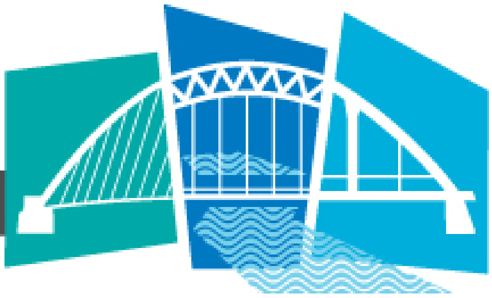
NHS
Newcastle Gateshead
Clinical Commissioning Group

Views and Experiences of End of Life Care for Adults in Newcastle: Engaging with Seldom Heard Groups

March 2017

Transforming lives together



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1.0 Introduction

NHS Newcastle Gateshead Clinical Commissioning Group (NGCCG) are undertaking a review of end of life services for adults in Newcastle and are developing an End of Life Strategy and Action Plan for Adults. As part of the review NGCCG identified a gap in evidence around people's experiences of end of life care and also their preferences at end of life particularly with regard to seldom heard groups. An engagement project took place between July and November 2016 which gathered the experiences, views and expectations of end of life care from people living in Newcastle. Patients currently on the palliative care register and people from five seldom heard groups took part. Within the latter group, both carers of people who had died within the last two years and people with no experience of end of life care services were targeted.

Two hundred and twenty-four people shared their views as part of this project:

- 8 patients and/or their carers who are currently receiving palliative care
- 147 people from Black and minority ethnic communities (BME)
- 31 people who are D/deaf or hard of hearing
- 22 people who are homeless
- 2 people who are blind and visually impaired
- 14 people who are living with a learning disability or difficulty

2.0 Findings

The findings discussed below are consistent with what is known about the general population in terms of what is important to people at end of life but this engagement has highlighted the scale of issues for seldom heard groups and added colour to the national picture. For example, there is already much information about the communication needs of the D/deaf community but the project has shown it is not just about hearing problems and issues of deference have also been highlighted.

2.1 Experience of end of life care services

For patients currently receiving end of life care, experiences were all very positive. They had support from caring, knowledgeable health workers, were able to be cared for in their own home and reported good communication between health professionals. Furthermore, they all felt involved in decisions about their care. However, when explaining their response some people actually cited examples of being informed of decisions around their care or being able to ask questions about it. Whilst patients are clearly happy with their level of involvement and being mindful of the fact that it is not always possible to be involved in every care decision (nor will everyone want to) these responses could suggest a misunderstanding around what actual involvement in decisions entail as per the NHS Constitution.

Carers of 23 people who had died within the last two years (and one who was still caring for someone) reported a more mixed experience, highlighting positive aspects but also some key issues with the services they had received.

Communication

Communication between health workers and patients and their carers was a key issue for BME and D/deaf and hard of hearing participants. A lack of access to interpreters or written information in a language other than English was identified with several examples highlighted where communication was impossible without family members being present to interpret information on the patient's (or carer's) behalf or carers having to lip-read what doctors were saying to them. This is concerning as these patients are not being offered the opportunity to be involved in their care or are only involved through the use of family members who are not trained and should not be expected to pass on complex health information to patients. Carrying out an interpreting role prevents carers from being able to be fully involved in decisions about their loved ones care and may, as one participant highlighted, be put in a position where they have to interpret very emotive information about withdrawing treatment to their own relative (the wife of the patient). This lack of communication support was evident in hospital and hospices and there was a belief amongst BME and D/deaf and hard of hearing participants that this would also be the case in care homes, resulting in their isolation. Sharing information about the communication needs of the patient with all care staff was also an issue as was a lack of support for carers who have communication needs and look after a patient at home.

Cultural needs
Services not meeting the cultural needs of patients and carers was another issue which arose. It was felt that there was a lack of staff awareness of the needs of D/deaf and BME patients and carers. For the former for example, there is a need to recognise a culture within deaf communities of deference to hearing people which often means they accept, without complaint, any services offered. For people from some BME communities, a lack of access to staff from the patient's community, a lack of support around their religious practices and a lack of same-sex staff to care for the patient and uphold their religious beliefs was reported. For example, in relation to faith needs, the family of one individual recounted having to "fight" to get a separate room in the hospital where they could recite the Quran to the patient.

Identifying patients at end of life
For one homeless person who was caring for a close friend who was also homeless and had drug and alcohol addictions, their issue was that the person was not identified as approaching end of life early enough and therefore no end of life care was received.

Awareness of end of life care services
The engagement has revealed a lack of awareness of what end of life care services actually include (167, 87.0% of participants) and this was most noticeable among BME participants.

Support for carers
Aside from communication needs, the engagment identified a gap in terms of support for carers after the death of their loved one; some said they received no support at all.

Recognition of next of kin/main carer
There were several examples where carers were overlooked or not able to get involved in decisions about the care of their loved one; for example, because a hearing family member was contacted instead or they were not officially recognised as such.

2.2 Preferences around end of life care

Discussing end of life care
Only 33 (15.7%) participants had discussed their wishes. This is not unsurprising however as much evidence exists which shows that death is still a taboo subject within

society and people do not like to talk about it; within this report people suggested it was too emotive a subject to talk about. Moreover, for some people it is simply not part of their culture or religious views to discuss these things. Other reasons for not discussing their wishes were because they had either never thought about it or felt that they were too young.

Place of death

When asked, almost half of people (45.8%) said that they would prefer to die at home; it is interesting to note that this figure is noticeably lower than the 70.0% of people suggested by the Dying Matters Coalition. A further 19.6% said that they had no preference about their place of death and 10.7% said they would want to die somewhere else such as their country of birth or at “Allah’s will”.

Other wishes

A peaceful and respectful death was most commonly mentioned. BME participants also wanted care from staff of their gender and if possible, from their background, who spoke their language. One fifth of participants (20.4%) held strong views about being kept alive and if and when they would want medical intervention and this was the area most frequently discussed by D/deaf and hard of hearing participants. For them there was concern that their communication needs would not be met, causing additional stress and giving the patient no dignity. Almost one fifth of people (19.0%) asked that their religious and cultural views be met whilst in receipt of end of life care. Participants specifically spoke about wanting to have a “Muslim burial”, for their “religious rituals [to be] upkept” (and in particular for the body to be released to the family in a timely manner) and several people wished to be buried in their home country. Moreover, people asked that no post-mortem was carried out without the family’s permission. For all wishes identified see 3.2.2.2.

Being able to communicate with staff was also key as was having same-sex staff (including when handling the body) and staff from their background who understood their cultural needs. Considerations around caring for the body were also highlighted as were prayer facilities and visiting the patient. Newcastle Hospitals NHS Foundation Trust has a ritual washing room and prayer facilities available to all patients and carers. For all cultural needs see 3.2.3.

3.0 Recommendations

Some of these recommendations are specific to end of life care services and others apply to any health care service. It is acknowledged that some of the recommendations relating to wishes at end of life are already in place however this highlights an issue around people’s awareness of these services and entitlements. Moreover, other recommendations may also be in place but highlight a need for improvements in these areas.

Discussing end of life care - consider a media campaign which encourages people, at any age to talk about their end of life care and what a good death would look like to them. There should also be consideration of targeted campaigns at a community level, for example, engaging with faith leaders around some BME groups or local organisations that support homeless people. Alongside this, there should also be information available around who to contact for additional help, be it practical advice or emotional support and this help should be accessible for all.

In addition to this, healthcare staff also need to initiate conversations around end of life care wishes. Although it is recognised that no particular healthcare staff have a duty to introduce these conversations, there needs to be an acknowledgement that it is everyone's responsibility. The roll-out of the Standards Project will be a useful tool in this respect. It is also suggested that GP Time In/Time Outs are used to share these messages where they could be a rolling agenda item.

Awareness of end of life care services – consider an educational awareness programme with seldom heard groups involved in this research in the first instance.

Identifying homeless patients at end of life - It is suggested that awareness training for any staff involved in the health care of homeless people is conducted to ensure that identification occurs in a timely manner.

Communication support

There are a number of areas where communication was a barrier to good care and support to both patients and carers with communication needs, as reflected in the recommendations below. However, the implementation of the Accessible Information Standard across Newcastle should go some way to alleviate the issues identified below. However for services such as care homes and hospices outside of the remit of the standard, the recommendations will still stand.

- Ideally, GPs should capture information about their patients' communication needs and this information should pass with them through the NHS services they use. However, to ensure this information is up-to-date and reflects the patients current needs, when a patient first arrives on a hospital ward, in a hospice or care home or begins to receive support from a service, there must be a system in place whereby their non-clinical needs are assessed and any information recorded and, crucially, passed on to all staff caring for the patient. The needs of the main carer should also be assessed. This assessment should also cover cultural needs (discussed below)
- Patients and carers should all be offered support not have to ask for it
- In hospital environments in particular it is suggested that qualified BSL and other language interpreters are available at all times. If face-to-face support is not possible, the use of a telephone interpreting service or a video relay service where appropriate, is recommended. Text messaging should also be offered to patients and carers as a means of communicating. Any communication support should also be available if the patient is receiving medical care at home or in another service
- A review of the process of booking interpreters should be carried out across all end of life care services to ensure that procedures are being followed
- Currently there is only one qualified Social Worker who can use BSL in the North East and to qualify for this support D/deaf people must have additional needs. Consider re-instating the support of BSL social workers to those who do not have additional needs
- Written information should be accessible, either available in other languages or written in plain English. The Patient Advice and Liaison Service holds some useful information and should be used where appropriate

Cultural awareness and need

- There is a need for cultural awareness training for staff providing end of life care so that they have the knowledge and understanding to be able to offer support in the most appropriate way. Any training should include information about the procedures involved in the preservation of the body and also how to explain to people the reasons for undertaking post-mortems. This should include all seldom heard groups involved in this project in the first instance. It is known that this training exists within the Hospitals Trust but there is perhaps a need for refresher courses after a certain period of time, to be put in place. Training is also needed within all other services caring for people at the end of their lives such as care homes and hospices and this should include both health professionals and other support staff
- As with communication needs, when a patient first begins to receive support from an end of life care service, it is suggested that there is a system in place whereby their cultural needs are assessed including any requirements regarding how the body is cared for after death and this should be disseminated amongst all staff caring for the patient
- There should be a physical, private space for prayer available in any environment where patients are receiving end of life care. These services are available within Newcastle Hospitals NHS Foundation Trust but there is perhaps a need for greater advertising of the facilities
- Where a need is identified, provide same-sex workers as the patients and continue this once the patient has died and the body is being cared for. If this is not possible patients should be informed in advance
- Consider the provision of information around returning to their country of birth at end of life or being buried there and working with Mosques and Imams in this respect
- In addition, some cultures and faith groups have particular requirements around moving the body and also how quickly the body is released to the family. It is recommended that wherever possible they requirements are upheld. Newcastle Hospitals NHS Foundation Trust has a ritual washing room but it is suggested that these facilities are available in all end of life care services such as hospices and care homes

Care at home

- It is suggested that when patients start receiving care at home that there is an agreement between all parties that this care is adequate to the needs of the patient. To ensure that patients and carers are fully aware of the scope of such services - exactly what they will be getting, how long the visits should be etc. patients and carers should also have access to a care plan
- It is recommended that every effort is made to ensure that provision of care at home meets the communication and cultural needs of people receiving care
- For carers who have communication needs and are looking after a patient at home it is suggested that a specific care plan should be produced which explains what to do if the patient's health deteriorates and they need medical help urgently

Last stages of life - once it was clear that the patient is in the last stages of life they should be moved to a private room in a timely manner; any restrictions on visiting times and numbers of patients should be lifted to enable family and friends to visit the patient at any time. Newcastle Hospitals NHS Foundation Trust do offer open visiting for anyone receiving end of life care, with more than two family members allowed at the bedside and this should be made clear to visitors. Consideration for other patients however must be given.

Recognition of next of kin/main carer - the main carer should be identified by all services providing end of life care to the patient and this information be captured and disseminated amongst the necessary staff. There should be an agreement that this person will always be contacted first with appropriate communication support in place to facilitate this and only in an emergency would another contact be used. However, it is acknowledged that it may be difficult to identify who the ‘main carer’ is where for example there are family breakdowns.

Support for carers - after the death carers should receive accessible information explaining the next steps, useful organisations to contact and any bereavement services that are available; these services should be accessible to all. It is expected that the roll-out of the Standards Project will assist GPs and hospital staff to disseminate this information.

Patient involvement in end of life care - Two GP practices which are part of the Standards Project declined to take part in this research as they felt uncomfortable asking these patients for their opinion. This perhaps suggests a need for education for GPs around interacting and involving patients who are receiving end of life care.

Section 1: Introduction

1.0 Introduction

NHS Newcastle Gateshead Clinical Commissioning Group (NGCCG) are undertaking a review of end of life services for adults in Newcastle and are developing an End of Life Strategy and Action Plan for Adults. The review will identify gaps and highlight areas for improvement in care and will involve meaningful patient, family and carer engagement. This will enable NGCCG to ensure that in the future, people and their families receive the care and support they need.

1.1 Context

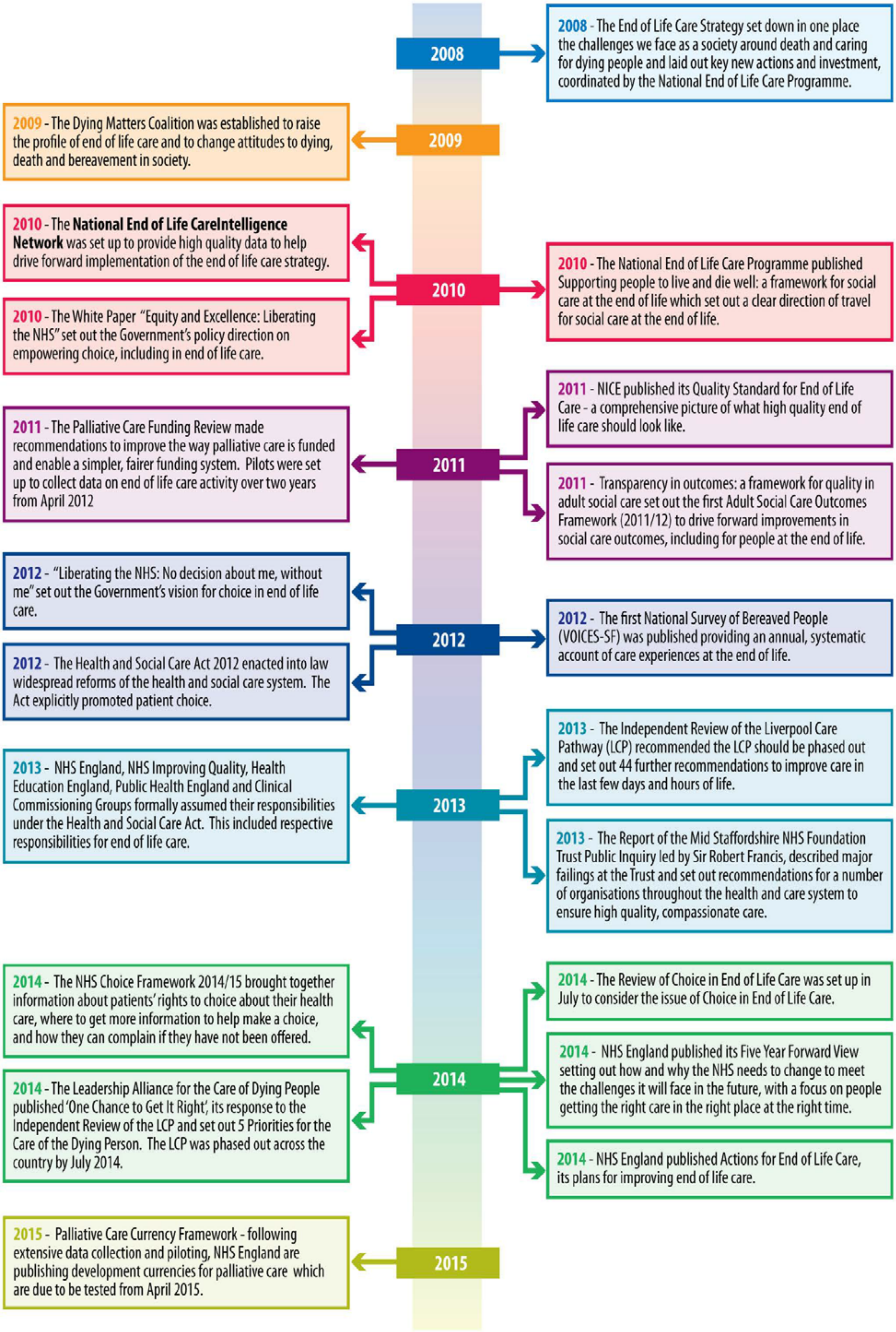
1.1.1 Definition

> "End of life care is care that: Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support".

Source: National Council for Palliative Care, 2006

1.1.2 National policy context

In 2008 the Department of Health developed the first End of Life Care Strategy 'Promoting High Quality Care for Adults at the End of Their Life' in England. Since the publication of the strategy there have been numerous developments around end of life care, with guidelines produced and reviews undertaken. The diagram below illustrates developments from 2008 to 2015. Other key publications since this date which focus on the views of patients, carers and the public are discussed in section 1.1.2.1 below.



2008 - The End of Life Care Strategy set down in one place the challenges we face as a society around death and caring for dying people and laid out key new actions and investment, coordinated by the National End of Life Care Programme.

2009 - The Dying Matters Coalition was established to raise the profile of end of life care and to change attitudes to dying, death and bereavement in society.

2010 - The **National End of Life CareIntelligence Network** was set up to provide high quality data to help drive forward implementation of the end of life care strategy.

2010 - The White Paper "Equity and Excellence: Liberating the NHS" set out the Government's policy direction on empowering choice, including in end of life care.

2010 - The National End of Life Care Programme published Supporting people to live and die well: a framework for social care at the end of life which set out a clear direction of travel for social care at the end of life.

2011 - The Palliative Care Funding Review made recommendations to improve the way palliative care is funded and enable a simpler, fairer funding system. Pilots were set up to collect data on end of life care activity over two years from April 2012

2011 - NICE published its Quality Standard for End of Life Care - a comprehensive picture of what high quality end of life care should look like.

2011 - Transparency in outcomes: a framework for quality in adult social care set out the first Adult Social Care Outcomes Framework (2011/12) to drive forward improvements in social care outcomes, including for people at the end of life.

2012 - "Liberating the NHS: No decision about me, without me" set out the Government's vision for choice in end of life care.

2012 - The Health and Social Care Act 2012 enacted into law widespread reforms of the health and social care system. The Act explicitly promoted patient choice.

2012 - The first National Survey of Bereaved People (VOICES-SF) was published providing an annual, systematic account of care experiences at the end of life.

2013 - NHS England, NHS Improving Quality, Health Education England, Public Health England and Clinical Commissioning Groups formally assumed their responsibilities under the Health and Social Care Act. This included respective responsibilities for end of life care.

2013 - The Independent Review of the Liverpool Care Pathway (LCP) recommended the LCP should be phased out and set out 44 further recommendations to improve care in the last few days and hours of life.

2013 - The Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry led by Sir Robert Francis, described major failings at the Trust and set out recommendations for a number of organisations throughout the health and care system to ensure high quality, compassionate care.

2014 - The NHS Choice Framework 2014/15 brought together information about patients' rights to choice about their health care, where to get more information to help make a choice, and how they can complain if they have not been offered.

2014 - The Leadership Alliance for the Care of Dying People published 'One Chance to Get It Right', its response to the Independent Review of the LCP and set out 5 Priorities for the Care of the Dying Person. The LCP was phased out across the country by July 2014.

2014 - The Review of Choice in End of Life Care was set up in July to consider the issue of Choice in End of Life Care.

2014 - NHS England published its Five Year Forward View setting out how and why the NHS needs to change to meet the challenges it will face in the future, with a focus on people getting the right care in the right place at the right time.

2014 - NHS England published Actions for End of Life Care, its plans for improving end of life care.

2015 - Palliative Care Currency Framework - following extensive data collection and piloting, NHS England are publishing development currencies for palliative care which are due to be tested from April 2015.

Source: 'What's important to me. A Review of Choice in End of Life Care' (2015)

1.1.2.1Patient, carer and public experiences

Some of the most recent publications highlighted the views of the general public around end of life care. ‘What’s important to me. A Review of Choice in End of Life Care’ (The Choice in End of Life Care Programme Board, 2015) identified seven themes around the kinds of choices people would like to make at the end of their life:

- I want to be cared for and die in a place of my choice
- I want involvement in, and control over, decisions about my care
- I want access to high quality care given by well trained staff
- I want access to the right services when I need them
- I want support for my physical, emotional, social and spiritual needs
- I want the right people to know my wishes at the right time
- I want the people who are important to me to be supported and involved in my care

Moreover, in ‘Every Moment Counts: a narrative for person centred coordinated care for people near the end of life’ (National Voices and the National Council for Palliative Care, 2015) five themes were highlighted which people felt were key to coordinated care near the end of life:

- We work for my goals and the quality of my life and death
- I have honest discussions and the chance to plan
- The people who are important to me are at the centre of my support
- My physical, emotional, spiritual and practical needs are met
- I have responsive, timely support day and night

These themes were summarised in the defining statement:

> “I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).”

In May 2016 the Care Quality Commission (CQC) published ‘A different ending: Addressing inequalities in end of life care’. The report considered what factors prevent people from experiencing good quality, joined-up care at the end of life. It focussed on end of life care for people who may be less likely to receive good care and spoke to people about their experiences of end of life care including any barriers to good care, from the following groups:

- people with conditions other than cancer
- older people
- people with dementia
- people from Black and minority ethnic (BME) groups
- lesbian, gay, bisexual and transgender people
- people with a learning disability
- people with a mental health condition
- people who are homeless
- people who are in a secure or detained setting
- Gypsies and Travellers

The report found that where commissioners and services take an equality-led approach that responds to people’s individual needs, people receive better care. Examining the report with regards to the seldom heard groups that were engaged as part of NGCCG’s project showed a number of issues.

For homeless people, who have a life expectancy which is significantly lower than the rest of the population, a number of issues were identified. Homeless people are not generally identified as approaching end of life early enough therefore death is not planned for. There is also a lack of awareness amongst commissioners and services about the numbers of homeless people locally and therefore a lack of specialist provision for homeless people with care needs; most homeless people with support needs end up in hostels which are not equipped to meet their care needs. Access to mainstream services such as care homes and hospices is challenging due to the fact that many homeless people have additional needs such as addiction and substance misuse.

For people from Black and minority ethnic communities, barriers include a lack of awareness, understanding and information about end of life care services and therefore what to expect from them. The role of hospices in particular was highlighted as people did not understand the scope of services available and felt that they would not be able to meet their cultural and spiritual needs. Language barriers were also an issue and further complicated difficult conversations. In terms of religious and cultural needs there were issues around limited chaplaincy services for non-Christian religions.

Finally, for people with a learning disability one of the main issues is that they are more likely to have unidentified health needs which makes recognising end of life difficult and in turn planning for and supporting this. Other barriers include staff having a lack of knowledge around learning disabilities which impacts on their end of life care and also difficulties around organising best interests decision meetings. Communication is also a barrier in terms of support needs, for example when assessing levels of pain, and staff making assumptions that a person would not be able to understand is also an issue.

In terms of what was important to them at end of life, people wanted family and friends nearby, to have privacy, peace and quiet, to not be in hospital, to be able to go outside, and to have the support of a care coordinator when needed. They also wanted services to talk more to people who have a learning disability to get their views.

1.1.3 Local context

The most recent data compiled by the Marie Curie End of Life Care Atlas shows that between 2010 and 2012, approximately 0.65% of the population were in need of palliative care across Newcastle however fewer than half had been identified on the Palliative Care Register.

