guides for others
- consider the appropriateness of 'generic' end of life care initiatives – the findings of this research would suggest that dementia specific approaches are necessary and this may also be the case for other conditions not explored as part of this research

8.4 For those setting up dementia-specific initiatives

People with dementia can have a number of barriers to participating in community initiatives – these should be considered by those setting up initiatives for people with dementia:

- consider not explicitly labelling sessions ‘dementia’ as this can be associated with stigma or cause problems for people who have forgotten, or are in denial of, their diagnosis. (*Initiatives* can be advertised as ‘dementia’ to signal their relevance (for carers) but the actual gatherings involving people with dementia could be less explicitly labelled)
- consider different initiatives for different stages across the dementia pathway as carers of people with early stage dementia can be hesitant to ‘expose’ friend/family members to those in later stages (in case it generates fear for their own future)
- consider timings of initiatives as many carers of people with dementia report that their friend/family members often sleep late, and can take a long time to get ready in the morning

Appendix 1: Topic guide and recruitment screener

Ap 1.1 Topic Guide

Introductions (NB – the following was not an exact script and was adapted to audiences. EG for dementia audience, focus was on dementia, not terminal illness).

- This research is going to be thinking about how people who are seriously ill or have a life-limiting condition, or dementia, and their carers and people who have been bereaved, are cared for and supported. But as well as considering the whole of the journey of the latter stages of life it also includes how we, as a community, consider end of life, including breaking the wider taboos and encouraging conversations about death. It is also about how we, as a community, can support one another, and thinking about how we might want our communities to support us at the end of our lives
- Check everyone is happy to discuss this topic
- Who we are, what we do
- MRS guidelines – anonymity, confidentiality, recording of data
- Who they are – name, family, job, hobbies (leave open-ended so that they can tell us about their personal experiences if they choose to – but do not prompt)

Establishing sense of community – open-ended, allow sufficient time **(5 mins)**

- Can you tell me about your local community? (Who is your community?)
- Do you feel that you belong to a local community? How supportive is it generally? Any examples of community support?
- How well do people deal with talking about and helping support those with serious illness/end of life kind of thing in the community?

Care and support currently provided **(5-10 mins)**

As we said, this research is considering people who are seriously ill / have a life-limiting condition / dementia and the way they and their carers, or bereaved people are cared for and supported as they move towards the last year of life (be clear that this is not about a person's final days – this is broader)

- What care and support do you/did you receive? (for person with condition/for self/for family) Moderator to create a mind-map on flip chart (NHS/Medical/Other care and support)

- How well are people in this situation helped, supported and cared for?
- What are the limitations of health and social care provided by the NHS and other professional staff? What do and don't they provide?
- What else might you need, or might be useful that isn't provided? What support or help would you like? (Consider person with condition and carer separately?)
Moderator to create a list on flipchart/separate sheet to refer to later
- Where else could help and support come from?
- What support could we expect from our communities?
- What support might you, as an individual, want to *provide* within the community?
- How would you expect to find out about locally available services and support, or other information?

Responses to the concept and rationale for public health approaches to end of life care
(20 mins)

There is a move now towards recognising the important role that communities play in supporting each other towards the end of life, or when someone has dementia. One of the really key points is that it is a broad approach, starting much early in the process – it is not just focused on the final days of life, but instead recognise that death and dying are going to happen to everyone as a part of life and that society needs to be more attuned to this.

- Community support alongside medical model: Currently, the focus is on care given by health professionals, however there is a move now towards healthcare services and communities working together in recognition that this has a positive impact on everyone's health and wellbeing – it's not about replacing professional care, but enhancing it
- Community involvement: this move is about encouraging communities to develop their own approaches to death, dying, loss and care by identifying their own needs and developing supportive networks. This ultimately leads to a greater sense of communities caring for one another and being compassionate towards each other
- There are three main themes in this new, broader, community-based approach. The first is about education – breaking the taboos around conversations about death and encouraging people to think about their needs and wishes much earlier. It's also about formal initiatives within the community – these might be started by individuals, or by organisations, eg voluntary, palliative or religious communities. Finally, it's about encouraging informal support for everyone involved in the process and acting compassionately
- What do you think of this approach? What does it mean to you?

- What is really interesting/news/have you heard about anything like that before?
- When you think about this, what kind of things can you imagine/anticipate actually happening in your own community?
- Refer back to own list of 'gaps' and 'needs'? Could any of this be provided by the community? Explore

- STIMULUS: Use community stimulus board here, with a list of potential community sources – words and images.
 - Reference community board stimulus – how would it work/fit in/what could they see happening?
 - What could they anticipate might be provided?
 - Who should provide these? At each point in the 'end of life journey'?

- Brainstorm 'current medical model' and 'community model' - what are perceived strengths/weaknesses of the community model?
- What does the community model offer over and above current care? Where could it supplement medical care?
- What words would you use to describe this type of care and support? (language)
- What might the benefits be as a recipient?
- What might the benefits be as a provider?
- (If necessary show benefits board stimulus and review key benefits that engage)
- What might the barriers be to participation in this? (as a Carer/Person with Condition)
- How could the barriers be addressed? What would be needed to address these?

Responses to case studies (15 mins)

We've got some examples to go through with you now, about how a variety of communities have implemented some of these ideas in practice. They cover a broad range of activities and support, from demystifying death through art, right through to providing direct support to people who are nearing the end of life. Review in themes across 'journey' - i.e. early education; support for carers; support for those with conditions; support for bereaved.

- *(Moderator note... please unpick fully both the theme and the specific ideas that sit within this)*

- Reactions to each of these themes - how interesting is this to you? (Understand concept - do they buy into this theme - why/why not?)
- Reactions to types of case studies included - what engages interest/doesn't engage and why? Detailed reactions to each - what are the triggers/barriers to engaging with each specific idea - name/idea/setting (i.e. group/individual); why does it/doesn't it work within this concept for them?

- If the specific case study ideas do not work within the theme for them why not
- What would work within this theme for them?
- How could it make a difference to you and your family?
- Where on a 'journey' would this kind of thing work?
- Would this kind of thing work in your community'
- If not the specific examples, what else could work for this 'theme' for them?
- What needs do they have within the 'theme' and how would they create an end of life care idea to fit their needs
- Refer back to their gaps; brainstorm

Brainstorm approaches for their own needs and community (**15 mins**, more freeform discussion based on session thus far)

- Brainstorm the gaps and types of support that they might benefit from (carer/person with condition) on consideration of all the issues
- What are their gaps (consider their initial list; consider thoughts now they have seen the case studies and description of new model of care; consider journey stages)
- Thinking about that and the ideas we've talked about, can you give me some thoughts on what community-based approaches might look like for your community?
- What type of organisation/individual might they accept this type of help from?
- Review barriers to accepting this type of help; brainstorm ways to address these?
- How would you expect to hear/be made aware of this kind of initiative?

Terminology

- Discuss use of terminology such as Community Based End of Life Care; Public Health approaches? What feels suitable for them to engage with?
- What best sums up the concept and what it offers?
- What would they 'call' these types of support and help?

Responses to supporting and participating in community initiatives (**10 mins**)

A key part of this approach is encouraging communities to be inspired to develop their own approaches – finding things that will work locally, given the people, cultures and organisations who are there.

- What are your thoughts on this? How well would your community respond to this?
- How do you think people could be encouraged to participate as well as to receive help and care?
- Do people see this as part of their responsibility as a citizen?

- Who might be willing to help? (Brainstorm the type of person who starts initiatives; who joins initiatives)
- What might encourage people to get involved in this?
- Discuss formal and informal types of support? (i.e. 'acts of compassion' 'v' formalised schemes)
- Brainstorm next steps to embed this within the community
- How can we best engage communities?