	NHS Newcastle North and East CCG*	NHS Newcastle West CCG*	England average
Palliative care need	883	975	1796
% of population with palliative care need	0.62	0.69	0.67
% of population with palliative care need identified	45.88	35.06	37.03
% of all deaths with palliative care need identified	0.35	0.27	0.28

Source: Marie Curie End of Life Care Atlas, 2010-2012
*Figures reflect the two CCGs that were operating in Newcastle before the merger with NHS Gateshead CCG in 2015

Considering place of death, in 2015 almost half of people living within Newcastle died in hospital with almost one quarter dying at home. Over two-fifths of people died in their usual place of residence.

	Newcastle		Cumbria and North East	England
Place of death	Count	Percentage (%)	Percentage (%)	Percentage (%)
Hospital	1273	48.4	47.7	46.7
Home	654	20.0	24.2	22.8
Care home	527	24.9	22.0	22.6
Hospice	131	1.7	3.7	5.6
Other place	44	5.0	2.4	2.2
Total	2629	100.0	100.0	100.0
Usual place of residence	1149	44.7	46.5	46.0

Source: Office for National Statistics, 2015

1.1.3.1 Patient, carer and public experiences

The National Survey of Bereaved People, 2014 (data from 2011 and 2012 surveys) produced by the Office for National Statistics provides an insight into people's experiences at end of life in terms of the quality of care delivered in the last three months of life. This is the most current data available but it must be acknowledged that it is now five years out of date. Also, before considering the data it must be noted that it is not possible to view the full responses to each question due to the small sample size and therefore disclosure issues.

The tables below provide data for the former Newcastle CCGs and show that the majority of people have positive experiences at end of life and in most cases better than the national average, however the data suggests that there is some room for improvement.

Overall, and taking all services into account, how would you rate his/her care in the last three months of life?

	Outstanding/excellent*	
	Number of responses	Weighted percentage
NHS Newcastle North and East	98	54.0
NHS Newcastle West	98	46.9
England	40045	43.2

*The options 'Good', 'Fair' and 'Poor' are not presented due to small numbers (fewer than 20)

In terms of how carers would rate the patient's overall care in the last three months of life, 54.0% of those in North and East CCG and 46.9% of those in the West CCG area described their care as outstanding or excellent. The remainder, 46.0% and 53.1% respectively, felt that care was either good, fair or poor.

How much of the time was he/she treated with dignity and respect by the district and community nurses?

	Always*	
	Number of responses	Weighted percentage
NHS Newcastle North and East	58	79.9
NHS Newcastle West	59	81.5
England	19,037	78.6

*The options 'Most of the time', 'Some of the time' and 'Never' are not presented due to small numbers (fewer than 20)

How much of the time was he/she treated with respect and dignity by the GPs?

	Always*	
	Number of responses	Weighted percentage
NHS Newcastle North and East	71	79.9
NHS Newcastle West	85	69.1
England	30,959	72.4

*The options 'Most of the time', 'Some of the time' and 'Never' are not presented due to small numbers (fewer than 20)

Considering whether the patient was treated with dignity and respect within a community care setting, four-fifths of people (80.7%) felt that they were always treated in this way. The remainder either felt that they were treated with dignity and respect most of the time, some of the time or never. In terms of GPs, again the majority of people (74.5%) felt that they were always treated in this way and for the remaining quarter (25.5%) this was either most of the time, some of the time or never. This was particularly noticeable with respect to GPs in the West CCG area where the figure also fell below the national average.

Looking at this data in terms of secondary care and specifically the patient's last admission to hospital, shows that on average, 71.5% of carers felt that the patient was always treated with dignity and respect by doctors, over a quarter (28.5%) therefore, felt that they were treated in this way most of the time, some of the time or never. Moreover, when interacting with nurses, two-thirds (65.7%) of carers felt that the patient was always treated with dignity and respect therefore a noticeable minority felt that they were not always treated in this way.

During his/her last hospital admission, was he/she always treated with dignity and respect by Doctors?

	Always*	
	Number of responses	Weighted percentage
NHS Newcastle North and East	55	74.4
NHS Newcastle West	72	68.6
England	24,396	57.9

*The options 'Most of the time', 'Some of the time' and 'Never' are not presented due to small numbers (fewer than 20)

During their last hospital admission, was he/she always treated with dignity and respect by Nurses?

	Always*	
	Number of responses	Weighted percentage
NHS Newcastle North and East	58	70.8
NHS Newcastle West	77	60.6
England	26,679	49.9

*The options 'Most of the time', 'Some of the time' and 'Never' are not presented due to small numbers (fewer than 20)

At the time of death the majority of carers (71.1%) felt that they were definitely given enough support by the healthcare team. Therefore, for a noticeable minority (28.9%) they either felt that to some extent they were, did not know or were not given enough support at all.

Were you or his/her family given enough help and support by the health care team at the actual time of death?

	Yes, definitely*	
	Number of responses	Weighted percentage
NHS Newcastle North and East	97	72.9
NHS Newcastle West	100	69.3
England	39,604	59.8

*The options 'Yes, to some extent', 'No, Not at all' and 'Don't Know' are not presented due to small numbers (fewer than 20)

After he/she died, did staff deal with you or his/her family in a sensitive manner?

	Yes*	
	Number of responses	Weighted percentage
NHS Newcastle North and East	94	97.9
NHS Newcastle West	97	96.9
England	38,560	93.5

*The options 'No' and 'Don't Know' are not presented due to small numbers (fewer than 20)

The vast majority of carers, felt that staff dealt with them in a sensitive manner.

Finally, in terms of their involvement in the decisions about the patient's care, the majority of people (78.9%) felt that they were as involved as much as they wanted to be. For one fifth of carers (21.1%) they felt that they would either have liked to be more involved or less than they actually were.

Looking back over the last three months of his/her life, were you involved in decisions about his/her care as much as you would have wanted?

	I was involved as much as I wanted to be*	
	Number of responses	**Weighted percentage**
NHS Newcastle North and East	96	79.5
NHS Newcastle West	97	78.4
England	39,121	77.9

*The options 'I would have liked to be more involved' and 'I would have liked to be involved less' are not presented due to small numbers (fewer than 20)

1.1.3.2NGCCG

NGCCG's Alliance Commissioner Plan 2016/17 sets out the organisation's priorities for the year ahead. Within the Older Person and End of Life Strategic Programme, Newcastle plans to:

> "For end of life, the pathway and strategy will be developed and work with practices will continue on palliative care standards. Care and support planning in primary care will be rolled out using Year Of Care as the model".

In conjunction with Newcastle Hospitals NHS Foundation Trust, the CCG are currently running a Standards Project. The project has been offering support and education to 10 GP practices around end of life care including how to initiate conversations with patients, how to run palliative care meetings and also providing signposting information around carers support and bereavement services. The Project will now be rolled out to more practices and the Trust is in the early stages of commencing the training.

In February 2015 NGCCG held an event around end of life care services in the city. End of life care specialists and service providers from across both adults and paediatric services attended the event to assist in the mapping of existing service provision to determine gaps in the system and current best practices. The event identified areas of good practice and actions that needed to be developed to enhance end of life care in Newcastle as shown in the table below.

Issues from Pathway event	Review areas to be agreed
Variation of end of life services	• Defining quality standards • Review services specifications • Undertake care plans audit • Review access to equipment including syringe drivers • Ensure outcomes are agreed with patient and family • Review fair access to care irrespective of prior long term condition e.g. dementia
Lack of integration of end of life services	• Understand role of community and specialist nursing • Develop/ensure shared records e.g. EPaCSS • Assess link to the other care a patient may be receiving e.g. LTC
Inconsistency of service delivery between sites days of the week/times of day	• Review demand and capacity to deliver 7 day working/new models of care
Lack of support services to families regarding bereavement	• Review of needs and options
Workforce issues –size and skills	• Workforce review
Resources available for development	• Review of existing contracts prior to assessing new resources needed
What do families and patients need	• Engage public in discussion
Whole system development inclusive of care home sector/third sector	• Review of skills in care homes and training available • Map responses within third sector
Inequality issues	• Dementia care • English not first language • Homeless • Lesbian, Gay and Transgender

To supplement this work a call for evidence was then undertaken to collate patient, carer and public views around end of life care in Newcastle. Although the evidence provided showed positive experiences of end of life care services and particularly those provided by Newcastle upon Tyne Hospitals NHS Foundation Trust, information was very limited and often out-of-date.

What emerged from the call for evidence therefore was a need for engagement with people living in Newcastle to understand their experiences of end of life care services and also their preferences at end of life. It was felt that evidence was particularly lacking around seldom heard groups and therefore five groups were identified to take part in the engagement. Patients currently receiving palliative care were also targeted to take part to enable up-to-date information and feedback about end of life services to be captured.

1.2 The project

1.2.1 Aim

The overall aim of this project was therefore to gather experiences, views and expectations of End of Life Care and determine the principles of good End of Life Care from seldom heard groups and also patients currently on the palliative care register in Newcastle.

1.2.2 Objectives

The key objectives of the project were to:

- Explore the experiences of patients currently receiving palliative care identifying good practice, gaps and improvements
- Engage with individuals who have cared for or supported a person who has died to understand both their experience and that of the person they cared for
- Engage with people who have not experienced end of life care and explore their expectations and wishes regarding their own end of life care

Section 2 - Methodology

2.0 Methodology

In order to meet the objectives of the project, qualitative techniques were used. A qualitative methodological approach was deemed to be the most appropriate as it is concerned with gaining a depth of understanding of how people feel, their beliefs, reasoning and motivations and therefore fitted with the objectives of the project.

2.1 Techniques

In order to enable as many people as possible to have their say, organisations were able to engage participants in whichever way they felt it was most appropriate to their target group. Some participants chose to complete either a paper-based or online questionnaire themselves, for others an interviewer-administered questionnaire was more appropriate and some people participated via a telephone discussion. Although the data collection techniques were varied, what remained constant was the set of questions that were asked of the participants (see Appendix 1). This ensured that the data collected was consistent, enabling meaningful analysis.

In addition to the questionnaire, all participants who had cared for someone who had received end of life care were offered the opportunity to take part in a case study to explore in more detail the issues and decisions they faced when caring for someone using these services.

2.2 Participants

As mentioned in section 1.2.3.2 above, the call for evidence revealed a lack of local insight into people's views and experiences around end of life care. Amongst the steering group there was confidence that national evidence was reflective of the average Newcastle resident however it was felt that there was a gap in understanding around the views and experiences of seldom heard groups within the city. The following five groups were therefore identified to take part in the project:

- People from Black and Minority Ethnic (BME) communities
- D/deaf and hard of hearing people
- Homeless people
- Blind and visually impaired people
- People living with a learning disability or difficulty

Within these groups the following groups were targeted:

- Carers of people who have died within the last two years
- People with no experience of end of life care services

As part of the project, the views of patients currently receiving palliative care and/or their carers were also sought.

2.2.1 Recruitment

2.2.1.1 Seldom heard groups

Five organisations were asked to take part in the project and gather the views of people within the identified groups:

- The Health and Race Equality Forum (HAREF) recruited and engaged people from BME communities. These include BME led community groups that are members of the HAREF Network, individuals and groups supported by organisations that are members of the HAREF Network and individual community members who were recruited directly by HAREF
- Deaflink recruited and engaged people who were D/deaf (Deaf with a capital ‘D’ refers to those who identify with the Deaf community and culture and deaf with a lower case ‘d’, to those who are deaf and do not identify with the Deaf community) or hard of hearing
- Involve North East recruited and engaged people who were homeless (this included people in temporary accommodation, rough sleepers and those labelled ‘sofa surfers’)
- Newcastle Society for Blind People (NSBP) recruited and engaged blind and visually impaired people
- Skills for People recruited and engaged people who are living with a learning disability or difficulty

In order to recruit participants the five organisations used various methods appropriate to their target group. This included direct requests via face-to-face or telephone contact with service users, advertisements in their newsletters and email bulletins, invitations via their Facebook page, attendance at existing groups within and outside their organisation and use of other contacts and networks.

Overall 216 people shared their views as part of this project:

- 147 people from BME communities engaged by HAREF
- 31 people who are D/deaf or hard of hearing
- 22 people who are homeless
- 2 people who are blind and visually impaired
- 14 people who are living with a learning disability or difficulty

For a full participant profile, see Appendix 2. Appendix 3 provides a breakdown by target group.

In addition Deaflink engaged with a number of interpreters who have experience of supporting BSL (British Sign Language) users through the ‘end of life’ stage. Their observations are also included in Deaflink’s report (Appendix 7).

2.2.1.2Patients receiving palliative care and/or their carers

Three GP practices who are currently part of the Standards Project around end of life care agreed to take part in the project. They identified patients who are currently on their Palliative Care Register and sent out letters to them explaining the background to the project (Appendix 4) with an enclosed questionnaire (Appendix 5) with a pre-paid envelope to return the completed form. In total eight completed questionnaires were returned; four of these were from patients themselves and four were completed on behalf of the patient. See Appendix 6 for a full participant profile.

2.3 Limitations

As highlighted above, only two people who were blind or visually impaired took part in the engagement; their views are therefore underrepresented in this report.

Also, only eight people who are currently receiving end of life care took part in the engagement. Due to the difficulty of the subject matter it is understandable that response rates are low. What is interesting to note is the fact that a further two practices (also part of the Standards Project) declined to take part in this engagement. They felt uncomfortable asking these patients for their opinion, perhaps suggesting a need for education for GPs around interacting and involving patients who are receiving end of life care.

Despite best efforts from the organisations involved in engaging participants, only 24 people from seldom heard groups shared their experiences of caring for someone who had received end of life care.

In addition, 27 people gave their residence as outside of Newcastle. Although people living within the city were targeted it was felt that as they were engaged as part of a group, their views should not be excluded.

Section 3 – Findings

3.0 Findings

This section provides a summary of the findings of engagement with the following groups:

- People from BME communities (147 participants)
- People who are D/deaf and hard of hearing (31 participants)
- Homeless people (22 participants)
- Blind and visually impaired people (2 participants)
- People living with a learning disability or difficulty (14 participants)
- Patients and/or their carers who are currently receiving palliative care (8 participants)

For a copy of Deaflink's individual report with recommendations, see Appendix 7.

3.1 Experience of end of life care services

As stated above, eight people (or their carers) who are currently receiving palliative care gave their views of the services that they are receiving (see Appendix 6 for a full participant profile and Appendix 5 for the questions asked of them). A further 23 people from seldom heard groups also gave their views on the services received by someone they had cared for who had passed away within the last two years. In addition, one participant who is D/deaf also shared their experience of caring for someone who is currently receiving palliative care (see Appendix 1 for a copy of the questions asked).

3.1.1 Patients currently receiving end of life care

3.1.1.1Support and services

Patients currently receiving palliative care were initially asked whether they felt that they were receiving the right support and services to meet their current needs.

All people feel that they are receiving services and support to meet their needs and eight people explained why they felt that this was the case.

The knowledgeable, caring nature of the health professionals they have been in contact with was most frequently mentioned by patients; this includes GPs, acute care and community based doctors and nurses. Being able to remain in their own home was important for one patient who appreciated the mobility aids they were about to receive and having home visits from nurses and doctors. The timeliness of care and also being kept informed of any changes to that care was key for another patient. Finally, good communication between staff at different hospitals regarding the patients care was also highlighted.

> "All health professionals have been very caring, helpful and supportive".

> "I'm getting a commode and a walker from hospital. The nurses and doctors call in".
>
> "The response received is understanding and action is immediate. An obvious and clear way forward is explained to resolve any queries".
>
> "Both the Freeman Hospital and RVI are communicating with each other about me".

3.1.1.2Involvement in decision-making

The NHS Constitution states that patients:

"have the right to be involved in planning and making decisions about your health and care with your care provider or providers, including your end of life care, and to be given information and support to enable you to do this. Where appropriate, this right includes your family and carers. This includes being given the chance to manage your own care and treatment, if appropriate".

All eight patients currently receiving palliative care feel that they are involved in decisions about their care. Two people simply stated that they and their carers were involved whilst another was supported to make decisions by their GP.

> "Carer/partner is always involved in decisions, always kept up-to-date and included in all and any discussions".
>
> "I make my own decisions with the support of Dr XXXX".

When explaining their response, the remaining four people actually cited examples of being informed of decisions around their care or being able to ask questions about it. Whilst patients are clearly happy with their level of involvement and being mindful of the fact that it is not always possible to be involved in every care decision (nor will everyone want to) these responses could suggest a misunderstanding around what involvement in decisions entail.

> "I am always told about what decisions have been made about any treatment I will get".
>
> "Consultant and nursing staff have explained my treatment as it went along".
>
> "At every stage we have been kept informed and updated. We have also been offered support and advice whenever we requested it".
>
> "If I want to know anything about my illness I ask and get the right answers".

Finally, one patient made a suggestion around future involvement in their care.

> “Maybe [have] a regular or quarterly update on things that are not known about? Suggestions by medical staff about options that could aid comfort or make daily life easier?”

3.1.2 Carers

Twenty-three people from seldom heard groups who have cared for someone who had received end of life care and passed away within the last two years gave their experiences of the services and support provided, alongside one D/deaf participant who is caring for someone who is currently receiving palliative care:

- 10 were from BME communities engaged by HAREF
- Five were people who were D/deaf or hard of hearing (three BSL users, one hard of hearing and one hearing child of a D/deaf father)
- Six were homeless
- Three had a learning disability or difficulty

There were no responses from people who were blind or visually impaired around caring for someone.

Of these people, 12 were children of the deceased, four were partners of the deceased and one is the partner of someone receiving palliative care, two were parents of the deceased, two were sisters/sisters-in-law, two were close friends and one was a grandmother.

As shown in the table below, the length of time people were in receipt of end of life care services varied considerably from one day to seven or eight years.

Length of time receiving end of life care	No. of participants
1 day	1
2 days	2
2 weeks	2
6-8 weeks	1
2.5 months	1
3 months	1
6 months	1
1 year	2
2 years	3
3 Years	2
4 years	1
7/8 years	1
Few years	2
Not sure	2
No response	1
Still receiving care (over two years to-date)	1
Total	24

End of life care is support for people who are in the last months or years of their life (NHS Choices) whilst it is acknowledged that seven years for example is a considerable period to be receiving end of life care, carers believed that this was the type of care there loved one had been receiving and therefore their views have been included. This is perhaps indicative of a lack of awareness of what end of life care services actually are and the engagement has provided further evidence for this, as discussed below.

3.1.2.1Support

Participants were initially asked whether they felt that their loved one had received the support they needed whilst receiving end of life care. Thirteen people (54.2%) stated that this was the case including all those engaged by Deaflink and all those with a learning disability, whilst the remaining 11 people (45.8%) believed that the person they were caring for did not receive the support they needed.

The people who were happy with the level of support cited general good quality care as well as specific interventions they received. One homeless participant also referred to receiving a carer’s allowance which helped him to look after his mother.

> “My husband had Parkinson’s disease. He received 24/7 care supported by the NHS staff for the last two years”.
>
> “Good care, Mum was comfortable”.
>
> “Yes most nurses, staff work there look after everything him, feed him, and give tablets and things.”

In terms of the five respondents who were D/deaf, hard of hearing or a hearing child of a D/deaf father, although they stated that they felt the person that they cared for received the right support, their explanations of this support suggest that this was not necessarily the case. Issues around the time taken to diagnose conditions, being moved between and within hospitals and also poor communication between health professionals, patients and carers were highlighted. See 3.1.3.1 for further evidence around a lack of communication.

> “Then his heart started getting weak, moved to RVI hospital for one day and his blood was too high warfarin, back to Freeman Hospital and stayed Ward 19 for Dementia ward, carry on and his heart get weaker and transferred to Ward 37 serious ward. Back to Ward 19, but getting worse and worse”.
>
> “No interpreter nothing, just me and five doctors around my husband’s bed. I said what I do as I’m Deaf? So the doctor said one is anaesthetist, one and each other one is something like professional operation etc., he wrote down on a bit of paper and I was over the head (overwhelmed) don’t know what it meant as hard words so I signed what time for the operation? He was easy to lip-read – 9 o’clock at night”.

> “My father [the patient] and mother and son are all deaf and BSL users. My daughter and I are both hearing. The doctors and nursing staff tried their best…either my daughter or I needed to be present at all visits to facilitate communication and to try to make sure that my father's needs were being met. However there was one occasion that we couldn't be there. When I went to pick my mother up she was clearly distressed and said that a Chaplain was there in Dad's room she took this as an indication that he was going to die very soon. This was not the case and really upset the family due to lack of communication…A discussion took place to advise that all treatment should be withdrawn to alleviate the pain and suffering. My daughter had to 'interpret' this message to her grandmother.”

Moreover, participants’ discussions with both Deaflink and HAREF revealed a lack of knowledge around what end of life care or palliative care actually is (see also section 3.2.1), what services are available and therefore what to expect from these services. Community groups approached by HAREF to participate in this research also made use of the opportunity to benefit from information sessions about end of life services, provided by the CCG.

> “A hospice stay was never mentioned. As a BSL Interpreter I have worked with terminally ill deaf people and have no knowledge of any mention of hospice, ever. I would strongly suspect that the majority of deaf people will not be aware of palliative or hospice care therefore a greater understanding and awareness of this by staff is paramount”.

It is therefore possible that carers could not accurately answer this question as they themselves did not know what support should be provided to patients and in fact one participant who felt their loved one had not received the support they needed stated that they were “not aware of all of the support services”.

Eleven people directly stated that they did not feel the person that they cared for received adequate support; six of this group were from BME communities engaged by HAREF and five people were homeless. For one BME respondent there were issues regarding a lack of information about the care they could expect and also with communication. The patient did not speak English and there were no staff who could speak their language, therefore communication was not possible unless a family member was present. This finding echoes that of the CQC’s May 2016 report ‘A different ending: Addressing inequalities in end of life care’ where language barriers were identified as an issue.

> “Lack of communication, lack of BME staff - language barriers as elderly have no English”.

Some people simply said that there should have been more support whilst others identified specific issues. For three people from BME communities it was felt that the care that they received within their own homes was limited. The case study in section 3.1.3.2 describes the prolonged process a family had to go through to get additional care to support their mother, identifying the patient’s social worker as a barrier in this respect. Moreover, care at home was seen as the only option for this patient, due to a lack of language support within hospital and hospices.

> "Home care was only provided for once a day in the morning - no other support was given".

> "They used to come three times a day for only half an hour. We needed way more support than that".

For one homeless person who was caring for a close friend who was also homeless, their issue was that the person was not identified as approaching end of life early enough. This mirrors the finding of the CQC's report (A different ending: Addressing inequalities in end of life care', 2016) which meant that death was not planned for. The patient had alcohol and drug addictions and was living in a hostel. It was clear to the carer that this person was deteriorating rapidly and they tried to inform the authorities who were "reluctant to intervene"; they were therefore not identified as in need of end of life care and no support was given.

One person felt that the length of time it took for the patient to be given a room after being admitted to hospital was too long whilst another felt that their loved one was not handled carefully when using the patient transport service.

> "It took them two to three hours to give us a room".

> "Wasn't happy with the way she was transported on the bus".

In terms of improvements to the support the patient received, for people engaged by Deaflink these were focused on communication. To enable carers to support the patient they requested appropriate communication methods to be used for example, access to interpreters in a timely manner and not contacting carers who are hard of hearing by telephone. For D/deaf patients themselves it was suggested that a qualified and known interpreter should be present during any discussions about their care. In addition, it was felt that there is a need for improved deaf awareness amongst medical and chaplaincy staff.

> "I don't think can improved anything but I need some interpreter in the hospital for emergency, that is the only thing I want to improve."

> "Other agencies used phone to contact us. I am hard of hearing and this was difficult".

> "The Chaplaincy service need some awareness and the distress that is caused by lack of communication. Any ward rounds or discussions should be done with a qualified interpreter present and an interpreter who is known with the patient and family as many interpreter booking agencies will not consider this vital service during a very difficult time".