Sum up (5 mins)

- As a way of supporting people with end of life needs how well do these approaches help people and in what way? What do they add to what is provided already?
- How can we find ways to create opportunities for these to be developed as an integral part of support? What are the challenges associated?
- Out of everything we've shared, what 3 things are they going to go home and talk about to friends and family?
 - What has inspired them / made them think about things in a different way?
 - What does this mean in terms of where they are now and in the future?
- Any further points they wanted to add

Ap 1.2 Example recruitment screener for bereaved people (separate screeners were used for each audience type)

A. Have you ever taken part in a group discussion or interview?

Yes

No

"NONE TO HAVE TAKEN PART IN A STUDY RELATED TO END OF LIFE CARE IN THE PAST 6 MONTHS"

B. What was the subject of your most recent market research?

"RECORD"

C. What was the date of your most recent market research?

___/___/___

"RECORD"

D. Please check the respondent has a good command of the English language.

Yes

No

"ALL MUST HAVE A GOOD COMMAND OF THE ENGLISH LANGUAGE"

E. What is your current working status?

Full Time

Non Working

Part Time

Retired

Student

"RECORD"

1. Do you or any of your immediate family work in any of the following occupations?

Advertising

Marketing/Market Research

Journalism/Press/PR

For any government or healthcare organisations (including health charities)

As a nurse or healthcare professional providing care for patients

None of the above

"ALL MUST CODE NONE OF THE ABOVE"

2. Please can you tell me your age?

"CLUSTER THE AGE GROUPS TOGETHER.

AIM FOR BEREAVED 65 + RESPONDENT 40-70 YEARS OLD

BEREAVED 65 OR YOUNGER- 30-60 YEARS OLD "

3. Record Gender:

- Male
- Female

"Q5 - FEMALE/BRISTOL

Q6. MALE/LIVERPOOL

Q7.MEN/BHAM

Q8. FEMALE/HACKNEY"

4. How would you describe your ethnicity?

- African
- American/Canadian
- Asian/Bangaldeshi
- Asian- Indian
- Asian- Pakistani
- Asian-Sri Lankan
- British Asian
- Caribbean
- Chinese
- Mixed White & Asian
- Mixed White & Black African
- Mixed White & Black Caribbean
- Other Asian background
- Other Black background
- Other Ethnic background
- Other Mixed background
- White British
- White Irish

**SCREEN OUT : PAKISTANI, BANGLADESHI, INDIAN, INDIAN, BLACK CARIBBEAN" –
USE BME SCREENER**

5. What is the occupation of the Chief Income Earner (CIE) of the household?

"Q5 - BC1/BRISTOL

Q6 - C2DE/LIVERPOOL

Q7 - C2DE/B'HAM

Q8 - C2DE/HACKNEY"

6. Have you been involved in caring for a family member who has passed away with advanced:

- Dementia
- Cancer
- MS
- Motor Neurone Disease
- Huntingdons Chorea
- Heart failure
- Severe COPD

Severe kidney disease

Other terminal illness

"Q5 - DEMENTIA/BRISTOL

Q6 - TERMINAL ILLNESS/LIVERPOOL

Q7 - DEMENTIA/B'HAM

Q8 - TERMINAL ILLNESS/HACKNEY

NO MORE THAN 1/3 TO HAVE HAD CANCER"

7. How long ago did your friend or family member pass away?

"ALL MUST HAVE BEEN BEREAVED IN THE PAST 2 YEARS BUT LONGER THAN 6 MONTHS AGO"

8. What was your relationship to the person that you provided care for?

"Q5 - DAUGHTER / FEMALE SIBLING / FRIEND OR PARTNER - BRISTOL

Q6 - SON / MALE SIBLING/ FRIEND OR PARTNER - LIVERPOOL

Q7 - SON /MALE SIBLING / FRIEND OR PARTNER -B'HAM

Q8 - DAUGHTER/ FEMALE SIBLING / FRIEND OR PARTNER - /HACKNEY

EXCLUDE CHILD BEREAVEMENTS"

9. Please can you tell me the age of the person that you provided care for when you were bereaved?

"RECORD AGE

Q6 - <65/LIVERPOOL

Q8 - >65/HACKNEY"

10. Was the person you provided care for in a residential care home or hospice during the final stages of life?

Yes

No

"RECORD"

11. Are you happy to be re-contacted regarding similar research in the future?

Yes

No

"RECORD "

12. How was the participant recruited?

"RECORD- DO NOT ASK "

Confidentiality

Any and all information provided to Acumen Fieldwork, our client or any other company or persons working on our behalf on this market research project, is strictly confidential and bound to us in accordance with the Data Protection Act 1998. Your details will not be passed on to any third party company and anything you say or do will be strictly confidential and will not be related directly to you in any post-research reporting.