The timeliness of support was a key issue for BME communities. As highlighted above, there is a lack of knowledge around end of life care services within BME communities and timely information was requested. It was also suggested that everyone should be offered care within their own home from the outset. Also, once it was clear that the patient was in the last stages of life there was a request for the provision of a private room in hospital in a more timely manner.

> "Information given to families about which support services are available to them as well as helping the family to access them at the start not after a few years".
>
> "Better to offer services such as home care, day care than refusing and having to fight all the time".
>
> "I wish they had given us a room sooner so we could have spent more time with my mum".

The workers who provide the support was also an issue for three BME people. They requested more male workers to assist male patients in their own homes, enabling them to follow Islamic requirements and more staff from BME communities who could speak their language (the case study in section 3.1.3.2 highlights the impact this latter issue also had on family carers). In addition more support within the home was requested.

> "Increase care at home service, I was supporting him, which was hard for me due to a gender difference, more male workers".
>
> "More budget for personal care and less involvement of the agencies, and more staff from BME community".

One homeless person also asked for better care planning whilst another felt that improvements were needed in terms of reducing stigma around people who are homeless including more awareness training.

3.1.2.2Joined-up working

This group were also asked how well they thought that the services they received worked together and 18 people answered this question. Two-thirds of people (66.7%) felt that services did work well together to provide care and support to their loved ones and amongst the D/deaf or hard of hearing participants, access to social workers and occupational therapists was particularly welcomed.

> "Yes worked well together".
>
> "Very good support and understanding".
>
> "GP and district nurse worked well together, other agencies very much on outside".

> "We have a chair stair lift from Occupational Therapist from Freeman Hospital, very good for him easy up and down. Wet room for him, he doesn't like showers because hurting his back, good handy for him. Loan equipment – bed, chair, toilet. Occupational Therapist come and training him walking, hoping he could improve, but never improved. Newcastle social worker, had a lot from her but she left because of the cuts".

However, as illustrated in the last quotation (see section 3.1.3.1 for more detail), cuts to local authority budgets have resulted in there being only one qualified Social Worker who can use BSL in the North East at present and to qualify for social work support D/deaf people must have additional needs. Therefore there is clearly a gap for this group in terms of communicating with and assisting agencies to provide joined-up care for their loved ones.

For those six people who felt that services did not work well together (three of whom cared for homeless people and three were from BME communities) it was felt that there was a lack of coordination between services and communication between medical professionals and other services was poor. For one carer a lack of joined-up working created a barrier for the patient in terms of getting them out of the hospital and back into their own home.

> "No co-ordinating between services".

> "There was lack of communication between professionals and staff".

3.1.2.3Dignity and respect

Twenty-three people responded to the question around whether they felt that the person receiving end of life care was treated with dignity and respect. Sixteen people, (69.6%) believed that their loved ones had been treated in this way which is slightly lower than the findings of the National Survey of Bereaved People, (Office for National Statistics, 2014) discussed in section 1.1.3.1. The survey asks about the quality of care delivered in the last three months of life including the question 'How much time was he/she treated with dignity and respect?' and the options given were 'Always', 'Most of the time', 'Some of the time' and 'Never'. This question was asked with regard to district and community nurses, GPs and also hospital doctors and nurses during the patient's last admission to hospital. Taking an average of all of the people who said that the patient was 'always' treated with dignity and respect, reveals a figures of 73.1%.

With regards to this project, those who said that they were treated with dignity and respect mentioned services being understanding of their needs amongst other things.

> "Last year of my grandson all services were very helpful and understanding of our needs and provided us with more care".

> "Respected family requests and visitors".
> "They explained things".

> "Yes hospital do very well".

> "Treated as normal human being".

One BME participant said that the patient was 'sometimes' treated with dignity and respect and another said that this was "most of the time" and stated that their mother was left unaided in the toilet for a long time which resulted in her falling over on several occasions (see case study in section 3.1.3.2 for more detail). The remaining five (21.7%) stated that they were not. For the hearing relative of a deaf patient, communication was the key issue.

> "Only his basic needs were being met so how could he be treat with dignity and respect he couldn't communicate his needs".

No care plan was the reason given by two BME participants whilst another stated that their father did not have access to male workers. The participant who was caring for their homeless friend reiterated that "staff were reluctant to intervene".

> "When they were asked to provide male staff for personal care they were not very keen to provide".

In terms of how things could be improved, suggestions from the D/deaf and hard of hearing and BME communities, focussed on communication. For BME carers, having information in their first language or if that was not possible, in plain English, was important so that they could actually understand, first hand, the care that they were receiving.

> "Staff who could speak the same language".

> "Given information at the start of the diagnosis and information in Urdu or easy English".

One BME carer asked for staff who were the same gender as the patient. Another requested visitors be allowed to visit the patient at any time, rather than set times (These services are available within Newcastle Hospitals NHS Foundation Trust). For another, they wanted more care and support available at home.

> "Male personal carer for male and female personal carer for female - that's called dignity".

For the D/deaf and hard of hearing carers there were requests for:

- Specialist BSL interpreting services – provided by qualified and chosen/preferred interpreters
- Ward round discussions to only take place when an interpreter is present
- Deaf awareness on the wards

- Accepting that a deaf person has the right to be next of kin and provide appropriate communication support to them
- Contact through text messaging or other format chosen by patient/family

3.1.2.4Involvement in decisions about care

Fourteen out of 24 people answered the question on how involved patients were in decisions about their care. Four carers identified that their loved one had dementia and this affected how much the patient was able to be involved in their own care.

Eight people (57.1%) felt that the patient was fully informed and had a say in their treatment and care, where possible. One learning disabled participant stated “She got to choose what care she got” whilst a BME participant, although stating that the patient was not particularly involved, felt happy that staff were caring for the patient in the most appropriate way.

> “Not much as we had full trust in the NHS staff”.

Six participants felt that to some extent, the patient was not involved. The inability to communicate with staff created a barrier to involvement for four patients; one was a D/deaf patient and three were from BME communities and did not have English as their first language. One homeless participant stated that they were “more of a support to her and her decisions”.

> “I had to take time off work and plan my hospital visits around meals to make sure he could communicate what he wanted to eat”.
>
> “Family members were involved as patient had language barriers”.
>
> “Fifty-percent due to cultural and language barriers”.

Deaflink’s and HAREF’s engagement highlights an issue for patients who are unable to communicate with healthcare staff. If they do not have timely access to independent, trained interpreters their views are either not heard or end up being communicated via family or friends. How do medical professionals know what is being communicated to the patient and that the views of the patient are being accurately communicated to them?

3.1.2.5Communication support

Although this was a common theme throughout answers to the previous questions, participants were also asked directly whether the communication needs of the patient were met; eighteen people responded to this question. Nine people (50.0%) felt that their loved one either had no communication needs or received the support they needed. However, nine people felt that this was not the case and four BME participants gave reasons for this. For one, there was simply not time as their mother was so ill but for the remaining three, as highlighted above, a lack of qualified interpreters or written information available in a language other than English, were the issues. One family who had asked for an interpreter in hospital but were not provided with one, reported operating a shift system with family members to minimise the time that the mother would be left alone without an access to language interpretation (this point is further explained in the case study in section 3.1.3.2). The lack of interpreters in the hospice also resulted in the stay being cut short. There was also a feeling amongst one family that staff felt that they were being racist in asking for this (also see case study in section 3.1.3.2 for more context to this issue).

> “Family help - no support was given around language. All health professionals depended on family to do the interpreting. They felt we were being racist as we were requesting staff from our community”.

> “No information was provided - information was not offered in any other languages as the patient was unable to read English”.
>
> “There was not any communication in staff and patient whatsoever at all and this was the most painful thing for us”.

For the family of the D/deaf patient, in addition to a lack of timely interpreters, they also experienced a lack of information-sharing amongst staff about the patient’s communication needs.

> “During a visit I encountered Health Care Assistants shouting at him. I explained that he is profoundly Deaf they were apparently told that he was hard of hearing”.

The case study in section 3.1.3.1 also details issues around a lack interpreting support for both the patient and carer for a prolonged period. An interpreter was eventually provided after a chance meeting.

In terms of improvements from BME participants there was a call for either more bilingual staff or interpreters available who can translate any information they are given. Interpreters were key to the communication support for D/deaf people. There were requests for professional BSL interpreters to be available as BSL users rarely have a good comprehension of English. It was also suggested that there should be an interpreter on ‘stand by’ in health settings at all times. Interpreters who are known to the patient was also requested as this gives them reassurance and comfort that they know it is someone they can understand and trust. Finally, it was suggested that staff need Deaf awareness training; for example, there is a need to recognise a culture within deaf communities of deference to hearing people which often means they accept, without complaint, any services offered.

For the remaining participants engaged by Deaflink, although their loved one did not have communication needs, they as carers did and these issues are explored in section 3.1.2.9.

3.1.2.6Cultural needs

Of the 22 people who responded to this question, seven people felt that their loved one did not have any specific cultural needs and a further one stated that they simply did not know. Eight people (36.4%) said that the patient's cultural needs had been met. Section 3.1.3.2 also evidences the positive experience one BME family had in this respect, at time of death.

> "He's Protestant. I think when I was not there, my partner said been a priest come and visited, talked before I came to visit him. What they talked about I don't know".

> "Mum was a Christian and got to go to church".

The remaining six people felt that the patient's cultural needs were not met and four people gave reasons for this answer. For the participant whose father was D/deaf the lack of staff awareness of the needs of D/deaf patients or their carers was key. For two BME participants, a lack of staff from their BME community, and lack of support around their religious practices were identified as issues, the latter being particularly important to patients at the end of their lives; a lack of same-sex staff to care for the patient and uphold his religious beliefs was also an issue. These issues reflect the findings of the CQC's report 'A different ending: Addressing inequalities in end of life care' (2016) where barriers to good end of life care included limited chaplaincy services for non-Christian religions.

> "On the ward they seemed to panic and didn't know how to cope with him and his deafness".

> "No staff from BME community - no prayer facilities. No staff offered support around religious routines".

Finally, for one participant who had been caring for their homeless friend, there was a feeling that services had little awareness of the lifestyles that people living in poverty lead.

> "General lack of understanding of lower socio-economic culture by those who are raised privileged".

Four participants had suggestions for how to ensure that patients' cultural needs are met which focussed mainly on awareness training for staff so that they have the knowledge and understanding to be able to offer support in the most appropriate way. Having the physical facilities available to allow this to happen is also key. In addition, ensuring the gender of care staff is the same as that of the patient was requested by one BME respondent.

3.1.2.7 Place of death

Place of death is a key indicator when measuring the quality of a patient's end of life care and there is a belief that most people would prefer to die at home. This was stated in the Department of Health's 'End of Life Care Strategy - Promoting High Quality Care for Adults at the End of Their Life' (2008) and more recently the Dying Matters Coalition stated that they believe around 70.0% of people would prefer to die at home, yet around 50.0% currently die in hospital.

However, it must be acknowledged that there are many reasons why achieving a preferred place of death is complex. For example, although people may want to die at home, sometimes their condition means that things change and that they need to be taken into hospital and may subsequently die there – they may not have preferred it, but it was the right thing for them at the time. Moreover people may change their mind at the end of their life and feel that they want to die somewhere other than their previously stated preference therefore, the context of when the question is asked is an important consideration.

Participants were asked whether their loved one had a preference about where they would like to die and whether they did in fact die in the place of their choice. Of the 22 people responding to this question only seven (31.8%) said that the patient did have a preference about where they would have liked to die and of those four did not die in the place of their choice; they wanted to die at home and all died in hospital. This was because they were too ill and needed specialist care that the hospital provided.

3.1.2.8Comfort

Carers were also asked whether patients were made to feel comfortable in the place where they died and 14 people answered this question. For the majority (78.6%), the answer was "yes". They cited the care they received in hospital including family being provided space to spend time with the patient and medication.

> "The RVI hospital really looked after her".
>
> "Was in hospital, was the safest place".
>
> "Family was present and we were provided with a separate room".
>
> "Got drugs she needed".

Three people however, felt that their loved one was not comfortable when they died. One patient who was receiving care at home died alone. The family felt that carers should have stayed with him although this example perhaps shows a lack of understanding of the role of home care services which are task driven rather than 'comforting'.

> "No one was with him when he died, care staff left after he refused to have breakfast rather than to spend that time with him by looking after and comforting him".

For the patient who was homeless and had not been identified as in need of palliative care, they died in hostel with no privacy. Finally, the family of a patient felt that the timeliness and willingness to provide support was an issue within the hospital environment.

> "Not at first. We had to fight it with the NHS staff in order to get a separate room where it was then possible for the family to recite the Quran to make the patient more comfortable".

Seven people suggested improvements that could be made to enable patients to be more comfortable. For one participant with a learning disability they simply wished that their loved one had "got to come home". The participant whose friend was homeless focussed on the need for support for people to ensure they do not become homeless (it is acknowledged that this is outside of the scope of this report) and also more awareness of the needs of homeless people with regards to healthcare. Whereas BME participants requested cultural awareness training around end of life care needs to enable staff to understand "the needs of the patient and providing facilities accordingly" and the extension of visiting hours in hospital and to allow more than two family members to visit the patient at one time. It is must be acknowledged however that Newcastle Hospitals NHS Foundation Trust do offer open visiting for anyone receiving end of life care, with more than two family members allowed at the bedside. Consideration for other patients on the ward is given.

A further two BME participants requested 24 hour home care for palliative care patients and one asked for greater involvement in decisions about their loved one's care.

> "The doctors were trying to resuscitate by pressing on his chest probably trying to restart his heart which I think they should ask family".

3.1.2.9Support for carers

In addition to sharing their views of the care their loved one received, this group were also asked about the support they received in the role of carer – how involved they felt that they were in decisions about the patients care and whether they as carers received the right support from end of life care services.

Eighteen carers responded to the question about involvement in decisions about their loved ones care. Over three-quarters (77.8%) felt that they were not very involved. Unfortunately as participants were not asked whether they were involved 'as much as they would like to have been' it is not possible to compare findings to the National Survey of Bereaved People.

Three people cited other commitments, being too far away from the patient or sharing caring responsibilities as reasons for a perceived lack of involvement but for others (and one of these was the carer referenced above who had not been consulted about whether they would have wanted their husband to be resuscitated) involvement was limited for a number of reasons. Again, difficulty communicating with health professionals was the main barrier identified with seven participants engaged by Deaflink and HAREF giving this reason. A lack of access to interpreters or information in other languages meant that, as with the patients themselves, they could not be fully involved in their loved one's care. Without interpreters D/deaf carers have to rely on lip-reading and as discussed above, BSL users rarely have a good understanding of English.

> "Not at all due to barriers for example language".
>
> "No BSL interpreters in the hospitals, only lip-read. I nodded sometimes".
>
> "Especially the hospitals, need to improve communication to tell more information, I have the right, but they tell me limited information, like I'm the 'second class' citizen but I want more information".
>
> "Never had interpreters, just writing, concerns, what I think best for treatments, I asked questions, yes or no they tell me limited information, not a lot. More depth over medical situations, I asked for more information to tell me, what it's meant, how it affects, how to improve, what is the plans in long term, things need to asked but never happened".

Where carers are reliant on the hearing patient to give them information any deterioration in their condition also makes involvement in care difficult.

> "Not very good I can't, I don't understand at all, lip-reading no good at all. Lip-reading, her teeth is gone. We tried fingerspelling, can do some alright but sometimes she was stuck on fingerspelling as her brain shut down, struggling but can't".

Finally, there were issues around health professionals speaking to other family members without communication needs instead of the next of kin. The case study in section 3.1.3.1 also illustrates this issue.

> "I told them I am the next of kin so contact me but they contacted like my wife's mother so I told them no it's me you need to tell me direct, not her. They were unsure, I said it's me important I need the information so I was not happy with the hospital".

One homeless participant who was caring for their friend felt that their lack of involvement was due to "not [being] officially registered as a carer" and for a further two people with learning disabilities it is unclear whether they may not have been recognised as carers by healthcare staff.

Participants were also asked whether they as carers received the right support before and after the patient's death. Looking at support before the death firstly, 18 people answered this question; seven (38.9%) felt that they did receive the right support and 11 (61.1%) felt that they did not. Those who were happy with the support identified hospital staff and Skills for People workers in particular; another participant described receiving counselling from Walkergate Hospital.

> “The hospital explained everything to me”.

> “Nurses were very sensitive to my feelings”

For those who did not feel that they received adequate support, one person did not live near to the patient and therefore accessing any support would have been difficult and for another the shortness of the illness meant that there was little time to offer support. For one homeless person they suggested that their lack of support was because they were not the official registered carer and for two BME families they simply stated that they did not receive any support.

> “No support was offered to family caring for her. We felt we were taken for granted”.

> “We as a family did not receive any support from anyone. This support can be more in need if your loved one is dying in the hospital”.

For D/deaf carers the main barrier to support was again focussed on communication. As interpreters were not available to support the carer, her hearing granddaughter had to interpret an incredibly difficult message to her.

> “A discussion took place to advise that all treatment should be withdrawn from my father to alleviate the pain and suffering. My daughter had to 'interpret' this message to her grandmother...my mother and son felt excluded – our family pulled together to help them understand what was happening and the hospital took advantage”.

There is a belief from carers that there is no point asking for interpreters as they are not available and particularly when time is critical. There was one example where the partner of a patient who had been in hospital for over a week had a conversation about switching off their life support machine. They were asked whether at any stage they had a BSL interpreter or ask for one?

> “No I haven’t asked for an interpreter, I know because interpreters can’t come emergency, I know most of them always work”.

Having no support within the home is also more challenging when the main carer is D/deaf. For one participant, trying to communicate that she needed urgent help for her husband when he suddenly became ill at home was the issue. On the day her husband died she asked a neighbour to phone her GP as she was worried about his health. She was sent a fax from the GP surgery saying that the doctor would visit that afternoon. She went to check on her husband and realised he had died; she then had to approach a stranger to phone 999 (see case study in section 3.1.3.1 for further detail).

Another participant stated that they “needed someone to support me like nurse”. They went on to describe an occasion when caring for their hearing partner who had dementia and heart problems, they were asleep and not aware that this partner had fallen. They had to bang on the wall to get the neighbour’s attention to come around and help them.

In terms of suggestions for improving the support carers receive prior to the death of their loved one, people simply asked for some appropriate support and for one BME participant, they felt that they could not explain how to improve the support due to “religious and cultural reasons”. It is important to note that D/deaf participants did not request support around communication despite this being a huge factor for them and it is suggested that this is because there is a culture of acceptance within this community. BSL users are very often prohibited from asserting their rights or informing agencies of problems or concerns because without interpreters they cannot communicate how they are feeling. One D/deaf person said that when they leave the ward the nursing staff ask if everything is okay and put their thumbs up, “how am I supposed to tell them anything? They can’t sign”.

For D/deaf carers an acknowledgement from staff that they are the main carer and should be involved and supported rather than speaking to hearing members of the family was an issue. Another participant requested a long term care plan that they could use which covered what to do in an emergency, for example, if the patient was at home.

Finally with regards to carers, they were also asked whether they received the right support after the patient had died. Of the 21 people answering this question seven (33.3%) stated that they did receive appropriate support. For one BME participant they appreciated the timeliness of releasing their loved ones body to meet their religious requirements, a participant with learning difficulties had support from carers and a homeless participant received support from staff at Virginia House (housing for homeless people).

> “We appreciate the staff making fast arrangements to release the body”.
>
> “Carers helped me, we emptied the house”.
>
> “Received support from my friends and the Virginia House staff”.

For ten people (47.6%) the appropriate support was not forthcoming. None said that they had received offers of support from any authorities. One homeless person said “everyone just turned their back on me” and a participant with learning difficulties stated “I missed her, nobody helped…I lost the death certificate”.

D/deaf and hard of hearing participants felt that they could not answer ‘yes’ or ‘no’ to this question. Reliance on family to navigate the requirements immediately after death was a key theme although there were also examples of agency support.

After the sudden death of a patient at home the D/deaf carer (who had had to rely on neighbours to make the phone call for help) received support from the police, an interpreter their GP.

> "So the police asked if need a BSL interpreter, I have a phone number of the interpreter I always choose for my husband, for his regular appointments. Quickly that interpreter came, good…They asked questions like who is doing funeral?... The coroner and my son talked…I was in the middle, couldn't follow…two weeks later…the doctor want to see me at 10.30 in the morning. So I went over, nice doctor (no interpreter), hugged me and said very, very sorry it happened this way, I know it's very hard for you to phone. Really, really, very, sorry. She realised".

> "My partner's son did most of the work, organised things and my partner's ex-wife and her husband both do a lot of things for me, arranged everything funeral, and wills and things".

Finally, for the participant whose mother is still in receipt of palliative care, they had concerns about how to arrange a funeral and how to actually contact services as communication is more difficult by email.

> "But I can't use the phone, look on the internet how to find information, emails etc. Email seems hard and being ignored as phone calls quick. Phone easy and straight away accept information and sort out. Email is ignored, I have noticed."

Suggestions for improvements were put forward by five people, four of whom were homeless. Two suggested having a "scheme to help people deal with bereavement" another simply wanted some support whilst a fourth requested:

> "More training, more inclusion, more community support, more awareness, more funding, more people with lived experience working in decision-making".

One BME family requested a signposting service for available support.

> "More support offered to family during and after the death of a family member by means of referring family members to relevant support services".

In terms of support for the D/deaf and hard of hearing community, in the past there would have been a BSL Social Worker on hand to help them to cope with their bereavement and organise the practical things needed when a person dies. If they do not have independent support there is a chance that their wishes will not be met.

3.1.3 Case studies

In addition to the information elicited from the questionnaires, two carers, one from the D/deaf community and one from a BME community took part in a case study.

3.1.3.1D/deaf carer

- Female, aged 71. Lives in Newcastle
- Cared for husband (aged 70) who had dementia, non-Hodgkin's lymphoma and diabetes

- Used RVI, Freeman and Walkergate, and had a Social Worker for the Deaf (2007-2009)
- Cause of death – heart attack, July 2014
- Both profoundly deaf and BSL users

Her husband started feeling ill in 2001 and had several visits to hospitals for tests. He was notified about these hospital appointments in writing with between 1 and 10 days' notice. He never had interpreters and relied on lip reading or reading notes and it was a struggle to for him to understand. Her husband had many appointments either to see a doctor or for scans. On one occasion, their son came along to the appointment and the doctors spoke at length to him. However, neither their son nor the doctor communicated this discussion with her or her husband.

In June 2007 her husband was off work for 10 weeks. He went to the doctors and got sick notes and painkillers for his back. Her husband didn't tell her much about what was happening. He was sent to the RVI for x-ray which didn't show anything. However, her husband began feeling worse and was becoming angry and frustrated. He also developed problems with walking.

One evening at midnight her husband felt so bad that they asked a neighbour to visit as she was a nurse. She came, saw him and called for an ambulance. He was taken to A&E, then in the morning transferred to RVI Leazes Wing Ward 40. He had an MRI scan and was then informed by a nurse that they were being transferred back to the General Hospital.

Her husband had an operation and stayed on ward 33/34 (the spinal ward) for two months after which he was transferred to a cancer ward as this was easier for accessing radiotherapy which was located downstairs. They were told he had non-Hodgkin's lymphoma and that his life expectancy would be 7-10 years.

Through this period, 2001-2007, and including the diagnosis of cancer, the couple did not have access to an interpreter. His wife felt overwhelmed as the words written by the doctors were difficult to understand and she did not know what they meant. For example, neither she nor her husband knew why he had an oxygen mask on his face or what the tube in his chest was for.

Whilst visiting him in hospital where he was recovering after his operation she bumped into a BSL interpreter who said she should have an interpreter for meeting doctors etc. She contacted Newcastle Communication Support Unit at the Council and they contacted the hospital and explained that an interpreter was needed. From then on an interpreter was booked for appointments because she would fax appointment dates to the communication support unit and they would liaise with the hospitals.