Recruiter Declaration

I confirm that this interview has been carried out with the respondent named, and that it was done in accordance with the instructions of Acumen Fieldwork and the Code of Conduct of the Market Research Society.

Recruiter Name:

Recruiter Signature:

Date:

Appendix 2: MRS guidelines and code of conduct

*Adapted from a document produced by Christine Roberts
(christine.roberts@phe.gov.uk)*

Does market research protect the values of ethics requirements?

- Yes it does, all the market research agencies on the cross government framework comply with a professional Code of Conduct as specified by the Market Research Society (MRS)
- This Code of Conduct is comprehensive and is used internationally
- As mentioned above, all commissioned market research follows the prescribed protocol of tendering a research brief (ITT) to relevant market research agencies via the Framework in collaboration with PHE procurement
- The comprehensive MRS Code covers research from the inception to design and from execution to use. It is relevant for market, social and opinion research. These regulations cover legal requirements and how these apply to research
- MRS members must adhere to the MRS Code of Conduct, Regulations and the associated disciplinary procedures. See link
[https://www.mrs.org.uk/pdf/code%20of%20conduct%20\(2012%20rebrand\).pdf](https://www.mrs.org.uk/pdf/code%20of%20conduct%20(2012%20rebrand).pdf)

How does the MRS Code of Conduct apply to Market Research?

- The Code of Conduct is designed to support all those engaged in market, social or opinion research in maintaining professional standards. The Code is also intended to reassure the general public and other interested parties that research is carried out in a professional and ethical manner. In brief, the main principles of the MRS Code of Conduct are listed below:
 - Researchers shall ensure that participation in their activities is based on voluntary informed consent.
 - Researchers shall be straightforward and honest in all their professional and business relationships.
 - Researchers shall be transparent as to the subject and purpose of data collection.
 - Researchers shall respect the confidentiality of information collected in their professional activities. See link

The Data Protection Act 1998 and Market Research: Guidance for MRS Members

- Researchers shall respect the rights and well-being of all individuals.
- Researchers shall ensure that respondents are not harmed or adversely affected by their professional activities.

- Researchers shall balance the needs of individuals, clients and their professional activities
 - Researchers shall exercise independent professional judgement in the design, conduct and reporting of their professional activities
 - Researchers shall ensure that their professional activities are conducted by persons with appropriate training, qualifications and experience
 - Researchers shall protect the reputation and integrity of the profession
- In addition there are guidelines on the MRS website for various different types of market research methodologies and different audiences, the link below covers qualitative research and there is a chapter called 'Ensure Emotional Well-Being' (pages 14 – 17) which is highly relevant to the issue of respondent well-being/ethics of the interview etc
- <https://www.mrs.org.uk/pdf/2014-09-01%20Qualitative%20Research%20Guidelines.pdf>

Appendix 3: Rapid literature review

Ap 3.1 Summary

A rapid review of literature was carried out prior to the qualitative research. This was to investigate and scope out the arena, to define the topic areas to be covered in the qualitative research, and to input into development of the topic guide and stimulus materials.

Ap 3.2 Key Findings

Ap 3.2.1 Low Awareness Among the General Public about Approaches to End of Life Care

Few studies directly examine general public awareness of, and attitudes to, public health community development approaches to end of life care. Most of the directly relevant research focuses on the experiences of those already engaging in such initiatives, eg informal carers, stakeholders such as hospice staff and terminally ill people, rather than on the wider general public.