During this stay at the RVI they both received counselling 'because the husband had a lot of frustration and anger and was awful to her'. The RVI arranged the sessions and booked a BSL interpreter for them. After 3 or 4 appointments her husband declined any more sessions as he felt they were a waste of time.

In October 2007, he was transferred to Walkergate Park Hospital where he stayed for 4 months until discharge in January 2008. In Walkergate Hospital, there was BSL interpreting support but her husband wanted to go home as he was the only deaf person there and felt isolated. She was asked by staff at the hospital if she would be able to look after him. She said she could but would need things like equipment; bed, chair lift etc. The social worker helped them get a grant and occupational therapy from the Freeman Hospital assessed their needs and provided new a chair lift, bed, bathroom (wet room) and outside ramp for his wheelchair. Her husband stayed at home during weekends and returned to hospital during the week.

Walkergate Park arranged for counselling again as her husband was struggling, nipping and hurting her and some staff members. Both received counselling sessions but neither had an interpreter. They cancelled after two sessions.

After discharge, her husband had regular check-ups every three months at the RVI with a BSL interpreter present. They then moved to the Freeman Hospital NCCC (Northern Centre for Cancer Care).

Their social worker left in 2009 due to cuts in funding. She could sign BSL but nobody replaced her.

Three years ago in early in 2014, her husband received a letter asking him to go for an appointment at his GP practice. At this check-up the nurse told her husband that he had diabetes and he was prescribed medication by his GP.

Three months later her husband felt ill and went upstairs to lie down. She checked on him through the morning and a few hours later thought he was worse. She asked a neighbour to contact the doctors for her, who confirmed a GP would do a house visit later. She then went to check on her husband and realised he had died. She found a person in the street to call 999. Emergency services arrived and she didn't know what was happening. A police officer asked her if she needed an interpreter and she confirmed that she did. An interpreter arrived within 30 minutes.

The coroner (via the son as an interpreter) confirmed he died of acute myocardial infarction.

Issues identified

There were certainly positive aspects of both the patient's and carer's experience in terms of:

- The general medical care received
- Interpreting support after a period of time
- Access to a BSL social worker for D/deaf people, who arranged aids and adaptations etc.

The case study however, also illustrates the following issues related to the care of the patient and their carer:

- A lack of communication support initially and interpreting services were only provided due to a chance meeting
- No interpreter for counselling sessions
- The carer being excluded from conversations with healthcare professionals
- The patient feeling isolated during a stay at a rehabilitation service as there were no other D/deaf patients there
- Social worker removed and not replaced
- A lack of communication support at home resulted in a neighbour having to contact healthcare services and a stranger having to call 999. There was a misunderstanding around the urgency of the request for help

3.1.3.2BME carer

- Female – main carer for her mother
- Mother lived alone and passed away in 2014
- Mother required care for seven years prior to death
- Mother had a range of health issues: diabetes, kidney problems, rheumatoid arthritis, pneumonia, glaucoma and dementia
- Mother spoke no English

The mother's husband passed away suddenly decades earlier following an accident and she lived alone as her children were all grown up with children of their own, ranging from young children to adults. Some of the mother's adult children lived relatively locally whilst others were overseas, though all have health issues of their own (all but one of the adult children have diabetes).

The daughter interviewed has a series of health related issues, was one of the mother's main carers, as she was the only daughter living nearby to mother, in the west of Newcastle. The mother spoke no English, which is a significant and recurring feature in relation to her experience of end of life care and support.

When it first became clear that mother required care, the family were assigned a social worker. Feedback from the daughter is that this first social worker was very understanding of the needs of the family. She also understood the effect that the language barrier had on mother as it prevented her from being able to communicate with most health and social care staff (although mother was able to communicate with her GP as they shared a common language).

The family felt that the first social worker was helpful although after a time they were assigned another social worker. Following this their experience changed, as several of the subsequent social workers (the daughter estimates they had six social workers in total) did not show an understanding of the effect of the language barrier and regularly disagreed with the views of the family as to the type and level of care mother needed. For example, the daughter recalled that the social worker was of the view that the mother could make toilet trips unaided, and the daughter was very clear that this was not the case, particularly when she had a flare up of arthritis. There were several disagreements with social workers about this, including in a multi-disciplinary meeting when health staff agreed with the daughter that the mother did need such help.

The mother had a care package of 21 hours per week which daughter felt was not enough for her needs and she recounted how she had applied for night care for her mother over a six year period. She said this was resisted by social workers and in the end, daughter applied through another fund which she described as “the doctor’s fund”. This application was successful and for this reason, mother had night care in the last year of her life. Daughter expressed that, because she and her siblings took good care of their mother she always looked well turned out, which perhaps added to some social workers’ views that she was not so much in need of care.

Before moving on from daughter’s reported experience of social workers, she offered quite a striking, reflection that she found younger social workers more likely to be dismissive of her mother’s specific language needs;

“The older social workers understood but the younger ones told us we were racist to ask for an Asian carer. I think they think that Asian people are against the English people. I am not against the English. But what is the point of leaving your mother alone with a carer if she cannot tell the carer what she needs or when she is in pain?”

Daughter went on to explain that she had wanted to use the time the carer would be with mother to have a break herself but whenever the carer and the mother could not communicate, daughter had to stay at mother’s house even during those hours of care.

Daughter reported that mother had several periods as in-patient in both the Freeman Hospital and the Royal Victoria Infirmary, in the last seven years of her life. There were some aspects of this experience which caused concern to the family. Firstly, daughter reports that her mother fell over several times when in hospital, mainly due to being left unaided in the toilet for too long;

“Sometimes they would take her to the toilet and leave her there. She would press the bell but nobody would come. I think maybe she fell around ten times in hospital and she had some bruises from these falls.”

Secondly, daughter fed back that language interpretation was never provided for her mother, although it was requested. She said there was a general response of “we will look into it” but it did not happen. When asked if they made a complaint about the lack of language interpretation she acknowledged that they had thought of it, but they were so busy focusing on their mother that they did not do so.

According to daughter, the concern caused by mother’s inability to understand others or be understood required her and her siblings to apply a shift system to minimise the time that mother would be left alone in hospital without access to language interpretation. She said they could not achieve 24 hour a day cover, but sometimes they were there all day and night. She recalled that some wards were more open than others to longer visiting hours and family members sitting up with patients. Daughter said that other aspects of the care received in hospital were good, but that being left unaided and the falls, did mean that the family did not wish for mother to be in hospital unless totally necessary.

Daughter also commented about the lack of access to space for prayer as a problem in hospital. Daughter fed back that mother spent two weeks in a hospice* just outside of Newcastle, but much the same problems applied in relation to not understanding or being understood. For this reason she did not stay longer.

Daughter explained that the above limitations of hospital and residential care generally were why the family fought so hard to have care at home for mother. The daughter said that she took good care of the carers and made sure they knew everything they needed to know to take care of her mother. She was quite happy with much of the care received as she fought to get the carers of her choice. Other positive aspects of support received that daughter recalled was, just before and immediately after her mother passed away in hospital (which was just before dawn). Firstly, when hospital staff advised that mother might not make it through the night, they arranged for mother to be moved to a private room, so that family members could gather around her and pray. She died surrounded by her loved ones. Secondly, the hospital did all possible to get the necessary certificates ready so that the family could arrange for her to be buried on the same day. Daughter explained that her mother died on a holy day so the family was especially appreciative of being able to bury her that afternoon.

The suggestions made by daughter were to have more training of social workers on the needs of older people, particularly when language barriers and dementia feature. She felt that social workers accepted yes and no answers from her mother, even if her mother did not fully understand what she was being asked. The other main suggestion was to have more multi-lingual care workers and nursing staff. As earlier indicated (but repeated here as it was stressed again towards the close of the interview) daughter was at pains to point out that she is not of the view that all Asian people should have Asian carers, or support staff. Daughter reiterated that she made the request in relation to her mother specifically because of the language barrier. She also observes that there are many older South Asian women in Newcastle, who also do not speak English, and is therefore of the view that this issue is likely to affect many families as an elderly relative reaches the end of their life.

*Please note that the interviewer is not clear as to whether the facility was a hospice or another form of residential care, as the geographical area mentioned is not thought to have a hospice.

Issues identified

There were again positive aspects of both the patient's and carer's experience:

- Caring social worker understanding for the communication needs of the patient
- Night support was provided in the final year of the patient's life
- Medical care in the hospital was good

- The patient was moved into a private room before she died enabling the family to gather and pray
- The hospital released the body in a timely manner

The case study however, also illustrates the following issues related to the care of the patient and their carer:

- First social worker was re-assigned. Following social workers were not understanding of the effect of the language barrier
- The carer had to fight to get the right level of support at home
- The 21 hour care package was felt to be inadequate and night support was needed
- A lack of understanding, particularly from younger carers of the language needs of the patient who told the family they were racist for asking for an Asian carer
- A lack of access to paid carers who could communicate with the patient leading to the daughter having to stay during the visit
- The patient was often left unaided in the toilet resulting in them falling
- Despite being requested, language interpreters were never provided during hospital visits. This resulted in the family providing constant round the clock support
- A lack of access to space for prayer in the hospital
- A hospice stay was cut short due to not being able to communicate with staff
- Care at home was the only option due to a lack of communication support in hospices/residential homes

3.2 Preferences around end of life care

The second part of the engagement focussed on people's preferences at end of life. All 216 participants gave their views in this respect.

When considering the responses given in this section it must be acknowledged that as people get closer to death or are faced with terminal illness, their preferences can and will change.

3.2.1 Understanding of end of life care services

Those who had not cared for a person who had been in receipt of end of life care services (192 people, making up 88.9% of all of those sharing their preferences) were initially asked whether they were aware of what services are termed as 'end of life'. In total 167 people, accounting for 87.0% of participants stated that they did not have an understanding of what end of life care services are and as shown in the table below this is most noticeable amongst the BME community engaged by HAREF. This supports the findings of the CQC's report 'A different ending: Addressing inequalities in end of life care' (2016) where a lack of awareness, understanding and information about end of life care services hindered BME communities from receiving good quality care. As discussed in section 3.1.2.1 above, this gap in knowledge has already been identified and NGCCG has already held a number of education sessions with BME community groups.

Awareness of end of life care services	HAREF		NSPB		Homeless		Skills for People		Deaflink	
	No.*	%**	No.	%	No.	%	No.	%	No.	%
Yes	8	5.8	1	50.0	3	18.8	2	18.2	11	42.3
No	129	94.2	1	50.0	13	81.2	9	81.8	15	57.7
Total	137	100.0	2	100.0	16	100.0	11	100.0	26	100.0

*Number of participants
**Percentage of participants

The data appears to demonstrate that participants engaged by Deaflink have a greater understanding of end of life services however when looking at their explanations of what the services cover it is clear that there is some lack of knowledge and understanding.

> "Is it about communication and pain?"
>
> "I remember (person who was dying) their signing was reduced and I just left them".
>
> "In my family – lots have died. All had expectations, they wanted to die suddenly and I get upset. The details... too hard".

Responses from the other participants were mostly accurate in their descriptions; they identified:

- Palliative care
- Hospital care
- Home care (including 24hr care at home)
- Hospice care
- GPs
- Nursing homes
- Pharmacies

- Social services
- Services provided by Marie Curie charity
- Macmillan nurses
- Support for carers
- Bereavement counselling

However four people mentioned other things. Two felt that a ‘meals on wheels’ type service would fall under end of life care services, one felt that it simply covered “health of the elderly” and one homeless respondent suggested they were services for assisted suicide.

3.2.1 Place of death

All 216 participants were asked this question and 214 responses were garnered. As shown in the table below almost half of people said that they would prefer to die at home and across all groups the largest proportion of people would choose to die at home. However, it is interesting to note that this figure is noticeably lower than the 70.0% of people suggested by the Dying Matters Coalition. The next largest group were those who said that they had no preference about where they died.

Preferred place of death	No. of participants	Percentage of participants (%)
At home	98	45.8
In a hospital	33	15.4
In a hospice	16	7.5
In a nursing home	2	0.9
In a care home	0	0.0
Somewhere else	23	10.7
No preference in place	42	19.6
Total	214	100.0

The vast majority of people suggesting somewhere else were from BME communities and a number of people specified the location. For seven people they would want to die in their country of birth or ‘home country’, another two said that it was “Allah’s will” that would decide where they died and one person simply stated an “important place to me”..

	HAREF		**NSPB**		**Homeless**		**Skills for People**		**Deaflink**	
Preferred place of death	**No.***	**%****	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
At home	60	40.8	1	50.0	12	54.6	11	78.6	14	48.3
In a hospital	28	19.0	1	50.0	2	9.0	2	14.3	0	0.0
In a hospice	6	4.1	0	0.0	0	0.0	0	0.0	10	34.5

In a nursing home	1	0.7	0	0.0	0	0.0	0	0.0	1	3.4
In a care home	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Somewhere else	22	15.0	0	0.0	0	0.0	0	0.0	1	3.4
No preference in place	30	20.4	0	0.0	8	36.4	1	7.1	3	10.3
Total	147	100.0	2	100.0	22	100.0	14	100.0	29	100.0

*Number of participants
**Percentage of participants

In terms of preferences for those with learning disabilities our engagement shows that only two people would choose to die in hospital. The CQC's report 'A different ending: Addressing inequalities in end of life care' (2016) also found that this group would prefer not to die in hospital.

Examining responses from Deaflink shows a marked difference between the preferences of BSL and hard of hearing participants. Seventy-two percent of BSL users would prefer to die at home followed by 22.0% who would choose a hospice (a further 5.0% chose nursing home and 5% did not mind) and this was reversed for people who are hard of hearing with 75.0% identifying a hospice and 12.5% home (a further 12.5% did not have a preference). In addition, three people gave reasons for why they would not choose a care home and for two people the isolation factor was key. There would be very little chance that any other residents would be D/deaf and there was a belief that care home staff would not be able to communicate with them.

3.2.2 Other wishes

Other than place of death, participants were also asked whether they had any other preferences regarding their end of life care and whether they had shared these wishes with anyone.

3.2.2.1Discussing end of life care preferences

Participants were initially asked whether they had ever discussed with anyone their wishes regarding end of life care. Two hundred and ten people responded to this question with only 33 (15.7%) stating that they had discussed wishes with someone. This is not unsurprising however, given the fact that death is still very much a taboo subject within society. A 2016 ComRes survey, 'Dying Matters Coalition – Public Opinion on Death and Dying' on behalf of the National Council for Palliative Care reported that 73% of people agreed with the statement: People in Britain are uncomfortable discussing dying, death and bereavement". Moreover the survey reported that 78% of people agreed with the statement: If people in Britain felt more comfortable discussing dying, death and bereavement, it would be easier to have our end of life wishes met.

As shown in the table below none of the homeless participants had spoken with anyone, over two-thirds of people who have a learning disability or are D/deaf or hard of hearing had not had a discussion with anyone nor had nearly nine in ten BME participants.

Discussions around end of life care wishes	HAREF		NSPB		Homeless		Skills for People		Deaflink	
	No.*	%**	No.	%	No.	%	No.	%	No.	%
Yes	18	12.6	1	50.0	0	0	4	30.8	10	33.3
No	125	87.4	1	50.0	22	100.0	9	69.2	20	66.7
Total	143	100.0	2	100.0	22	100.0	13	100.0	30	100.0

*Number of participants
**Percentage of participants

Of the 177 people who did not discuss their wishes, 158 gave reasons for this. As shown in the table below, there were two main reasons for this; the participant had simply not thought about it or they felt it was too emotive a subject to consider. The fact that that they felt that they were too young and had time to consider it were also mentioned.

Reason for not discussing wishes	No. of participants*	Percentage of participants (%)
Not thought about it	70	44.3
Too emotive a subject	68	43.0
Not discussed in our culture	23	14.6
Too young	20	12.7
No choice	2	1.3
No one to discuss it with	2	1.3
Total	185	

*Participants could give more than one reason

The table below shows responses by group. In terms of those who state they had not considered their wishes at end of life, over four-fifths of homeless participants cited this as a reason. The chaotic and often stressful nature of their lives means that this group will not necessarily plan for future events, their focus is on survival day-to-day and considerations of death are not their priority.

> "Haven't come around to it, been concentrating on my own recovery".
>
> "It did not occur to me about end of life".
>
> "I don't think this necessary".

In terms of the emotive nature of the subject, people felt that they did not want to upset their families with discussions about their death or they felt scared when thinking about it and this was particularly true of BME participants engaged by HAREF. All participants of an Asian Men's group said that they "like to think positively all the time and don’t want to pressure my family”. Furthermore, two participants with a learning disability felt too “scared to talk about it” whilst another simply stated that they “find it very emotional and sensitive to talk about”.

The fact that dying and preferences around end of life care are not usually discussed within their culture was also mentioned by BME groups and individuals engaged by HAREF. These included participants in two mosque based women’s groups, an older South Asian women’s and a group of older Chinese people. People do not discuss death and preferences at the time of death because it is not part of their culture or religious views.

> “It’s not part of [our] culture, believe when time comes, it comes therefore don't discuss”.
>
> “Not discussed in families as not part of culture”.
> “It's something we don't think and discuss amongst ourselves even little things like will and property”.
>
> “Because we believe in one ‘God’ whatever HE will do, it will be good for everybody”.

	HAREF		**NSPB**		**Homeless**		**Skills for People**		**Deaflink**	
Reason for not discussing wishes	**No.***	**%****	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
Not thought about it	42	37.2	0	0.0	13	81.3	6	66.7	9	47.4
Too emotive a subject	61	45.9	1	100.0	1	6.3	2	22.2	3	15.8
Not discussed in our culture	23	20.4	0	0.0	0	0.0	0	0.0	0	0.0
Too young	6	5.3	0	0.0	4	25.0	3	33.3	7	36.8
No choice	1	0.9	0	0.0	1	6.3	0	0.0	0	0.0
No one to discuss it with	0	0.0	0	0.0	1	6.3	0	0.0	1	5.3
Total	133		1		20		11		20	

*Number of participants
**Percentage of participants

Finally, 20 people (12.7%) felt that their young age was a factor in why they had not considered their wishes around end of life care.

> “Even though death can happen at any age, being young it has never crossed my mind”.
>
> “People say I haven't had my life yet”.

> "I am too young to die. Do not think about it".

3.2.2.2Preferences

Thirty-three people said that they had discussed their wishes around end of life care with someone and twenty-seven shared those wishes. In addition, 120 of the 177 people who had not previously discussed their wishes went on to identify some preferences.

End of life care preferences	No. of participants*	Percentage of participants (%)
Peaceful and respectful	48	32.7
Female/BME staff	37	25.2
Do not attempt resuscitation/ switch off life support	30	20.4
Religious/cultural needs	28	19.0
Pain control/comfort	25	17.0
With family	24	16.3
Ease for family	20	13.6
Place of death	20	13.6
Funeral plans/plans after death	18	12.2
Separate room	10	6.8
BSL communication needs	3	2.0
Legal things in order	2	1.4
Involvement in care	1	0.7
Organ donation	1	0.7
Total	269	

*Participants could give more than one reason

As shown in the table above, nearly one third of people simply hoped that their care would enable them to have a peaceful end to their life and one where they were respected as a person and this was particularly true of BME and homeless participants. This echoes the 'End of Life Care Strategy', (2008) and the findings of 'What's important to me. A Review of Choice in End of Life Care' (2015) where both found that people wanted to be treated with dignity and respect at the end of their lives.

> "I want to die with dignity and not alone".
>
> "To be valued and respected".
> "Just somewhere peaceful, where my family can be in peace".

“Want to die in peace with my family”.

“Respectful NHS staff”.

Preferences regarding end of life care	HAREF		NSPB		Homeless		Skills for People		Deaflink	
	No.*	%**	No.	%	No.	%	No.	%	No.	%
Peaceful and respectful	40	37.0	0	0.0	3	37.5	3	27.3	2	11.1
Female/BME staff	37	34.3	0	0.0	0	0.0	0	0.0	0	0.0
Do not attempt resuscitation/switch off life support	21	19.4	1	50.0	1	12.5	0	0.0	7	38.9
Religious/cultural needs	27	25.0	0	0.0	0	0.0	0	0.0	1	5.6
Pain control/ comfort	20	18.5	0	0.0	0	0.0	3	27.3	2	11.1
With family	16	14.8	0	0.0	2	25.0	4	36.4	2	11.1
Ease for family	18	16.7	1	50.0	0	0.0	0	0.0	1	5.6
Place of death	12	11.1	1	50.0	0	0.0	2	18.2	5	27.8
Funeral plans/ plans after death	5	4.6	0	0.0	2	25.0	7	63.6	3	16.7
Separate room	10	9.3	0	0.0	0	0.0	0	0.0	0	0.0
BSL communication needs	0	0.0	0	0.0	0	0.0	0	0.0	3	16.7
Legal things in order	0	0.0	0	0.0	0	0.0	0	0.0	2	11.1
Involvement in care	0	0.0	0	0.0	0	0.0	0	0.0	1	5.6
Organ donation	0	0.0	0	0.0	1	12.5	0	0.0	1	5.6
Total	206		2		9		19		30	

*Number of participants
**Percentage of participants

There was also a request by over one quarter of participants (25.2%), who were all from BME communities that there were female workers available to care for female patients and also to receive care if possible, from staff from their background who spoke their language and understood their cultural needs.

> "To receive care and all treatment by female staff preferably from my background [Pakistani]".
>
> "More GPs speaking Hindi".
>
> "Care from BME staff".
>
> "Would like to receive services according to my religious needs e.g. female staff, female doctors, care home for BME people".

One fifth of participants (20.4%) held strong views about being kept alive and if and when they would want medical intervention and this was the area most frequently discussed by D/deaf and hard of hearing participants. For them there was concern that their communication needs would not be met, causing additional stress and giving the patient no dignity.

> “Do not resuscitate as don't want communication problems to stress my end of life. There are no agency or carers use BSL, nor NHS or Macmillan nurse”.
>
> “If I was diagnosed with a terminal illness or been seriously injured, where the quality of life have been robbed, I would rather to die than have too many people come and go and can’t communicate with me at all - I would feel I’ve been left with no dignity”.
>
> “Do not keep resuscitating me or keep me on life support machines if no real prospect of recovery. I do not want to be killed (no euthanasia) but not pointlessly kept breathing”.
>
> “Wouldn’t want to slow death down”.

Almost one fifth of people (19.0%) asked that their religious and cultural views be met whilst in receipt of end of life care and this is discussed further in section 3.2.3 below. Aside from one person who was hard of hearing, BME participants accounted for this group. This desire also reflects the findings of several end of life care reports (‘What’s important to me. A Review of Choice in End of Life Care’, 2015, End of Life Care Strategy, 2008) where people asked for their emotional and spiritual needs to be supported. Participants specifically spoke about wanting to have a “Muslim burial”, for their “religious rituals [to be] upkept” and several people wished to be buried in their home country.

> “According to Islamic rituals”.
>
> “Good caring service with all the comfort and rituals”.
>
> “I would like to be cared for at home where my religions and cultural needs are met and respected by the professionals”.
>
> Be buried straight-away, follow religious obligations”.
>
> “Proper cloths from the hospital”.

Twenty-five people (17.0%) asked that their end of life be pain free and comfortable and again this is in keeping with national reports (End of Life Care Strategy, 2008, ‘What’s important to me. A Review of Choice in End of Life Care’, 2015).

> “Pain control at end of life”.
>
> “As little pain as possible”.

> “Somewhere comfortable with friends around”.

Being with family or ensuring that their family was at ease were other common themes.

> “To die peacefully around my family if it is possible”.
>
> “Don't want to make it hard for my family as they may find it hard to look after me”.

Twenty people (13.6%) considered the place that they would like to die when discussing their end of life care needs. Fifteen people said that they would like to die at home, one a hospice and another nursing home.

In addition to the religious requirements of BME participants above, a further 18 people discussed how they would like their funeral arranged and this was particularly true of participants with a learning disability. Some people would prefer cremation whilst others would like to be buried.

> “If she (wife) is cremated or buried I would like to be with her”.
>
> “People to wear happy clothes when the time comes”.
>
> “I would like Human by the Killers and Abba at my funeral”.
>
> “I'd like everyone to wear a Newcastle top”.
>
> “I would like to be cremated and put beside my Dad at West Denton Crematorium”.

Finally, three D/deaf or hard of hearing participants also requested having staff who could communicate with them and had an awareness of the needs of deaf patients.

> “I would like to be communicated to using Lip Speaker. I want to be cared for by people/professionals who are Deaf aware. I want to know what options I have and to be fully involved. I want people to use plain English and communicate with me as an equal I don't want anything discussed about me without me”.
>
> “BSL interpreter, nurses that can communicate with me”.

3.2.3 Cultural needs

All 216 people were asked whether they had any specific end of life needs due to their culture or identity. One hundred and ninety-eight people responded to this question with an even split between yes and no responses. Looking at responses per group engaged, it is clear to see that participants from BME communities engaged by HAREF were most likely to identify needs due to their culture or identity (81.8% of all those who identified a need).

End of life care needs due to culture or identity	HAREF		NSPB		Homeless		Skills for People		Deaflink	
	No.*	%**	No.	%	No.	%	No.	%	No.	%
Yes	81	59.1	0	0.0	1	5.9	2	15.4	15	51.7
No	56	40.9	2	100.0	16	94.1	11	84.6	14	48.3
Total	137	100.0	2	100.0	17	100.0	13	100.0	29	100.0

*Number of participants
**Percentage of participants

End of life care needs due to culture or identity	No. of participants*	Percentage of participants (%)
Communication needs	37	37.4
Female/BME staff	34	34.3
Care of the body	28	28.3
Family involvement	24	24.2
Prayer facilities	19	19.2
Dignity and respect	18	18.2
Separate room	14	14.1
Visiting times	11	11.1
Islamic burial	8	8.1
Funeral plans	5	5.1
Appropriate clothing	2	2.0
Church of England beliefs followed	2	2.0
Close to family	2	2.0
Last rites read	2	2.0
Halal food provided	1	1.0
Laid to rest in home country	1	1.0
Total	99	

*Participants could give more than one reason

Examining their responses shows that communication needs were most commonly mentioned. People wanted care staff to be able to communicate fully with them so that they were aware of their needs, either cultural or otherwise. In terms of BME participants this was ideally in their language and referred to both spoken and written word. A care home for BME people was also mentioned. For D/deaf and hard of hearing participants this was their key requirement and again they wanted staff who could communicate in BSL and are deaf aware or timely access to an interpreter. As with the BME groups engaged by HAREF, having a hospice or care home for D/deaf people was also suggested.

> “Written information in Chinese”.
>
> “Information about end of life care in plain English if not possible in other languages, audio or video format available online for family to access”.

"BME care home".

"I need someone who has sign language skills and to understand deaf culture".

"I am deaf, so I would like to be somewhere where people can communicate with me properly, maybe a care home for deaf and Deaf people".

Having female staff to care for female patients and their body once they have died and having BME staff who understand the cultural needs of the patient was the next most common need identified and was the key theme to emerge from the BME engagement conducted by HAREF.

End of life care needs due to culture or identity	**HAREF**		**NSPB**		**Homeless**		**Skills for People**		**Deaflink**	
	No.*	**%****	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
Communication needs	25	30.9	0	0.0	0	0.0	0	0.0	12	80.0
Female/BME staff	33	40.7	0	0.0	0	0.0	0	0.0	1	6.7
Care of body	28	34.6	0	0.0	0	0.0	0	0.0	0	0.0
Family involvement	24	29.6	0	0.0	0	0.0	0	0.0	0	0.0
Prayer facilities	19	23.5	0	0.0	0	0.0	0	0.0	0	0.0
Dignity and respect	17	21.0	0	0.0	0	0.0	0	0.0	1	6.7
Separate room	14	17.3	0	0.0	0	0.0	0	0.0	0	0.0
Visiting times	11	13.6	0	0.0	0	0.0	0	0.0	0	0.0
Islamic burial	7	8.6	0	0.0	0	0.0	0	0.0	1	0.0
Funeral plans	4	4.9	0	0.0	0	0.0	0	0.0	1	0.0
Appropriate clothing	2	2.5	0	0.0	0	0.0	0	0.0	0	0.0
Church of England beliefs followed	0	0.0	0	0.0	0	0.0	2	100.0	0	0.0
Close to family	1	1.2	0	0.0	1	100.0	0	0.0	0	0.0
Last rites read	0	0.0	0	0.0	0	0.0	0	0.0	2	13.3
Halal food provided	1	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Laid to rest in home country	1	1.2	0	0.0	0	0.0	0	0.0	0	0.0
Total	187		0		1		2		18	

*Number of participants
**Percentage of participants

"Female staff to care for and examine us after death".

"BME doctor and staff…more female nurses from Indian community".

"More BME care staff, staff from my culture who are aware of my needs".

Care of the body after death was another important consideration for BME participants and in particular the earlier-mentioned Chinese, South Asian and mosque based women's groups which HAREF engaged. People in some cultures, namely Chinese, would prefer the body not to be moved immediately after death. In accordance with faith, Muslim families require the body to be released to the family as quickly as possible so that a funeral can take place within 24 hours. Newcastle Hospitals NHS Foundation Trust has a ritual washing room and prayer facilities available to all patients and carers.

> "Don't move body for 12 hours as soul stays in body for that long".
>
> "Release my body as soon as possible to be buried".
>
> "Body to be released to family quickly".

The involvement of the family in any caring decisions was also important to two Asian BME groups. It was felt that "caring need[s] should be decided with family" and that there should be "no post mortem without family's permission" as this was felt to disrespect the body.

Prayer facilities within hospitals and in other care facilities are also important to some people. This could be used by both patients and their family and friends who come to visit them.

In terms of other 'practical' needs, having a separate private room available in the hospital/hospice for family to come and visit the patient, allowing visiting outside of normal times and allowing large numbers of people to visit the patient just before death is important for some.

3.4 Summary

From the information above it is clear to see that there are certainly some positive experiences around end of life care services and this is particularly true of patients currently in receipt of these services, where the support of healthcare staff is especially welcomed. However, the engagement has shown a lack of awareness amongst seldom heard groups of what end of life care services actually include and a lack of planning or in fact any discussions at all, around end of life care wishes. However, once prompted, people did make some suggestions around what a good death would look like to them and these reflected the findings of national reports.

Discussions with carers of people who have received end of life services have identified some areas where improvements could be made. For BME and D/deaf and hard of hearing people in particular, this is predominantly around communication support for both patients and carers to allow them to be fully informed and involved in the patient's care and also to have access to services that can meet their needs. There is also a need for greater cultural awareness amongst healthcare staff to ensure that people are offered appropriate end of life care.

These findings are consistent with what is known about the general population in terms of what is important to people at end of life but this engagement has highlighted the scale of issues for seldom heard groups and added colour to the national picture. For example, there is already much information about the communication needs of the D/deaf community but the project has shown it is not just about hearing problems and issues of deference have also been highlighted.

Section 4 - Recommendations

4.0 Recommendations

It is suggested that NGCCG takes time to analyse the findings of this project in order to understand what people would like their end of life care to look like and help inform the End of Life Strategy and Action Plan for Adults. However, from the findings of this engagement some specific recommendations have been made below which should be considered in terms of practicality and implementation. Some of these recommendations are specific to end of life care services and others apply to any health care service. It is acknowledged that some of the recommendations relating to wishes at end of life are already in place however this highlights an issue around people’s awareness of these services and entitlements. Moreover, other recommendations may also be in place but highlight a need for improvements in these areas.

4.1 Discussing end of life care

Very few people (15.7% of 210 participants) had discussed wishes regarding their end of life care, supporting national findings that show people do not like to talk about death and dying. Participants felt that it was too emotive a subject, they had simply never considered it or felt that they are too young to consider end of life care. Furthermore, for some BME communities it is not discussed within their culture.

It is recommended that NGCCG considers a media campaign which encourages people, at any age to talk about their end of life care and what a good death would look like to them. There should also be consideration of targeted campaigns at a community level, for example, engaging with faith leaders around some BME groups or local organisations that support homeless people. Alongside this, there should also be information available around who to contact for additional help, be it practical advice or emotional support and this help should be accessible for all.

In addition to this, healthcare staff also need to initiate conversations around end of life care wishes. Although it is recognised that no particular healthcare staff have a duty to introduce these conversations, there needs to be an acknowledgement that it is everyone’s responsibility. The roll-out of the Standards Project will be a useful tool in this respect. It is also suggested that GP Time In/Time Outs are used to share these messages where they could be a rolling agenda item.

4.2 Awareness of end of life care services

There is a lack of awareness amongst D/deaf and BME participants engaged by HAREF around what end of life care services actually cover and therefore, what is available and what people can expect from such services. It is sensible to assume that this is not unique to these groups. Some BME groups have also taken proactive steps to address the issue and it is suggested that an educational awareness and myth-busting programme be commenced with the other seldom heard groups involved in this project in the first instance. People cannot plan for or consider their death without having all of the information available to them.

4.3 Identifying patients at end of life

For one homeless person who was caring for a close friend who was also homeless and had drug and alcohol addictions, their issue was that the person was not identified as approaching end of life early enough. As a result, no end of life care was received and this reflects national findings. It is suggested that awareness training for any staff involved in the health care of homeless people is conducted to ensure that identification occurs in a timely manner.

4.4 Communication support

The report highlights a number of areas where communication was a barrier to good care and support to both patients and carers with communication needs. Since August 2016 all organisations that provide NHS care or publicly funded adult social care are legally required to follow the Accessible Information Standard. The aim of the standard is:

> “to make sure that people who have a disability, impairment or sensory loss are provided with information that they can easily read or understand and with support so they can communicate effectively with health and social care services”.

The standard is currently being applied in Newcastle and its implementation should go some way to alleviate the issues identified below. However for services such as care homes and hospices outside of the remit of the standard the recommendations will still stand.

4.4.1 Identifying communication needs

- A situation should never arise where for example, staff are shouting at a D/deaf patient because they do not know that they are D/deaf. Ideally, GPs should capture information about their patients’ communication needs and this information should pass with them through the NHS services they use. However, to ensure this information is up-to-date and reflects the patients current needs, when they first arrive on a hospital ward, in a hospice or care home or begin to receive support from a service relating to their end of life care, there must be a system in place whereby their non-clinical needs are re-assessed and any information recorded and, crucially, passed on to all staff caring for the patient. The needs of the main carer should also be assessed. This assessment should also cover cultural needs (discussed in 4.5.1 below).

4.4.2 Communication support

- Although carers may be able to communicate on their loved ones' behalf and at times may want to, there should never be an assumption that this is the only way to communicate with patients. This puts additional pressure's on carers who feel they have to be present at all times to support the patient and also adds emotional strains if they then have to communicate bad news. In addition, without professional support it is possible that information is not being interpreted accurately or some information in fact could be withheld from the patient. Patients and carers should therefore be offered support rather than having to ask for it. This is especially important within the D/deaf community where there is a culture of acceptance and a belief from carers that there is no point asking for interpreters as they are not available, particularly when time is critical.

  There should not be occasions where the patient or the carer cannot communicate with health professionals to understand what care they or their loved one is being given or make decisions about their care. In emergency situations this is obviously difficult and no one would want care to be held up in any way but in hospital environments in particular it is suggested that qualified BSL and other language interpreters are available at all times. If face-to-face support is not possible the use of a telephone interpreting service or a video relay service where appropriate, is recommended. Text messaging should also be offered to patients and carers as a means of communicating. Any communication support should also be available if the patient is receiving medical care at home or in a hospice or care home.

- It is further recommended that a review of the process of booking interpreters is carried out across all end of life care services to ensure that procedures are being followed.

- Cuts to local authority budgets have resulted in there being only one qualified Social Worker who can use BSL in the North East at present and to qualify for social work support D/deaf people must have additional needs. Therefore there is clearly a gap in support for this group in terms of communicating with health services but also around practical things such as will-making and funeral arrangements. It is suggested that this support be reinstated.

- For BME participants, having accessible written information was also important and ideally in their first language. There was however an acknowledgment that this may not be possible and instead it was suggested that information be produced in plain English. The Patient Advice and Liaison Service holds some useful information and should be used where appropriate

4.5 Cultural awareness and need

Appropriate end of life care which is respectful of their cultural needs should be expected for all patients and their carers. There is a need for cultural awareness training for staff providing end of life care so that they have the knowledge and understanding to be able to offer support in the most appropriate way. Any training should include information about the procedures involved in the preservation of the body and also how to explain to people the reasons for undertaking post-mortems. This should include all seldom heard groups involved in this project in the first instance. It is known that this training exists within the Hospitals Trust but there is perhaps a need for refresher courses after a certain period of time, to be put in place. Training is also needed within all other services caring for people at the end of their lives such as care homes and hospices and this should include both health professionals and other support staff.

4.5.1 Identifying cultural needs

As with communication needs there should be no assumptions made about cultural needs. When a patient first begins to receive support from an end of life care service, it is suggested that there is a system in place whereby their cultural needs are assessed including any requirements regarding how the body is cared for after death and this should be disseminated amongst all staff caring for the patient.

4.5.2 Prayer facilities

There is a need for patients’ and carers religious needs to be met in terms of a physical, private space for prayer. This should be available in any environment where patients are receiving end of life care. These services are available within Newcastle Hospitals NHS Foundation Trust but there is perhaps a need for greater advertising of the facilities.

4.5.3 Gender of healthcare staff

In order to meet their cultural needs and uphold their dignity it is important to some BME groups to have male care staff for male patients and female care staff for female patients and this should be the case for any care received within any environment. This separation should continue once the patient has died and the body is being cared for. If this is not possible patients should be informed in advance.

4.5.4 Place of death and burial

For some BME participants there was a desire to end their lives in their country of birth or to be buried there. It is suggested that information is made available to BME communities around the processes that would be involved in leaving the country when very ill or transporting the body. It is also suggested that there should be some collaboration specifically with Mosques and Imams on this issue.

In addition, a requirement of the Chinese culture is for the body not to be moved immediately after death, whilst in accordance with faith, Muslim families require the body to be released to the family as quickly as possible so that a funeral can take place within 24 hours. It is recommended that where ever possible they requirements are upheld. Newcastle Hospitals NHS Foundation Trust has a ritual washing room but it is suggested that these facilities are available in all other end of life care services such as hospices and care homes.

4.6 Care at home

Care at home was particularly important for some people who required communication support. It was felt by some BME people who do not speak English as their first language and those who require a BSL interpreter, that hospices and care homes could not cater for their needs and would result in them being isolated.

There was demand from some people for more support for patients receiving paid care within their own home and some confusion around the role of these carers. It is important that when a decision is made that a patient in receipt of end of life care services will be begin to receive care at home, there is an agreement between all parties that this care is adequate to the needs of the patient. To ensure that patients and carers are fully aware of the scope of such services - exactly what they will be getting, how long the visits should be etc. patients and carers should also have access to a care plan.

To meet their cultural and communication needs there were also requests for care staff who could speak the patients language or were the same sex as the patient. It is recommended that every effort is made to ensure that provision of care at home meets the communication and cultural needs of people receiving care.

In terms of non-paid carers who have communication needs who are looking after a patient at home, there should be acknowledgement of the added challenges around this and it is suggested that a care plan should be produced which explains what to do if the patient’s health deteriorates and they need medical help urgently.

4.7 Last stages of life

Once it was clear that the patient is in the last stages of life they should be moved to a private room in a timely manner; any restrictions on visiting times and numbers of patients should be lifted to enable family and friends to visit the patient at any time. Newcastle Hospitals NHS Foundation Trust do offer open visiting for anyone receiving end of life care, with more than two family members allowed at the bedside and this should be made clear to visitors. Consideration for other patients however must be given.

4.8 Recognition of next of kin/main carer

There were several examples where carers were overlooked or not able to get involved in decisions about the care of their loved one either because a hearing family member was contacted instead or they were not officially recognised as such. It is suggested that as with communication requirements, the main carer, regardless of their label or relationship to the patient, be identified by all services providing end of life care to the patient and this information be captured and disseminated amongst the necessary staff. There should be an agreement that this person will always be contacted first with appropriate communication support in place to facilitate this and only in an emergency would another contact be used. However, it is acknowledged that it may be difficult to identify who the ‘main carer’ is where for example there are family breakdowns.

4.9 Support for carers

Aside from communication needs, the engagement identified a gap in terms of support for carers particularly after the death of their loved one. It is also known that formal support provided by Newcastle Carers is restricted to 12 weeks after the death of a loved one; moreover, they cannot accept referrals after a person has died. It is suggested that at the very least, after the death of someone, they receive accessible information which explains the next steps, useful organisations to contact regarding funeral arrangements for example and any bereavement services that are available. For D/deaf people there are particular barriers in terms of actually being able to contact bereavement support services and any services need to consider their accessibility to all groups. It is expected that the roll-out of the Standards Project will assist GPs and hospital staff to disseminate this information.

4.10 Patient involvement in end of life care

- Two GP practices which are part of the Standards Project declined to take part in this project as they felt uncomfortable asking these patients for their opinion. This perhaps suggests a need for education for GPs around interacting and involving patients who are receiving end of life care.

Appendices

Appendix 1 - Questionnaire for seldom heard group participants

NHS Newcastle Gateshead Clinical Commissioning Group (NGCCG) is undertaking a review of End of Life Care for adults in Newcastle. This review will consider the care and support provided to adult patients, their relatives and carers during their last years of life, death and in the period afterwards. The work will also engage with people who, although have no experience of End of Life services, are willing to share their expectations, priorities and views on what good End of Life Care should look like.

The review is targeting groups and communities which are often seldom heard and is focusing on:

Black and Minority Ethnic communities
Deaf and hard of hearing
Homeless
Blind and visually impaired
Living with a learning disability or difficulty

We would really appreciate it if you could take 10 minutes to give us your views and any recent experiences you have had of End of Life Care. Your feedback is important to us and anything you say will be held confidentially and anonymously.

Questionnaire

1. Have you cared for someone who has received End of Life Care (and passed away) within the last two years?

Yes	☐	**Go to section 1 ↓**
No	☐	**Go to section 2 →**

Section 1: People with experience of End of Life Care

2. What was your relationship to this person?
   ……………………………………………………………………………………………

3. How long were they receiving palliative care before they died?
   ……………………………………………………………………………………………

4. Do you feel they received the support they needed?

Yes ☐ No ☐

a. Please explain your answer

……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………

b. How could this have been improved?

……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………

5. How well did the different services they received work together?
For example, the patient may have had a stay in hospital, had health professionals care for them at home and had time in a hospice

……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………

6. Do you think that they were treated with dignity and respect?

Yes ☐ No ☐

a. Please explain your answer

……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………

b. How could this have been improved?

……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………

7. How involved were they in decisions about their care?
……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………

8. Do you feel they received the appropriate support around their communication needs? *For example, was information provided in plain English? Were they offered BSL support or alternative languages?*

Yes ☐ No ☐

a. Please explain your answer

…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………

b. How could this have been improved?

…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………

9. Do you feel that their cultural needs were met?

Yes ☐ No ☐

a. Please explain your answer

…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………

b. How could this have been improved?

…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………

10. Did they have a preference about where they would like to die?

Yes ☐
No ☐ **Go to question 12 ➔**

11. Did they die in the place of their choice?

Yes ☐ **Go to question 12 ➔**

No ☐

a. If not, was there a reason behind this?

For example, because of the timescales from diagnosis to when they died?

…………………………………………………………………………………………

12. Were they made comfortable in the place where they died?

Yes ☐ No ☐

a. Please explain your answer

……………………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………

b. How could this have been improved?

……………………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………

13. How involved were you in decisions about their care?

……………………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………

14. Did you as their carer, receive the right support before they died?

Yes ☐ No ☐

a. Please explain your answer

……………………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………

b. How could this have been improved?

……………………………………………………………………………………
……………………………………………………………………………………

……………………………………………………………………………………

15. Did you receive the right support after they died?

Yes ☐ No ☐

a. Please explain your answer

……………………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………

b. How could this have been improved?

…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………

16. Do you have any other comments about End of Life Care for patients and for carers?
…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………

The next questions relate to your views of End of Life Care

17. Thinking about yourself, when the time comes, where do you think would be your preferred place to die?

At home	☐	In a care home	☐
In a hospital	☐	Somewhere else	☐
In a hospice	☐	…………………………….	
In a nursing home	☐	Don't mind	☐

18. Have you ever discussed with someone your wishes regarding End of Life Care?

Yes ☐

a. If yes, what are these wishes?

…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………

Go to question 19 🡇

No ☐

b. If no, why have you not discussed your wishes?

…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………

c. Do you have any wishes? What are they?

…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………

19. Do you have any particular End of Life needs due to your culture or identity?

Yes ☐
No ☐ **Go to Section 3 ➔**

a. If yes, what are they?

……………………………………………………………………………………………

……………………………………………………………………………………………
……………………………………………………………………………………………

Go to Section 3 ➔

Section 2: People with no experience of End of Life Care

1. Are you aware of what services are termed as 'End of Life Care'?

Yes ☐
No ☐ **Go to question 2 🡇**

a. What are they?

……………………………………………………………………………………………
……………………………………………………………………………………………

2. Thinking about yourself, when the time comes, where do you think would be the best place to die?

At home ☐
In a hospital ☐
In a hospice ☐
In a nursing home ☐
In a care home ☐
Somewhere else ☐
……………………………
Don't mind ☐

3. Have you ever discussed with someone your wishes regarding End of Life Care?

Yes ☐

a. If yes, what are these wishes?

……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………

Go to question 4 🡇

No ☐

b. If no, why have you not discussed your wishes?

……………………………………………………………………………………………

……………………………………………………………………………………………
……………………………………………………………………………………………

c. Do you have any wishes? What are they?

……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………

4. Do you have any particular End of Life needs due to your culture or identity?

Yes ☐
No ☐ **Go to Section 3 🡻**

a. If yes, what are they?

……………………………………………………………………………………………

……………………………………………………………………………………………

Go to Section 3 🡻

Section 3: Monitoring

Are you…?

Blind/visually impaired ☐
From a Black or minority ethnic community ☐
D/deaf or hard of hearing ☐
Homeless ☐
A person with a learning disability ☐

Gender

Male ☐ Female ☐ Transgender ☐

Age

Under 18	☐	18 – 24	☐	25 – 34	☐
35 – 44	☐	45 – 54	☐	55 – 64	☐
65 – 74	☐	75 – 84	☐	85 and over	☐

How do you describe your sexuality?

Lesbian	☐	Bisexual	☐
Gay	☐	Prefer not to answer	☐
Straight	☐		

Do you consider yourself to have a disability?

Yes ☐ No ☐

Please indicate your ethnic background:

White ✓		Asian or Asian British ✓	
British		Indian	
Irish		Pakistani	
Central/Eastern European		Bangladeshi	
Any other White background		Any other Asian background	
Mixed		Black or Black British	
White and Black Caribbean		Caribbean	
White and Black African		African	
White and Asian		Any other Black background	
Any other mixed background			
Other ethnic groups			
Chinese			
Any other ethnic group (*write in)* …………………………………………………………………………………………			

What is the first part of your postcode?...

Case studies

As part of this work we would like to develop a number of case studies to explore the issues and decisions you faced when caring for someone who received End of Life Care.

If you would be happy to take part in a case study please tick the box below and leave your contact details

☐ **I am happy to be contacted to discuss my experience in more detail**

Name……………………………………………………………………………………….
Telephone………………………………………………………………………………......
Postal address……………………………………………………………………………….
Email……………………………………………………………………………………...