Studies that have included a general public sample suggest low awareness of end of life care generally, least of all of community-approaches. Discussion of end of life is widely acknowledged to be unpleasant and uncomfortable, often resulting in it not being addressed until diagnosis of a terminal illness. Even then, studies suggest that the issue is not often fully considered (Abba et al, 2013) – conversations typically focus on where a person would prefer to die rather than of the full set of factors that comprise a ‘good death’, and of how a community-based approach might enhance this.

Ap 3.2.2 Potential for Community End of Life Care to be Well-Received

Studies consistently report the benefits of community-developed end of life-care. By engaging communities, it is possible to expand and extend the reach of more traditional medical palliative care, therefore addressing a greater range of needs of people with conditions, their carers or the bereaved. Such needs can encompass social, psychological and spiritual needs. These can include the ability to access better care at end of life, and lower levels of mental health issues, including lower rates of depression in the last week of life (patients) and lower levels of depression, anxiety and stress six months after the death of a friend/family member (carers). Furthermore, community-developed end of life care can also raise awareness about death, dying, loss and care.

However, most of these studies typically focus on participants who are, or have previously been, involved in community initiatives. Few studies have directly considered the issue of whether community-developed end of life care would be well received by the general public (i.e. those who are not yet engaged in end of life considerations).

When considering the body of literature as a whole, there is considerable anecdotal and implicit evidence suggesting that – when properly framed, considered and discussed – the general public’s appetite for community-developed end of life care could be considerable. Several of the factors that are considered key in why people would prefer to die at home could be included in community-based approaches, alongside some of the more practical aspects (eg quality of care, ability to provide symptom-relief) of dying in a medical facility.

Ap 3.2.3 Focusing on Possible Inequalities – Ethnic Minority Audiences

Aside from two case studies – one focused on South Asian Muslims in Scotland, and another on African Americans in the USA – few of the supplied studies specifically consider community-based end of life care for ethnic minority audiences.

One of these, by Gaveras et al (2013; secondary data analysis) focuses on the social support needs of South Asian parents living in Scotland who were severely ill and also had young children, while the other looks at perceptions of advanced care planning for end of life among seriously ill African-American older adults (Saith et al, 2014; abstract only).

Gaveras et al (2013) identify concerns that ethnic minorities in the UK may be less likely to use formal supportive care services, which may be due to either less need for such services, or to inequalities in access and acceptability of healthcare. With regards to end of life care, factors found to be associated with the lack of uptake of palliative care services among ethnic minorities include socioeconomic status, attitudes towards palliative care, lack of knowledge of available services, mistrust of healthcare providers, lack of referrals and dissatisfaction with healthcare providers. Gaveras et al further suggest that ethnic minorities in the UK may have a more fragile social support system than has previously been assumed, and that even those with large extended social networks may have inadequate social support, particularly at end of life.

Pertinent findings of the study identified some further needs (beyond those experienced by ethnic minorities) that South Asians may experience, that could be considered/addressed in a community development approach to end of life care. These include the fact that some extended friend/family members who may have assumed caring duties may live overseas, and cultural factors involving the gender of the patient and primary carer.

Ap 3.2.4 Focusing on Inequalities – Dementia End of Life Care

Although people with dementia and their carers are included in some studies, the results of such studies are often aggregated and dementia specific elements are not differentiated in the results of these studies. Only one study focused specifically on dementia when looking at caring for people with dementia (Dening et al, 2013).

In their recent study (2013), Dening et al examine how much consideration is given to a dementia patient's preference for end of life care, as opposed to the preferences of their carer(s). This qualitative study considers how people with dementia (who were able to give informed consent to take part in the study) define their wishes and preferences for their end of life care, how family carers define preferences for their own end of life care, and whether the expression of the wishes and preferences of the person with dementia are facilitated or inhibited by the carer being present during the discussion. Results found that people with dementia can have difficulty considering their future selves, and that their carers want to have a great deal of control at the end of life. The authors conclude that, to ensure that the wishes of people with dementia are respected, their views should be ascertained early in the disease before their ability to consider the future is compromised. This has particular relevance to public health community-based approaches to end of life which emphasise, among other elements, on the importance of breaking the taboo around the discussion of death and dying.

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