Appendix 2 – Overall participant profile for seldom heard groups

Gender

	No. of participants	% of participants
Male	67	31.0
Female	147	68.1
Transgender	1	0.5
Gender Fluid	1	0.5
No response	0	0.0
Total	216	100.0

Age

	No. of participants	% of participants
Under 18	3	1.4
18-24	19	8.8
25-34	36	16.7
35-44	29	13.4
45-54	33	15.3
55-64	38	17.6
65-74	41	19.0
75-84	14	6.5
85 and over	0	0.0
No response	3	1.4
Total	216	100.0

Sexuality

	No. of participants	% of participants
Lesbian	5	2.3
Gay	1	0.5
Heterosexual	183	84.7
Bisexual	7	3.2
Pansexual	1	0.5
Prefer not to say	10	4.6
No response	9	4.2
Total	216	100.0

Do you consider yourself to have a disability?

	No. of participants	% of participants
Yes	64	29.6
No	135	62.5
No response	17	7.9
Total	216	100.0

Ethnic background

	No. of participants	% of participants
White British	64	29.6
White Irish	2	0.9
Central/Eastern European	9	4.2
Any other White background	1	0.5
Mixed White and Black Caribbean	0	0.0
Mixed White and Black African	1	0.5
Mixed White and Asian	0	0.0
Any other Mixed background	3	1.4
Asian or Asian British - Indian	30	13.9
Asian or Asian British - Pakistani	49	22.7
Asian or Asian British - Bangladeshi	10	4.6
Any other Asian background	3	1.4
Black or Black British	1	0.5
Black or Black British – Caribbean	0	0.0
Black or Black British - African	4	1.9
Any other Black background	0	0.0
Chinese	19	8.8
Any other ethnic group	15	6.9
No response	5	2.3
Total	216	100.0

Location – first part of postcode

	No. of participants	% of participants
NE1	3	1.4
NE2	17	7.9
NE3	26	12.0
NE4	66	30.6
NE5	4	1.9
NE6	20	9.3
NE7	7	3.2
NE13	2	0.9
NE15	8	3.7
Outside Newcastle	27	12.5
No response	36	16.7
Total	216	100.0

Appendix 3 – Participant profile by group

BME communities engaged by HAREF

Gender

	No. of participants	% of participants
Male	39	26.5
Female	107	72.8
Transgender	1	0.7
No response	0	0.0
Total	147	100.0

Age

	No. of participants	% of participants
18-24	2	1.4
25-34	11	7.5
35-44	21	14.3
45-54	20	13.6
55-64	18	12.2
65-74	30	20.4
75-84	35	23.8
85 and over	8	5.4
No response	2	1.4
Total	147	100.0

Sexuality

	No. of participants	% of participants
Lesbian	3	2.0
Gay	0	0.0
Heterosexual	132	89.8
Bisexual	1	0.7
Prefer not to say	4	2.7
No response	7	4.8
Total	147	100.0

Do you consider yourself to have a disability?

	No. of participants	% of participants
Yes	115	78.2
No	18	12.2
No response	14	9.5
Total	147	100.0

Ethnic background

	No. of participants	% of participants
White British	2	1.4
White Irish	1	0.7
Central/Eastern European	9	6.1
Any other White background	1	0.7
Mixed White and Black Caribbean	0	0.0
Mixed White and Black African	0	0.0
Mixed White and Asian	0	0.0
Any other Mixed background	3	2.0
Asian or Asian British - Indian	30	20.4
Asian or Asian British - Pakistani	48	32.7
Asian or Asian British - Bangladeshi	8	5.4
Any other Asian background	3	2.0
Black or Black British	1	0.7
Black or Black British – Caribbean	0	0.0
Black or Black British - African	3	2.0
Any other Black background	0	0.0
Chinese	19	12.9
Any other ethnic group	15	10.2
No response	4	2.7
Total	147	100.0

Location – first part of postcode

	No. of participants	% of participants
NE1	2	1.4
NE2	12	8.2
NE3	24	16.3
NE4	47	32.0
NE5	3	2.0
NE6	14	9.5
NE7	6	4.1
NE13	2	1.4
NE15	5	3.4
Outside Newcastle	11	7.5
No response	21	14.3
Total	147	100.0

People who are D/deaf or hard of hearing engaged by Deaflink

Gender

	No. of participants	% of participants
Male	7	22.6
Female	24	77.4
Transgender	0	0.0
No response	0	0.0
Total	31	100.0

Age

	No. of participants	% of participants
Under 18	1	3.2
18-24	06	19.4
25-34	3	9.7
35-44	5	16.1
45-54	3	9.7
55-64	4	12.9
65-74	4	12.9
75-84	5	16.1
85 and over	0	0.0
No response	0	0.0
Total	31	100.0

Sexuality

	No. of participants	% of participants
Lesbian	2	6.5
Gay	1	3.2
Heterosexual	23	74.2
Bisexual	2	6.5
Prefer not to say	1	3.2
No response	2	6.5
Total	31	100.0

Do you consider yourself to have a disability?

	No. of participants	% of participants
Yes	4	
No	27	
No response	0	
Total	31	100.0

Ethnic background

	No. of participants	% of participants
White British	26	83.9
White Irish	1	3.2
Central/Eastern European	0	0
Any other White background	0	0
Mixed White and Black Caribbean	0	0
Mixed White and Black African	1	3.2
Mixed White and Asian	0	0
Any other Mixed background	0	0
Asian or Asian British - Indian	0	0
Asian or Asian British - Pakistani	1	3.2
Asian or Asian British - Bangladeshi	2	6.5
Any other Asian background	0	0
Black or Black British – Caribbean	0	0
Black or Black British - African	0	0
Any other Black background	0	0
Chinese	0	0
Any other ethnic group	0	0
No response	0	0
Total	31	100.0

Location – first part of postcode

	No. of participants	% of participants
NE1	1	3.2
NE2	2	6.5
NE3	1	3.2
NE4	1	3.2
NE5	0	0.0
NE6	3	9.7
NE7	1	3.2
NE13	0	0.0
NE15	0	0.0
Outside Newcastle	11	35.5
No response	11	35.5
Total	31	100.0

People who are blind or visually impaired engaged by NSBP

Gender

	No. of participants	% of participants
Male	1	50.0
Female	1	50.0
Transgender	0	0.0
No response	0	0.0
Total	2	100.0

Age

	No. of participants	% of participants
18-24	0	0.0
25-34	0	0.0
35-44	0	0.0
45-54	0	0.0
55-64	0	0.0
65-74	1	50.0
75-84	1	50.0
85 and over	0	0.0
No response	0	0.0
Total	2	100.0

Sexuality

	No. of participants	% of participants
Lesbian	0	0.0
Gay	0	0.0
Heterosexual	2	100.0
Bisexual	0	0.0
Prefer not to say	0	0.0
No response	0	0.0
Total	2	100.0

Do you consider yourself to have a disability?

	No. of participants	% of participants
Yes	2	100.0
No	0	0.0
No response	0	0.0
Total	2	100.0

Ethnic background

	No. of participants	% of participants
White British	2	100.0
White Irish	0	0.0
Central/Eastern European	0	0.0
Any other White background	0	0.0
Mixed White and Black Caribbean	0	0.0
Mixed White and Black African	0	0.0
Mixed White and Asian	0	0.0
Any other Mixed background	0	0.0
Asian or Asian British - Indian	0	0.0
Asian or Asian British - Pakistani	0	0.0
Asian or Asian British - Bangladeshi	0	0.0
Any other Asian background	0	0.0
Black or Black British – Caribbean	0	0.0
Black or Black British - African	0	0.0
Any other Black background	0	0.0
Chinese	0	0.0
Any other ethnic group	0	0.0
No response	0	0.0
Total	2	100.0

Location – first part of postcode

	No. of participants	% of participants
NE1	0	0.0
NE2	0	0.0
NE3	0	0.0
NE4	0	0.0
NE5	0	0.0
NE6	0	0.0
NE7	0	0.0
NE13	0	0.0
NE15	2	100.0
Outside Newcastle	0	0.0
No response	0	0.0
Total	2	100.0

People who are homeless engaged by Involve North East

Gender

	No. of participants	% of participants
Male	13	59.1
Female	8	36.4
Transgender	0	0.0
Gender Fluid	1	4.5
No response	0	0.0
Total	22	100.0

Age

	No. of participants	% of participants
18-24	1	4.5
25-34	11	50.0
35-44	2	9.1
45-54	6	27.3
55-64	1	4.5
65-74	0	0.0
75-84	0	0.0
85 and over	0	0.0
No response	1	4.5
Total	22	100.0

Sexuality

	No. of participants	% of participants
Lesbian	2	9.1
Gay	0	0.0
Heterosexual	17	77.3
Bisexual	1	4.5
Pansexual	1	4.5
Prefer not to say	1	4.5
No response	0	0.0
Total	22	100.0

Do you consider yourself to have a disability?

	No. of participants	% of participants
Yes	6	27.3
No	13	59.1
No response	3	13.6
Total	22	100.0

Ethnic background

	No. of participants	% of participants
White British	20	90.9
White Irish		0.0
Central/Eastern European		0.0
Any other White background		0.0
Mixed White and Black Caribbean		0.0
Mixed White and Black African		8.3
Mixed White and Asian		0.0
Any other Mixed background		0.0
Asian or Asian British - Indian		0.0
Asian or Asian British - Pakistani		0.0
Asian or Asian British - Bangladeshi		0.0
Any other Asian background		0.0
Black or Black British – Caribbean		0.0
Black or Black British - African	1	4.5
Any other Black background		0.0
Chinese		0.0
Any other ethnic group		0.0
No response	1	4.5
Total	22	100.0

Location – first part of postcode

	No. of participants	% of participants
NE1	0	0.0
NE2	3	13.6
NE3	0	0.0
NE4	14	63.6
NE5	0	0.0
NE6	0	0.0
NE7	0	0.0
NE13	0	0.0
NE15	0	0.0
Outside Newcastle	2	9.1
No response	3	13.6
Total	22	100.0

People who are living with a learning disability or difficulty engaged by Skills for People

Gender

	No. of participants	% of participants
Male	7	50.0
Female	7	50.0
Transgender	0	0.0
No response	0	0.0
Total	14	100.0

Age

	No. of participants	% of participants
18-24	1	7.1
25-34	1	7.1
35-44	2	14.3
45-54	6	42.9
55-64	3	21.4
65-74	1	7.1
75-84	0	0.0
85 and over	0	0.0
No response	0	0.0
Total	14	100.0

Sexuality

	No. of participants	% of participants
Lesbian	0	0.0
Gay	0	0.0
Heterosexual	9	64.3
Bisexual	1	7.1
Prefer not to say	4	28.6
No response	0	0.0
Total	14	100.0

Do you consider yourself to have a disability?

	No. of participants	% of participants
Yes	11	78.6
No	3	21.4
No response	0	0.0
Total	14	100.0

Ethnic background

	No. of participants	% of participants
White British	14	100.0
White Irish	0	0.0
Central/Eastern European	0	0.0
Any other White background	0	0.0
Mixed White and Black Caribbean	0	0.0
Mixed White and Black African	0	0.0
Mixed White and Asian	0	0.0
Any other Mixed background	0	0.0
Asian or Asian British - Indian	0	0.0
Asian or Asian British - Pakistani	0	0.0
Asian or Asian British - Bangladeshi	0	0.0
Any other Asian background	0	0.0
Black or Black British – Caribbean	0	0.0
Black or Black British - African	0	0.0
Any other Black background	0	0.0
Chinese	0	0.0
Any other ethnic group	0	0.0
No response	0	0.0
Total	14	100.0

Location – first part of postcode

	No. of participants	% of participants
NE1	0	0.0
NE2	0	0.0
NE3	1	7.1
NE4	4	28.6
NE5	1	7.1
NE6	3	21.4
NE7	0	0.0
NE13	0	0.0
NE15	1	7.1
Outside Newcastle	3	21.4
No response	1	7.1
Total	14	100.0

Appendix 4 – Letter sent to Palliative care patients

Dear

I am writing to you as we need your help.

Our GP practice is part of Newcastle Gateshead Clinical Commissioning Group (NGCCG) which is responsible for planning, purchasing and improving the health services you use.

NGCCG is currently undertaking a review of adults in Newcastle which will help to inform a new Palliative Care and End of Life Strategy, due to be published in March 2017.

Within this review we would like to hear from patients like yourself, or a carer on your behalf, who are currently receiving treatment, care or support from our practice. We are interested in patients whose health has recently deteriorated or who may have an illness we are unable to cure but we are actively treating your symptoms and keeping you in the best health possible sometimes referred to as Palliative Care. We would like to hear about your experiences of receiving this care, whether the services and support are right for you and anything you think is missing.

It is acknowledged that thinking about and talking about your experiences of care at this stage in your illness can be a sensitive topic and we really appreciate you taking the time to do this survey for us. Please be assured that your views will be completely anonymous.

If you feel able to share your views we would be very grateful if you (or someone on your behalf) can complete the questionnaire, included with this letter and return it in the pre-paid envelope within the next **14 days**.

If you would prefer to speak to someone about your experiences or have any queries about this letter, please contact Dr XXXX or Dan Duhrin at Involve North East on 0191 226 3450 or via his email address dan@involvene.org.uk. who is looking at data for the NGCCG.

I really hope you will consider taking part as your views are really important to us.

Yours sincerely

Appendix 5 – Questionnaire for patients currently receiving palliative care

1. Are you…?

Completing this questionnaire yourself ☐
Completing this questionnaire on behalf of the patient ☐

2. Are you getting the right support and services for you?

Yes ☐

a. If yes, what has made it right for you?

……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………

Go to question 3 🡻

No ☐

b. If not, what is missing?

……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………

3. Do you feel involved in decisions about your care?

Yes ☐
No ☐

a. Please tell us more about this

……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………

Please turn over ➔

4. Gender

Male ☐ Female ☐ Transgender ☐

5. Age

Under 18 ☐ 18 – 24 ☐ 25 – 34 ☐
35 – 44 ☐ 45 – 54 ☐ 55 – 64 ☐
65 – 74 ☐ 75 – 84 ☐ 85 and over ☐

6. How do you describe your sexuality?

Lesbian ☐ Bisexual ☐
Gay ☐ Prefer not to answer ☐
Straight ☐

7. Do you consider yourself to have a disability?

Yes ☐ No ☐

8. Please indicate your ethnic background:

White ✓		Asian or Asian British ✓	
British		Indian	
Irish		Pakistani	
Central/Eastern European		Bangladeshi	
Any other White background		Any other Asian background	
Mixed		Black or Black British	
White and Black Caribbean		Caribbean	
White and Black African		African	
White and Asian		Any other Black background	
Any other mixed background			
Other ethnic groups			
Chinese			
Any other ethnic group (*write in)* …………………………………………………………………………………………………			

9. What is the first part of your postcode?...

10. Which GP practice are you a patient of?……………………………………………

Appendix 6 – Participant profile for patients currently receiving palliative care

Gender

	No. of participants	% of participants
Male	5	62.5
Female	3	37.5
Transgender	0	0.0
No response	0	0.0
Total	8	100.0

Age

	No. of participants	% of participants
18-24	0	0.0
25-34	0	0.0
35-44	0	0.0
45-54	0	0.0
55-64	1	12.5
65-74	2	25.0
75-84	3	37.5
85 and over	1	12.5
No response	1	12.5
Total	8	100.0

Sexuality

	No. of participants	% of participants
Lesbian	0	0.0
Gay	0	0.0
Heterosexual	7	87.5
Bisexual	0	0.0
Prefer not to say	1	12.5
No response	0	0.0
Total	8	100.0

Do you consider yourself to have a disability?

	No. of participants	% of participants
Yes	2	25.0
No	6	75.0
No response	0	0.0
Total	8	100.0

Ethnic background

	No. of participants	% of participants
White British	8	100.0
White Irish	0	0.0
Central/Eastern European	0	0.0
Any other White background	0	0.0
Mixed White and Black Caribbean	0	0.0
Mixed White and Black African	0	0.0
Mixed White and Asian	0	0.0
Any other Mixed background	0	0.0
Asian or Asian British - Indian	0	0.0
Asian or Asian British - Pakistani	0	0.0
Asian or Asian British - Bangladeshi	0	0.0
Any other Asian background	0	0.0
Black or Black British – Caribbean	0	0.0
Black or Black British - African	0	0.0
Any other Black background	0	0.0
Chinese	0	0.0
Any other ethnic group	0	0.0
No response	0	0.0
Total	8	100.0

Location – first part of postcode

	No. of participants	% of participants
NE1	0	0.0
NE2	0	0.0
NE3	0	0.0
NE4	0	0.0
NE5	8	100.0
NE6	0	0.0
NE7	0	0.0
NE13	0	0.0
NE15	0	0.0
No response	0	0.0
Total	8	100.0

END OF LIFE RESEARCH

November 2016

Heidi Jobling
heidi@deaflink.org.uk

Contents

METHODOLOGY

Deaflink invited feedback from our members for 9 weeks through September-October 2016. We offered one to one interviews and 75% of the input from people who had recent experience of supporting someone in receipt of palliative care were through this method. British Sign Language (BSL) adapted paper questionnaires were also available and online questionnaires (with BSL video clips) accessed through our website.

We supported the research by going to our group and forums and raising awareness of the research and of the topic itself. In recognition that we were raising a potentially difficult topic with people we research local services available for people requiring emotional support and how BSL users would access them, from this we produced a leaflet of services.

We had 31 responses - 21 D/deaf, 8 hard of hearing (HoH) and 2 Child of Deaf Adults (CODA). The Online questionnaire was open to anyone and we did have replies from people living outside the area.

We asked people to answer questions relevant to their recent experience. We had 3 different questionnaires:

- **Group A** for people receiving End of Life care, we had 0 replies.
- **Group B** People with end of life care experience in the last 2 years. In this group we had replies from 5 people, 3 BSL users, 1 HoH and 1 hearing child of D/deaf Father.
- **Group C** People with no recent end of life care experience. We had replies from 18 BSL users and 7 HoH and 1 hearing child of D/deaf Adults.

BSL users generally do not feel comfortable communicating in written English. For the purposes of clarity we have amended some of the replies to into clearer English, where possible checking with the author if the amendments were correct.

To assist in comparisons we have colour coded replies – BSL user replies will be in black font, the HoH responses will be in green, the CODA replies are in dark red.

SUMMARY OF FINDINGS

In this section we will focus on two sections. The first will identify the key points from the interviews with people who have cared for or are caring for a person experiencing 'end of life care'. The second part will pull together the thoughts people had about their own end of life needs.

PEOPLE WITH EXPERIENCE OF CARING

The person who was hard of hearing was not interviewed, they chose to complete the online questionnaire.

At the start of each interview we asked the person 'do you know what 'end of life' or palliative care is? The responses highlighted that, matching the people with no experience of caring, the carers generally did not know what it was "No never had one like that before" "no?" "Yes, it's PALS". When we explained what the services were we then asked how long they had been receiving palliative care? The answers ranged from several years to 2 days.

They received the support they needed?

Every one of the respondents said that they felt that the person dying had received the support they needed. One of them gave an example of good communication - "They kept informing me with information that's good. I don't feel left out," in reference to a psychologist service.

When replying to this question the examples were often focussed on medical treatment "staff work there look after everything him, feed him, and give tablets and things" or "Very good support from GP and nurse" and there was a consensus of everyone had been helpful. However their stories show that there had been several years of struggle for diagnosis and looking after their loved one i.e. "She had been having accidents, not fair and too much of mess, hard work." In one case asking a medically trained next door neighbour for help "So I went to next door, Sandra she work as nurse for cancer in Freeman Hospital, asked her to do me a favour to come and have a look at my husband as he was not very good,".

The response to this question is from the perspective of the carer and therefore less likely to be negative as they would, naturally, hope that the person they cared for received the right support in the last few days and months of their lives. There was consensus feeling of 'they only want me' 'he doesn't want them' and did this mean that people were less likely to look for help or support as they felt they should provide the assistance?

When reflected with the general responses there is a theme of fear and communication barriers, a higher percentage of BSL users wanting to die at home.

> "either my daughter or I needed to be present at all visits to facilitate
> communication and to try to make sure that my Father's needs were
> being met."

Did this affect the carers request for help? Or to communicate or to understand the situation or even perhaps a lack of knowledge of what was available? Few of the carers could identify services, other than hospices, that were there to help them.

None of them suggested that communication with an interpreter was a regular occurrence. Throughout the research there were examples of when communication was a problem, for example, "During a visit I encountered Health Care Assistants shouting at him. I explained that he is profoundly Deaf they were apparently told that he was **Hard of Hearing".** Or the partner of a patient who had been in hospital for over a week having a conversation about switching off his partners defibrillator machine, we asked *at any stage did you have a BSL interpreter or ask for one?* "No I haven't asked for an interpreter, I know because interpreters can't come emergency, I know most of them always work."

In terms of improvements the suggestions were, understandably, to use appropriate communication methods e.g. to use an interpreter (preferably one they know and have used), not to use the telephone. Another common element was a need for improved deaf awareness and an understanding of the distress that is caused by lack of communication – from medical staff, from chaplaincy staff.

Different Services

Whilst other services were mentioned the main agency referred to was Social Services, there were a few references to Social Workers who helped them access other services and equipment.

> "Newcastle social worker, had a lot from her but she left because of the cuts"

Recent cuts to local authority budgets has seen the closure of all specialist sensory support units and result is that there is one qualified Social Worker who can use BSL in the North East. To qualify for social work support today D/deaf people must have additional needs. In the past a deaf person could rely on a Social Worker who would assist in communication with other agencies, co-ordination of services, understanding events and arranging funerals and helping with administration. There are no statutory agencies who currently offer these services to the deaf community.

There are fundamental assumptions regarding the level of BSL users understanding and knowledge of services available. If they are not already aware, and no-one takes the time to explain options, then access to some services will always be limited as promotional information if not accessible.

> "As a BSL Interpreter I have worked with terminally ill deaf people and have no knowledge of any mention of Hospice, **ever**."

Dignity and respect?

The majority of respondents had high praise for medical staff and felt that they 'did very well', they did the best they could' and there was a recognition that staff were very busy. There was also an acknowledgment that in some cases that the patient was not easy to look after.

Each one of the respondents had expressed using the services without interpreters and as this is extremely common for BSL users they do not necessarily identify this as an issue or problem.

> "No bad experiences, just natural, not hate. Just want someone there like interpreter that all."

The hearing daughter of deaf parents said:

> "only his basic needs were being met so how could he be treat with dignity and respect he couldn't communicate his needs"

The examples given by the interpreters in the Professional Observation section of this report highlights the affect that communication will have on an individual's quality of care and experience at end of life stage.

- "He had no control or decision making at the end of his life."
- "Towards the end she was unable to communicate all. But she was given the chance to. She stated that she had had a good life and accepted her pending death."
- "She told me she had cancer but she said no more, only that her family did not want anyone to know. I felt it was taken completely out of her hands"

How can this be improved?

- Specialist BSL Interpreting services – provided by qualified and chosen/preferred interpreters
- Ward rounds/discussions only taking place when an interpreter is present
- Deaf awareness on the wards
- Accepting that a deaf person has the right to be next of kin and provide appropriate communication support to them
- Contact through Text messaging or other format chosen by patient/family

How involved were they in decisions about their care?

80% of the respondents identified that their loved one had dementia and this affected how much the patient was able to be involved in their own care. There is little information about what was discussed at early stages of ill health with the exception of a request to be cared for at home. There were examples of the services relying on family members to communicate with the patient.

> "I had to take time off work and plan my hospital visits around meals to make sure he could communicate what he wanted to eat."

A professional interpreter observed the following 'Interpreters were rarely used during her illness rather her deaf family wrote messages to doctors, etc. and withheld info from her. She could not stand up to them.'

The issue of involvement in care is a concern. Not only are patients and carers denied information by not using interpreters but this is also removing choice and control. Medical professionals are often reliant upon family and friends communicating with the patient – how do the medical professionals know what is being communicated to the patient? Most family members will not be qualified interpreters.

This also highlights the issue of power imbalances, whether patient or carer, if the medical staff rely on family/friends to interpret then this means that the needs of the deaf person is open to being disregarded. There are examples of where deaf carer wanted an alarm to notify him if partner was in need, the partner did not want this – did anyone spend time discussing concerns with carer, explored alternatives? A patient whose deaf family withheld information from her, nor did they inform anyone of her stay in hospital and she did not receive visitors – was this the choice of the patient, advised by the medical staff or the choice of the family?

Support around their communication needs?

Communication is a common thread through all of the research. From the carers perspective it affects how much they understand or feel involved in their loved ones care.

> "No BSL interpreters in the hospitals, only lip-read. I nodded sometimes"

There is another the example where a carer is struggling to communicate with their hearing parent

> "(Mother is hearing) Not very good I can't, I don't understand at all, lip-reading no good at all. Lip-reading, her teeth is gone. We tried fingerspelling, can do

> some alright but sometimes she was stuck on fingerspelling as her brain shut down, struggling but can't. Same my wife (also Deaf)" They go on to say "She telling less and less to me, most of the time I tell her but her response is not much."

Failing to recognise the need for and to provide an interpreter to support the communication between mother and son is having a massive impact on the relationship, with the son saying he goes to see his mother fewer times and stays only 5 minutes.

How could communication have improved?

- "Interpreters should be available in emergencies, find someone on 'stand by' through the day.
- "We want the same interpreter (*they*) know all his background."
- "Not enough news, know it's hard, not easy!
- "Deaf awareness and understanding of the need for specialist interpreters."

The health care professionals are reliant on interpreters to communicate with BSL users. Note writing and lip-reading are limited. Many people do not appreciate that BSL users rarely have a good comprehension of English, it is a different language. The interpreter will assess how much the BSL user is taking on board, do they understand what is being said? Do they know the options available? And the interpreter will ensure that the health professional has answered all questions. Using familiar or preferred interpreters should be used during this time as it gives people reassurance and comfort that they know it is someone they can understand and trust.

There is also a need to recognise a culture within deaf communities of deference to hearing people. An acceptance, without complaint, of services offered.

Communication, with BSL users, without interpreters, is meaningless

Were cultural needs met?

60% of respondents said yes, their needs were met – but with reference to their religion, or that they didn't have any needs. The 40% who felt that their needs were not met felt that this was a lack of deaf awareness.

> "On the ward they seemed to panic and didn't know how to cope with him and his deafness"

Preference about where they would like to die?
Only one person said that their loved on had any preference (to die at home), and they did not die where they wanted to (hospital) and this was because of the specialist treatment required in hospital. The majority never mentioned it only the burial/cremation plans. Given that they were receiving palliative care this seems strange that they have not had discussions about where they would prefer to die, perhaps a lack of knowledge about the options available is a factor.

Were they made comfortable in the place where they died?
One person answered this question and they said, yes, the patient was comfortable. In explaining this others felt that they didn't know.

This question is, again, quite difficult for a carer to reply to, it is their perspective of events. One person said that her husband died peacefully at home and yet the description of events of that day doesn't necessarily support this. Her husband went to bed feeling ill and she checked on him regularly over the next few hours. He asked for a doctor and, before medical professionals arrived, he died.

How involved were you in decisions about their care?
The replies below highlight the issues:

- "Most of the time I was in the decisions"
- "They contacted my wife's mother! so I told them no it's me you need to tell me direct, not her"
- "Back to ward 19, but getting worse and worse. Before that, the doctor knew he had a weak heart, said 'do you want to switch off his defibrillator?' I was unsure and said no not yet. One week later, other doctor came in and said he still have a very weak heart do you want to switch off the defibrillator?' I was unsure I rather someone tell me, his son was quiet, I looked at son said nothing."
- "I've asked the staff ward sister team, I asked what treatments, arrange what, what best for her etc. I asked and asked. Been regularly writing, emails etc. Been writing to give information about what I will do, can do, monitoring care etc. up to the doctor to decide, I don't see the doctor. Wrong time, wrong place. What plans? Inform me when? carry on tablets or plans in the future, etc., nothing."
- "Especially the hospitals, need to improve communication to tell more information, I have the right, but they tell me limited information, like I'm the 'second class' citizen but I want more information"
- "Never had interpreters, just writing, concerns, what I think best for treatments, I asked questions, yes or no they tell me limited information, not a lot. More depth over medical

situations, I asked for more information to tell me, what it's meant, how it affects, how to improve, what is the plans in long term, things need to asked but never happened"

- "Freeman hospital never mentioned to me about diabetes"
- "End of care staff need to be more deaf aware for the family as well. My mother and son felt excluded – our family pulled together to help them understand what was happening"

These responses illustrate issues not only around communication but access to information about how best to care for the patient, if the wife was unaware of diabetes how could she ensure that it was managed? The need to communicate quickly often overrides the person's right to be next of kin and involved in the decisions. This is highlighted the examples above - his mother in law was contacted to relay information about his mother or having to make a decision about life changing treatment without an interpreters and then asked again a week later, without an interpreter. The fact that the conversation was repeated a week later meant that an interpreter could have been booked – if someone had thought about it.

"A discussion took place to advise that all treatment should be withdrawn from my father to alleviate the pain and suffering. My daughter had to 'interpret' this message to her grandmother."

It may be important to note that the person who felt 'very' involved in the decisions about their partner is hard of hearing and therefore easier to communicate with.

Did you as their carer, receive the right support?
60% of respondents felt that they did receive the right support, but what is the 'right' support?

"I have no right to support given ..." This was the reply from a man who had been looking after his hearing partner who had dementia and heart problems. He was asleep and not aware when his partner fell and banged on the wall for attention. His partner had previously refused equipment that may have helped - an alert buzzer. He received no formal support during the several years he cared for his partner.

"I had the daughter role and the professional interpreter role."

"Nothing, informed me nothing, never asked me 'would like to offer you ... or arrange support?' never mentioned nothing. I think nothing about this and just normal carry on, not mentioned or bring up to me nothing."

One woman had received counselling when her husband was received treatment at Walkergate Hospital. On the day her husband died she asked a neighbour to phone her GP as she was worried about her husband’s health. She was sent a fax from the GP surgery saying that the doctor would visit that afternoon. She went to check on her husband and realised he had died, she then had to approach a stranger to phone 999.

How could this have been improved?
“A lot of them talked to my partner’s son because he is hearing …… But why don’t they come to me directly?”

“I would like to get the ‘picture’ of what happens in the long term plans, what will happen, what to do, like what happens after she dies then what to do? If illness serious, what to do? Link to that I would like to plan long term and get information I wish.”

The culture of acceptance is massive factor in D/deaf communities, for example “Only lip-reading, never got an interpreter, my fault.” BSL users are not strong in asserting their rights or informing agencies of problems or concerns because they can’t – without interpreters they cannot let people know how they are feeling. One D/deaf person said that when they leave the ward the nursing staff ask if everything is ok, put their thumbs up, “how am I supposed to tell them anything, they can’t sign”.

Did you receive the right support after they died?
No-one felt that they could identify yes or no to this question.

In the comments one person describes how his step son and his partner’s ex-wife and her husband help sort out the ‘funeral and wills and things’.

“but I can’t use the phone, look on the internet how to find information, emails etc. Email seems hard and being ignored as phone calls quick. Phone easy and straight away accept information and sort out. Email is ignored, I have noticed.”

“I need to know how it works to solve the problem, if I don’t know what to do I am stuck.”

“doctor talked too quick I didn’t understand her”

“A lot of people talked around and I was lost, said nothing.” “The coroner and my son talked, both knew well. I was in the middle, couldn’t follow.”

3 years ago support to a BSL user would have been a role for a Social Worker, helping them cope with the death of a loved one, understanding what needs to be done, informing the right people, arranging the funeral and helping with the administration of the estate. If the deaf person does not have family support the potential for abuse and deception is high, recently one BSL user in North Shields was recently charged an extortionate amount for a funeral, unaware of options and what she was purchasing.

There is also a danger that the family members are disempowering carers by making decisions on behalf of BSL users, patients or bereaved carers, without checking the understanding or needs of the individual. The lack of accessible information continues this disempowerment and total reliance on hearing people.

GENERAL FEEDBACK

This section looks at the 31 replies and how they feel personally about end of life issues.

The first question was only to the 26 people who have no experience of end of life care and they were asked if they were aware of end of life services. 58% of respondents were not aware of services. As stated earlier in this report some BSL users can believe that they are aware or informed but looking at the replies from the 42% of people who that they were aware of services it is clear that there is some lack of knowledge and understanding. The responses from the hard of hearing people show a higher level of understanding.

Where is the best place to die?

There was a very clear difference in the thoughts of the BSL and the hard of hearing respondents

72% of the BSL user replies identified the home as the place they wanted to die, their 2nd choice was a Hospice 22% and a 5% didn't mind and 5% a Nursing Home. The HoH people replies were reversed with 75% identifying a hospice and 12.5% don't mind and at Home.

The explanations identified key issues of isolation and communication issues as major factors. In fact throughout the replies, communication, lack of interpreters or BSL using staff was a consistent theme and concern. Anecdotally several relayed stories of people they know having difficulties

- "She was so alone and not able to communicate with her Deaf community"
- "Don't want to be the only one deaf isolated in care"

- “All the nurses at the hospital, and the workers, I never saw same person, different staff, no chance really to them to learn sign language because of staff turnover.”

When contemplating the end of their life and the plans one person said that they needed to meet with funeral director, they were asked if they would need an interpreter. The reply was “No I can talk” the deaf person is oral – they can speak and make themselves understood by hearing people however what about his needs to be understand the replies? The lack of availability of interpreters or services to assist in these circumstances has led to a number of BSL users resigned to ‘making do’ and not fully understanding what is happening and what their choices are.

Have you had a discussion with anyone about your wishes?

HoH yes 50% no 50%   BSL yes 28% no 72%

What were the wishes?

In most replies this was because they held strong views that they wanted to be upheld when they died, such as the right to refuse medical treatment or that they want (or don’t want) to die at home. Communication, specifically the ability to communicate using BSL was a factor and some said they would be happy to use a nursing home if they had staff who could sign to a good level.

Why have you not discussed your wishes?

Most felt that there was enough time in the future or that they were too young to worry about this. It was never mentioned or being given the opportunity, or permission, to talk about the subject.

“Expect to discuss it when a terminal illness has been diagnosed.”

“I feel I am too young to worry about this, but I do wonder about this. However, I don't feel comfortable discussing this with another person, as it's quite a sensitive issue and they may not want to discuss it.”

Do you have any wishes?

Even though they had not expressed them to anyone many respondents did have very clear wishes and at least one person realised that they may need to address this topic with their next of kin.

- No idea but would like to see options
- To die peacefully around my family if it is possible
- don't want communication problems
- my religious beliefs are followed

Do you have any particular end of life needs due to your culture or identity?
61% of BSL users stated that they did have particular needs as opposed to 20% of HoH people who responded in the affirmative. This is to be expected as BSL users have a different culture, and perhaps more importantly, a different language. With the exception of one reply, who referenced religious needs, BSL users have noted the necessity for their communication needs to be met.

Fundamentally the replies are unified in the request for respect - for communication needs, for their sexuality and for their religion.

Any Comments?
"I would expect the NHS to provide training to interpreters about end of life care and then book these specialist interpreters only."

"There need be homes for the deaf in north east - too many elderly are being left in care home with no communication and their health deteriorated rapidly! It's hard enough to put hearing people into care home and it would be 10x harder for deaf people due lack of communication / understanding of their culture and their needs aren't being met they will end up very isolated and it affects their mental health wellbeing. Where's their equality access to the service?? "

"Deaf people cannot have their family ring them. If this is an issue an alternative could be video calls to their families."

"Teach communication and how to improve confidence etc. It's good, need deaf awareness all over really. Don't want (Deaf patients) to become isolated,"

"I need to prepare for my future, I never thought about this."

Additional Information

Prior to interviews we identified that we were asking people very sensitive questions and would potentially raise concerns or feelings of loss for example. In preparation for this we approached agencies and services in the Newcastle/Gateshead area who provide emotional support and asked them how a person who use BSL would ask for help from their services. These were:

- Talking Matters Northumberland,
- Sunderland Psychological Wellbeing Service
- Talking Helps Newcastle.

- Samaritans
- Cruse

The name ‘Talking therapies’ creates an immediate barrier for BSL users – who generally do not relate to the word ‘talking’. The majority of these organisations take referrals by telephone or email. One organisation had telephone only and when asked what a deaf BSL user would do they suggested that the client could ask a friend or family member to contact them.

There is one organisation who specialise in support to BSL users with low level mental health needs, run by the organisation Sign Health, Healthy Minds is delivered by people who can sign. When questioned about access to this service we received the following reply:

> As the CCG already commissions many bereavement/counselling and support organisations we wouldn’t be in a position to pay for patients to access Sign Health. We understand that Sign Health provide support for people who sign, however, the contracts we have in place require these organisations to support patients who have additional needs.
>
> If you do identify someone through the engagement that needs extra support, the advice would be for them to contact their GP and ask to be referred to bereavement/counselling services. The GP can then advise, as part of the referral that the patient has additional communication needs.

Our research shows that being able to ask the GP for help will depends upon whether they have booked an interpreter.

As a result of this preliminary work we have started discussions with several statutory and voluntary organisations with regard to accessibility for BSL users. A further benefit is that through the process of this work we have had feedback from BSL users and Interpreters that they were very grateful we had raised this topic, they had never thought and never had opportunity to raise it. That they ‘didn’t think about me or family needs’. They said that the discussion was very helpful and they were going away to talk to family.

RESPONSES

Black = BSL User Green = Hard of Hearing Red = Hearing Child of Deaf Adults

People with end of life care experience in the last 2 years

1 Have you cared for someone who has received end of life care within the last two years?

Yes	5	No	0

3 BSL users – one caring/cared for husband who was deaf, partner who was hearing and mother who is hearing.

1 Hard of Hearing person cared for wife who was hearing

1 Hearing CODA caring for parents both deaf

Has this person died?

Yes	4	No	1

2 What was your relationship with them?

Partner Wife Husband Mother Father

3 How long they were receiving palliative (end of life) care before they died?

2 years before died May 2016

2 days

1 is still alive and has been receiving palliative care for over 2 years.

6-8 Weeks

4 Do you feel they received the support they needed?

All 5 respondents felt that the person they were caring for did receive the support they needed.

a. Please explain why you think that?

"Well first time maybe two years ago he fell over a bag - to the hospital because his warfarin was too high because he lost lot of blood made his warfarin high so keep him in RVI then transferred to Freeman Hospital keep him in for 2-3 days until finally his warfarin blood back low then came home. After that he was alright but still not 100% and 2 years ago he started to fall lots. , he fell, I saw he have weak legs when he fell. So know what happened, phoned ambulance, neighbours helped clean my partner up.

Back and forward to the hospitals when he kept falling, then he got Dementia. When he started Dementia, I told doctor really he have dementia, the doctor said right will sort out with the General Hospital Dementia Ward, will get questioned there. When talked to my partner, he said 'I have no dementia no!’ he really have, they gave him tablets. He won’t listen and in a bad mood and after a while get worse fall, diarrhoea, hard work.

Then his heart started getting weak, moved to RVI hospital for one day and his blood was too high warfarin, back to Freeman Hospital and stayed ward 19 for Dementia ward, carry on and his heart get weaker and transferred to ward 37 serious ward. Back to ward 19, but getting worse and worse, Yes most nurses, staff work there look after everything him, feed him, and give tablets and things.”

“Very good support from GP and nurse”

“Really 2001 from started in his armpit non-Hodgkin’s lymphoma. Then 2007 back and forward from hospitals, last minutes (emergency admission) in hospital, no time for BSL interpreters. Next few months go to doctors and get sick note to off work, he went to the doctor again but they gave him nothing, just painkillers for his back. Then still frustration and in August, he was like to go mad himself and couldn’t sleep in the night. Stayed awake through the night, then other way around he sleep through the day. So I was puzzled. Doctor sent him to x-ray in RVI and they said nothing there, we were puzzled and said it was impossible.

So then it was starting to get worse and worse, he getting more frustrated and get angry himself. I told him what can I do? He got problems with his legs, can’t walk, and affected him. So I went to next door, Sandra she work as nurse for cancer in Freeman Hospital, asked her to do me a favour to come and have a look at my husband as he was not very good, it was at 12 o’clock at night. She came around and talked with my husband, he replied ‘I want to go to the hospital’. So Sandra rang for an ambulance and it arrived quickly. They asked my husband if he can stay at home until the next morning, he replied ‘no I want to go to the hospital’ but it was Sunday and no doctors available.

So they took him to Newcastle General Hospital about 1 o’clock in the morning. Wide awake through the night, but can’t do anything until in the morning. Then the nurse said you have to be transferred to RVI, so we waited and waited. Got in the ambulance and gone over to RVI Leazes Wing Ward 40. Put my husband on the wheelchair to Victoria Wing for MRI scan.

Then a nurse came in and said you have to be transfer to General Hospital. Again oh dear! So waited for the ambulance to go back to General hospital and got across to there and into Ward 32 or 33. Special Spine Ward, for injuries like head injuries in car crash. No interpreter nothing, just me and 5 doctors around my husband’ bed. I said what I do as I’m Deaf? So the doctor said one is anaesthetist, one and each other one is something like professional operation etc., he wrote down on a bit of paper and I was over the head (overwhelmed) don’t know what it meant as hard words so I signed what time for the operation? He was easy to lip-read – 9 o'clock at night. We were there around 5pm in the afternoon, so I texted to my son then he came.

I go downstairs for something to eat as hungry. When I came back up, I was shocked he wasn't there and the bed gone, no one told me where he is, it was 7 o' clock he was missing. So I tried to find the nurse, there was no one telling me where my husband is. So my son and I walked to home and didn't say one word nothing. Then came back the next morning, my husband laid on the bed, I asked him if he's alright? He nodded yes. He stayed in that ward for 2 months because ward 34/33 was the spine ward then he moved to cancer ward, easier for radiotherapy downstairs.

Then 2 years ago he was diagnosed with Diabetes. My husband had counselling at RVI with interpreter, for him and me problems as he had a lot of emotion through him. So he talked to the counsellor first, then swapped with me and I met the counsellor."

"From Gateshead Council, arranged through Social Services, agreed to register mentally incapable, means a proper organised service to look after and support what she needs. Very good support, social worker very good to me. Organised things and recommended what best for her future and provide interpreters. I have a right to access to the information that I need, good service. From social services, I have a lot of enquiries what best for her future and agreed to put her in the care home which was best for her, can't stay at home 24 hours impossible. **She had been having accidents, not fair and too much of mess, hard work**. Tried to arrange nurses, home visits to support her, she refused, some did happen but she want to be independent. Told her need more care, she refused and she's stubborn. Really very hard, been tried to persuaded her to go into a care home, she declined and said "give me time to think about it". So I leave her can't force her. But her talking now deteriorated, struggling and her brain shut down couldn't bring out words out of her mouth, stuck. I can see she tried to say something but gave up. Awful."

"With regard to my family circumstances, my Father and Mother and son are all deaf and BSL users. My daughter and I are both hearing. The doctors and nursing staff tried their best. However without the support of the Interpreting service and the Interpreter who had worked with my father for over 20 years I dread to think how much more difficult this would have been. It meant that **either my daughter or I needed to be present at all visits to facilitate communication and to try to make sure that my Father's needs were being met.**

However there was one occasion that we couldn't be there. When I went to pick my Mother up she was clearly distressed and said that a Chaplain was there in Dad's room she took this as an indication that he was going to die very soon. This was not the case and really upset the family due to lack of communication. When Dad was transferred to 'end of life' care Mam should have been his next of kin but this proved problematic. During a visit I encountered Health Care

Assistants shouting at him. I explained that he is profoundly Deaf they were apparently told that he was **Hard of Hearing.** A discussion took place to advise that all treatment should be withdrawn to alleviate the pain and suffering. My **daughter had to 'interpret' this message to her grandmother."**

b. How could this have been improved?

Nurse or Doctor never say will book interpreter, so not expected, I thought few more days go on. Some know I am Deaf so they know to let me know and some will come help me, could help me to get an interpreter if the nurse know where to get an interpreter will and tell me 'will get an interpreter for you'. But I can lip-read. How could be improved? **I don't think can improved anything but I need some interpreter** in there hospital for emergency, that is the only thing I want to improve."

"No. He doesn't want anybody, only prefer me. Hard work though. I bathed him, made cup of teas, fed him, everything for him, no one else come, he doesn't want them."

"Other agencies **used phone to contact us**. I am hard of hearing and this was difficult"

"**It was difficult to communicate** so I asked my mother to repeat, lip-reading impossible to understand, her teeth is broken so I couldn't follow. Communication support provided from Care Home, they booked BSL interpreters, provide interpreters from Northern Sign and good service. A lot of support, arranged everything and sort out smoothly. Very good contacting me a lot because I am the 'next of kin' important. Texted and informed me about my mother when have an accident, falls, something happened in bed, for example, ill caught chest infection and sent to hospital, informing me all the time very good. Doctors visited, petty cash need more money, and other things like that, very good contacted me and informed me."

"The staff although they tried their best some of them admitted that they really struggled with caring for my father. The Chaplaincy service need some awareness and the distress that is caused by lack of communication. Any ward rounds or discussions should be done with a qualified interpreter present and an interpreter who is known with the patient and family as many interpreter booking agencies will not consider this vital service during a very difficult time"

5 How well the different did services work together?

"Yes, but not emotional help, like a lot of them come and help e.g. do you want a wheelchair? Stairs? Thing like panic neck button but he won't use the button. Things provided, toilet and everything all helpful. Now when he gone all gone."

"g.p. and district nurse worked well together, other agencies very much on outside"

"We have a chair stair lift from Occupational Therapist from Freeman Hospital, very good for him easy up and down. Wet room for him, he doesn't like showers because hurting his back, good handy for him. Loan equipment – bed, chair, toilet. Occupational Therapist come and training him walking, hoping he could improve, but never improved. **Newcastle social worker, had a lot from her but she left because of the cuts**".

"She paid for help in her home, when mother fall I contact them they came and special equipment lifted her up as can break back so carefully support when lifting, 2 people staff must support. Yes the service good give equipment like easy access for her, lift up from chair, have special toilet seat. But mother refused, would help her to go to the toilet but they provide nappies but problems in the end so had enough and better to be in a care home because more accessible service and support better for her 24 hours care. It was not possible for me to look after her at home. I only visit her twice a week that's all, Deaf Awareness well **no deaf patients there, I am the only one Deaf.** If any problems, just write down and show, emails and texts. Most of the time not much, only when serious happened to my mother they inform me. Arranged to take her home from family events like Christmas, I inform them what happens. Just briefly. Nothing bad. Very good service. Queen Elizabeth Hospital 2 years ago in Elderly patients department

I complained brought up in hospital over bad attitude, I told them I am the next of kin so contact me but **they contacted like my wife's mother so I told them no it's me you need to tell me direct, not her**. They were unsure, I said it's me important I need the information so I was not happy with the hospital. Told them to text me please, they said no so I challenged by complained to PALS, sort out and solved the problem they investigate and they changed to contact me directly. Some staff couldn't be bothered, busy looking after patients so it's happened please let me know. But now last few years contacted me regularly so been happened back to hospital and forth. Really awful times.

Must be 2 years ago, as I remembered my brother-in-law visited, I can see the hospital staff want to pass on information to my sister, I said no so I straightaway writing to them (that I am the next of kin) they realised. I said me information not yours, everything what going on must be writing, the nurse accepted not them. They backed down.

Been good support from the psychologist, checked IQ memory information test, been contacted me said its good then 3 months later drop dramatically**, they kept informing me with information that's good. I don't feel left out,** I have the right to access to information report of what been happened. Hospital and care home contacting me, also the social worker in the early days then no longer with social worker later as my mother gone into a care home. Then more focus on care home, no social worker anymore."

"A hospice stay was never mentioned. As a BSL Interpreter I have worked with terminally ill deaf people and have no knowledge of any mention of hospice, ever. I would strongly suspect that the majority of deaf people will not be aware of palliative or hospice care therefore a greater understanding and awareness of this by staff is paramount

6 Do you think that they were treated with dignity and respect?

Yes 4 No **1**

a. Please explain why?

"Yes Hospital do very well"

"Treated as normal human being"

"Happy with General hospital, fantastic, but he was not happy with Walkergate Park, Not going to the dining room, we stayed in his room it was quiet. Because in the dining room my husband see the others like someone who can't lift a fork and upset him. My husband **was the only one deaf there.** Some ward rooms, people had accidents, one boy and one woman had her legs cut. They all had to have rehab it was difficult."

"Care home yes really good treating us, can't force my mother it's her choice, choose to decide, like for example, I have told the manager my mum need new glasses and teeth sort out, can see my mother refused so they have to respect her and leave it. Her choice, can't force her. **I asked for treatments like podiatry, haircut, clothes for her**. Problems with clothes mixed with others and lost, so complained, clothes lost asked them to put her name and room number on the label, they said alright."

"The staff were not able to communicate with my dad or his wife therefore if the interpreter, my daughter or I were not present then **only his basic needs were being met so how could he be treat with dignity and respect he couldn't communicate his needs**"

b. How could this be improved? How can be better?

"No bad experiences, just natural, not hate. Just want someone there like interpreter that all."

- Specialist BSL Interpreting services

- Ward rounds/discussions taking place when an interpreter is present
- Deaf awareness on the wards
- Accepting that a deaf person has the right to be next of kin
- Contact through Text messaging

7 How involved were they in decisions about their care?

"I don't know because dementia he can't remember anything. No idea as couldn't see him in general hospital, I only see him when visits."

"Good the patient was not deaf. As a deaf carer, I was treated well, and with consideration"

"Dementia treatment is not easy to cure, increasing number of people have dementia, I have seen in care home, many of them have dementia, they don't talk and just stare. Really bad, they (care home) are aware of the situation and try to talk and encourage them. They can't one-to-one all the time, too many of them and staff running around. All the staff are aware of the situation, so just leave it. Not easy."

"He wasn't, because he didn't understand, towards the end he didn't understand. He started biting staff and getting frustrated. I had to take time off work and **plan my hospital visits around meals to make sure he could communicate what he wanted to eat.**

8 Do you feel they received the appropriate support around their communication needs?

Yes 1 No **1**

a. Please explain your answer.

"no interpreter needed"

"**No BSL interpreters in the hospitals, only lip-read. I nodded sometimes** but realised I had to push myself to move forward, I had to look after myself. After discharged, he have regular check-up for every 3 months with a BSL interpreter in RVI then moved to Freeman Hospital NCCC (Northern Centre for Cancer Care)"

"(Mother is hearing) Not very good I can't, I don't understand at all, lip-reading no good at all. Lip-reading, her teeth is gone. We tried fingerspelling, can do some alright but sometimes she was stuck on fingerspelling as her brain shut down, struggling but can't. Same my wife (Deaf) when she visited but can't communicate with her because of her teeth, can't follow. When I try she understand I have to repeat and repeat but I talk about what? She became disconnected.

Meeting with social service last year they mentioned booking interpreter, I thought it would be nice why not, booked say for one hour but 5 minutes my mother forget can't talk more, she may forget or don't know. Long term memory she can talk she remembers, she telling me it's hard, **she telling less and less to me, most of the time I tell her but her response is not much**."

"No, not without us being there to help them understand him"

b. How could communication have improved?

"I had difficulty with some phone calls, and also hearing the door bell, when workers called."

"Lucky I hold 3 phone numbers of BSL interpreter we like, one for his background saving repeating all over again, we want the same interpreter know all his background."

"Northern Sign, really through care home, because not under social services, private company, I know one of the interpreters his family live there (care home) so I know happy to contact for information to provide me to arrange an interpreter I'm sure one hour once a month. Because every week, no good as only few minutes and talk about what? Not enough news, know it's hard, not easy. **Social worker for old age, as social worker for Deaf finished**. Interpreters should be available in emergencies, should be but need to find someone on 'stand by' through the day. Through the night interpreters are available but through the day is a question mark. Depends on which interpreter have cancellation, or two interpreters working together one can come to me (in an emergency) something like that.

"Deaf awareness and understanding of the need for specialist interpreters."

9 Do you feel that their cultural needs were met?

Yes	3	No	**2**

a. Please explain your answer

"He's Protestant. I think when I was not there, my partner said been a priest come and visited, talked before I came to visit him. What they talked about I don't know."

"No special needs"

"That why funeral director, no priest, Humanist funeral."

"No, not really. No cultural needs she have."

"Nor mother or my sons (*cultural needs*), on the ward they seemed to panic and didn't know how to cope with him and his deafness"

b. How could have improved?

"Deaf awareness"

10 Did they have a preference about where they would like to die?

Yes 1 No 3

11 Did they die where they want to be?

Yes **2** No **1**

a. If not, was there a reason behind this?

"Never said much about death, but he said 'If I die abroad rather cremated there, save bringing his body back. Other that he know want cremated. "

"No never mentioned, he like to be at home. Want cremated. Why? He love to be at home, watch TV."

"Never mentioned to me, never. Never say anything to my sister, never mentioned to me, any word never nothing. Difficult question, I don't know, could happen in hospital or care home, nobody know, I don't know. **She hate hospital, I know she wants to go home, she get annoyed**. I said treatment need to be until finished then she can get discharged. She moaned. Care home ok, really preference number one her own house, lived too long. Very hard for her to change lifestyle, more quiet, drowsy sleep, communication no good. Sad. Not like as 20-30 years ago she was active, walking around and exercise. Then when mild stroke happened, changed her life, seemed quieter same as other older people I've seen."

12 Were they made comfortable in the place where they died?

Yes **1** No **0**

a. Please explain your answer

"I don't know if he was comfortable, but I think he rather want to be at home."

"Nurse readily available, by phone"

"Never mentioned, just happened peaceful at home. Peace in bed. "
This is the description of what happened:
"Later suddenly, My husband' mouth was trembling and moving a lot, he rubbed his arms and his tummy so I thought he only wanted the toilet he never said anything and went upstairs, but sounds were a bit funny so I went up and saw him in bed. So I tapped him on the arm, his arm was freezing, asked him if was ok, he said alright so I went into the shower, then I tapped him again on the arm, his left arm was very cold, I asked if he's alright, he said oh yes. So I told him to have a rest for one hour. I went downstairs, I became not sure, so I checked him again and he was asleep, asked him if he was alright, he replied 'want doctor'. So I became concerned and how to get a doctor? What can I do as can't phone?

b. How could this have been improved?

"I wanted to be there. Because when I'm there he know I'm there and his son will be there, want to keep company."

At least 2 of the respondents said that their partner had said that they only wanted them to care for them. It is not clear if they were offered support (or training) to provide this physically and emotionally difficult task. j

13 How involved were you in decisions about their care?

"One nurse said 'are you family?' I said 'no just partner', she said 'you are family, partner same as family just go on as family, if not I will separate but you are family'. **Most of the time I was in the decisions**, my partner's son sit back waiting for me to say things what they want or not, my decisions. My partner's son sit back, when I said I agree with doctors, he agreed.

He was on ward 37 serious ward (Freeman), then next day fine, started eating sandwich I was puzzled what wrong with him? Back to ward 19, but getting worse and worse. Before that, the doctor knew he had a weak heart, said 'do you want to switch off his defibrillator?' I was unsure and said no not yet. One week later, other doctor came in and said he still have a very weak heart do you want to switch off the defibrillator?' I was unsure I rather someone tell me, his son was quiet, I looked at son said nothing. Alright I decided yes, son said alright yes. I know my partner don't want to be 'cabbage' don't want to be still, want to keep moving on, so I have to think for my partner, said have to switch off so he's gone.

His son and daughter came. I didn't expect he will die that night or anytime soon. I thought plenty time maybe one week or more. His son and daughter left, I stayed an extra hour because I

never before had an extra hour visiting, so I stayed and he was still not good so I kissed him bye after 9pm I went. In the morning I got up, his son texted me said Dad died at 3 o'clock morning. He texted me about 8 o'clock in the morning so I rushed to the hospital, he already died and cleaned up finished. So I stayed and doctor came in quick.
At any stage did you have a BSL interpreter or ask for one? No I haven't asked for an interpreter, I know because interpreters can't come emergency, I know most of them always work.

"very involved"

"Never mentioned to me, only social worker arranged care home and offer treatments, **hospital never mentioned to me nothing.** I've asked the staff ward sister team, I asked what treatments, arrange what, what best for her etc. I asked and asked. Been regularly writing, emails etc. Been writing to give information about what I will do, can do, monitoring care etc. up to the doctor to decide, I don't see the doctor. Wrong time, wrong place. What plans? Inform me when?, carry on tablets or plans in the future, etc., nothing.

Never had interpreters, just writing, concerns, what I think best for treatments, I asked questions, yes or no they tell me limited information, not a lot. More depth over medical situations, I asked for more information to tell me, what it's meant, how it affects, how to improve, what is the plans in long term, things need to asked but never happened"

"Freeman **hospital never mentioned to me about diabetes**, what level is good, then I found out from GP later my husband got Diabetes, I was puzzled. In Walkergate hospital, there were doctors around my husband, nurses, social worker (Sue who can sign) and doctors over my husband he wanted to go home, he couldn't stand the hospital. They asked me if I can look after my husband, I said yes I can manage look after him. But need something for him like equipment like bed, chair lift etc. "

"End of care staff need to be more deaf aware for the family as well. **My mother and son felt excluded – our family pulled together to help them understand what was happening** and the hospital took advantage"

14 Did you as their carer, receive the right support before they died?

Yes	3	No	**0**

a. Please explain your answer

“**I have no right to support given** but I needed someone to support me like nurse, just my partner’s son come, if we needed any help.

Next door neighbour, he helped when I was heavy sleep in bed, my partner fall in passageway and banging the wall with his walking stick, I couldn’t hear as my hearing aids were off. The people next door watching TV heard the banging and came around to the front door, tried knocking, I was still heavy asleep. I felt I needed to go to the toilet and saw my partner was not there, I got up and found my partner lying in the passageway. My partner said ‘downstairs someone at the door’. I said ‘who?’ I opened and realised it was next door and came up I couldn’t lift him up he was too heavy because he not helping to get up, he was just slumped. So next door Liz helped lift him up to bed but after that he got worse and worse.”

“I don’t know! A lot of interpreting had to be done, **I had the daughter role and the professional interpreter role.** During that time I was struggling with work because I couldn’t let deaf people down and understanding and helping my father.”

“Nurses were very sensitive to my feelings”

“Nothing, informed me nothing, never asked me ‘would like to offer you … or arrange support?’ never mentioned nothing. **I think nothing about this and just normal carry on, not mentioned or bring up to me nothing**.”

“Walkergate Park Hospital arranged counselling, for me because of my husbands’ behaviour, he was very bad tempered, scared me awful, really ungrateful with me in Walkergate Park as he expected to go home, I said “no you need to stay for rehab for 4 months, he wasn’t happy. He was horrible to me, so I got counselling.”

The day her husband died he was in bed and ill …..

“I saw out of the window, I saw neighbour David and his car, so I went down to him and left my husband, I didn’t know how long died or live, I went up to the neighbour and said “my husband want to see the doctor” so he find a phone number and phoned the doctor in Saville Place. He was on the phone for long time, I said want the doctor to come out now, the neighbour said sorry busy that morning. The receptionist want me to talk on the phone, I said ‘Me? I’m Deaf! I can’t talk’. David said ‘she is deaf and not good talk, can’t hear’. The receptionist said ok and will send me a fax, I said need now! Come now! She said no sorry. When I got the fax, it read doctor will come around in the afternoon – I was shocked!

So I better walk up to see my husband, saw him and he is already dead! I tapped him and thought what to do?? David gone to work, but still texted him. Saw someone on the third house up the road, saw a woman putting in the bin, so I walked up to her and said hello, excuse me can you do me a favour? Can you help me, my husband have problems, I think he passed away. She came with me to see my husband, she phoned 999. I never thought of press 999, my mind was blank."

b. How could this have been improved?

"**A lot of them talked to my partner's son because he is hearing,** when something to tell they not come to me, they come to my partner's son and talked, I asked 'what?' he said wait and when they go he tell me, I asked 'what wrong'? **But why don't they come to me directly?** Maybe if say what time doctor want to see you then book an interpreter".

"It might have been nice to have some-one just for me"

"I would like to get the 'picture' of what happens in the long term plans, what will happen, what to do, like what happens after she dies then what to do? If illness serious, what to do? Link to that I would like to plan long term and get information I wish. I haven't received and read nothing, from care home nothing. No information. "

16 Did you receive the right support after they died?

Yes 0 No 0

a. Please explain your answer

b. How could this have been improved?

"My partner's son did most of the work, organised things and my partner's ex-wife and her husband both do a lot of things for me, arranged everything funeral, and wills and things. Now a little bit cleared. Now I can manage myself, I don't need a lot of support now, because my partner's son there. Ex-wife's husband is good work with accounts, tax form and things for me. A lot of money and now waiting for probates that will be sorted and told wait need more time before give up the will."

"I don't know how it works, I know when my father passed away, my mother sort it out. I know the house already sold, I have to contact people to stop post, electric, gas, council tax, and other things have to stop. Finished that it's sorted out. Information from her solicitor, the will, they have information. I have power of attorney, already arranged. Talk about bereavement and things, how to contact the newspapers, have to inform her good colleagues from her old work. I think best my sister in Australia to inform our family, aunties, uncles and cousins to let them know. Need publicity in newspapers, like Evening Chronicle, funeral arrangements, how to pay funeral? I know it's expensive. I don't know everything about arranging funeral. Never used to it, same as everyone else get shocked when someone died and don't know how to do funeral, get support etc. **How to phone, but I can't use the phone, look on the internet how to find information, emails etc. Email seems hard and being ignored as phone calls quick. Phone easy and straight away accept information and sort out. Email is ignored, I have noticed.** Access for Deaf people become barriers and stuck. Like that happened, not easy to access to information. I will have to talk to the care home, to plan and prepare for what will happens and for support, how to arrange etc. **I need to know how it works to solve the problem, if I don't know what to do I am stuck**."

"Police came quick, a man and a woman, then a woman **doctor talked too quick I didn't understand her** so I asked the policeman what she said, it was a special machine for heart rhythm, he said she asked where is your husband? I pointed to upstairs, she went upstairs.

So the two police officers, the doctor went upstairs, the woman neighbour were there, then the first neighbour David came back to make sure. So the police asked if need a BSL interpreter, I have a phone number of the interpreter I always choose for my husband, for his regular appointments. Quickly that interpreter came, good. Then I explained what happened in the morning same story all the way through on that day. They asked questions like who is doing funeral? I got the Sun Life insurance papers and showed them, contacted with Co-op funeral director. They phone Co-op and the director came. Ooh a lot of people there.

Then my son phone (he lives in the south of England) my husband's sister and niece and they came to visit to see my husband. It was awful. A lot of people talked around and I was lost, said nothing.

Director said have to go back to RVI, because my husband died at home. So he phoned and Civic Centre coroner said Wednesday morning at 10am. With my son, he stayed at my house. Took my husband' body to RVI. Next morning, Civic Centre Coroner, we sat and said nothing one word. The coroner and my son talked, both knew well. **I was in the middle, couldn't follow**. My son said 'RVI been took a sample, a square off the arm or body, like a stamp, square taken out'. But the coroner need permission for post-mortem as wanted to know what was the cause of death. So I signed the paper then he went to RVI for the post-mortem by Thursday, he will let us know the results on Friday. But my son was too busy, working, no time and heard on the Saturday, confirmed he got acute myocardial, quick heart attack, just died with heart.

When husband died, 2 weeks later, received a letter from GP. The doctor want to see me at 10.30 in the morning. So I went over, nice doctor (no interpreter), hugged me and said very very sorry it happened this way, I know it's very hard for you to phone. Really really very sorry. She realised. The funeral went smooth, as had the life insurance so they sorted it out for me, with my son. So I have a lot of time now, better out with my friends. Only lip-reading, never got an interpreter, my fault."

17 Do you have any other comments about end of life care for patients and for carers?

"Fewer people involved the better. Any involvement needs to be incorporated with main care. **We had workers saying they would do things, then didn't**"

"**Especially the hospitals, need to improve communication to tell more information, I have the right, but they tell me limited information, like I'm the 'second class' citizen but I want more information.** I like to meet the doctors but really they are busy, hard to see them. The staff can't do anything to decide, stuck, 'have to ask the doctor, they know best'. So I feel helpless. Maybe worthwhile I contact the care home, plus the doctor, to arrange and can give me a report, I have the right to access the information what I need to know, what is the long terms, what is impact etc. My mother can't tell me, because of her dementia. So they can tell me, I will bring up with them soon as possible."

People with no end of life care experience

1. Are you aware of what services are termed as 'end of life care'?

Yes 11 No 15

a. What are they?

- Do they do things on video?
- Is it about communication and pain?
- I remember (person who was dying) their signing was reduced and I just left them.
- In my family – lots have died. All had expectations, they wanted to die suddenly and I get upset. The details... too hard.
- Macmillan nurses, Social services, Marie Curie.
- Palliative care befriending hospice respite care.
- Provide help for the patients who are going to die soon and support the people around the patients.
- Patient offered options of services, the environment and how they wish to end their life
- Hospital, Carers coming daily or 24hrs
- I'm assuming they can mean any range of health and social care services supporting those at the end of their life. That could range from hospice care to the support from local GPs, Macmillan nurses, pharmacies, meals on wheels and help with personal care.
- Hospice Bereavement Counselling

ALL RESPONDENTS

1 Thinking about yourself, when the time comes, where do you think would be the best place to die?

Where	**Group B BSL**	**Group B HoH**	**Group C BSL**	**Group C HoH**
At home	2		11	1
In a hospital				
In a hospice			4	6
In a care home				
In a nursing home			1	
Don't mind	1	1		1

Somewhere else **1** please say where...**South Africa**

Comments

Care home

"My grandmother lived on her own, she was lonely, no communication with staff there. I used to go to see her and she missed the deaf world. Two days before she died, she said she had had enough, she was lonely, isolated and when she died I got such a shock. **She was so alone and not able to communicate with her Deaf community** that was 17 years ago. She did not have the communication she needed."

"Don't trust care home, because sell the house to pay them, no. Rather at home, prefer. Or natural die at peace. "

"Don't want to be the **only one deaf isolated in care home** or they not bothered about me. Who to talk to me? No way."

Death at home

"my uncle did and know that the nurses came in, I went in, but communication impossible, and it was hard to explain, I never forget that a few years ago."

"**All the nurses at the hospital, and the workers, I never saw same person, different staff**, no chance really to them to learn sign language because of staff turnover."

2 Have you ever discussed with someone your wishes regarding end of life care?

Yes **10 (hoh 4)** No **20 (hoh 4)**

a. If yes, what are these wishes?

- If I was diagnosed with a terminal illness or been seriously injured (where the quality of life have been robbed) I would rather to die than have too many people come and go and can't communicate with me at all - I would feel I've been left with no dignity. I would rather choose to die peacefully in my own home - in an environment that I am comfortable with or even if there was a deaf residential home for elderly / illness / injuries where all staff are signed fully at minimum of level 2/3 to enable good communication between both parties.
- Not properly, will get talk with the funeral director, I have no life policy, and my partner didn't let me have a life policy. I said should have. That why I have heavy tax after everything. Better will ask my partner's son to try get me a life policy but I think I will go

myself to talk with the funeral director. *Would you need a BSL interpreter for this?* No I can talk.

- Offered little and lost ability to make a decision so very difficult could understand family moved to hospice but ignored lots in hospital
- I wish I would travel all the world and try new things.
- Have signed a living-will and my relatives know I a) want a D.N.R. b) my brain goes to Newcastle University Brain Tissue Resource plus Age UK. Funeral plan with H. Duckworth Funeral Service
- I want to die at home. And if not possible I will just shoot myself.
- I don't want to be kept alive
- home if practical for family
- Not hospital. If lose capacity refuse all treatment except pain relief. Written in living will so no one can argue.

b] If no, why have you not discussed your wishes?

- Unless its sudden death, **I consider there is time** to give family my personal wishes of what I want, and would be addressed when, or if, an illness couldn't be treated or improved.
- Expect to discuss it when a terminal illness has been diagnosed. **If I drop dead on the spot don't really care what happens next.**
- Not got around to it but probably should.
- Too young and I am a carer of Deaf family, not Deaf myself.
- My family think I am being morbid. However **I've told them I am on the donor Register** and expect them to let them use whatever organs are fit for use
- Just there is no one to discuss with!?
- **Too young to worry about this**.
- Because I don't know and my parents didn't talk me about life of end
- Because they never told to me.
- Because I am young and would not discuss about my wishes right now but I will be able to discuss my wishes when the time is possible for me.
- They are too old to worry as have enough on their plate.
- Never mentioned, never think about this. It not in my mind. I have noticed, 21st century culture changed, more like for my children, busy lives, 'Can't be bothered' and concentrating on parties or their lives come first and ignore family. In my time, I do more care on my family, I have seen the change in society, no respect, and people become not bothered, put old people in care home and just relax. I have noticed the change in society become less loving, they concentrate on their own lives. Difficult

question, Deaf really hard send into care home, number one problem is communication breakdowns. Become stuck and decline quickly to finish, become depressed and isolated. I want to see a Deaf care home for Deaf people only but the problem is money/funding plans etc. but I would like to see that one day in the future set up. But I think all staff need Deaf Awareness training set up by the government. Like if the council won't set up a care home for Deaf people only because of the money, should provide Deaf Awareness training to all staff. Perhaps need to talk one day.

- Never think about it
- I hope that I'm too young for this at the moment
- Never got around to it as still under 30
- Haven't talked about anything, I never told my son not yet. But my son and his dad always hid from me, they talked to each other. I don't know what they talked about.
- I feel I am too young to worry about this, but I do wonder about this. However, I don't feel comfortable discussing this with another person, as it's quite a sensitive issue and they may not want to discuss it.
- **Find it difficult to talk about end of life**
- I have never really thought about death, and end section of my life. It is a sensitive topic indeed to talk with anyone, and I would say it is because I am still young but then people younger than me dies anyway.

3 Do you have any wishes? What are they?

- Depending on the illness, I would have peace of mind knowing that I could be cared for, if lucky enough to be offered a place in a Hospice. The holistic services, nursing staff and environment are simply the best way to end one's life.
- As little pain as possible - get it over as quickly as possible.
- I would like to be communicated to using Lip Speaker. I want to be cared for by people/professionals who are Deaf aware. I want to know what options I have and to be fully involved. I want people to use plain English and communicate with me as an equal I don't want anything discussed about me without me I expect that if I make a decisions about my care/treatment that they are respected and carried out. **I want to die with dignity and not alone**
- No idea but would like to see options
- Setting up wills, end of life care.
- I need bit support for communicate used BSL
- **To die peacefully around my family if it is possible**, to give someone in my family my will. If I have some illness I may want my family to support that charity in a memory of me.

- Do not resuscitate as **don't want communication problems** to stress my end of life. **There are no agency or carers use BSL, nor NHS or Macmillan nurse.**
- Never thought. Home, better than suffering in hospital etc. Awful, best peace in home. If on Life Machine, my brain is 'cabbage' what is the point living like that? Haven't brought up like that, haven't made a will, arranging funeral, end of life, and haven't thought about this. I don't want to be cremated, rather be buried, what is the point?
- Buried. If had accident **would not want machine switched off.**
- To not be in too much pain
- **BSL interpreter**, nurses that can communicate with me
- Yes I want to make sure that **my religious beliefs are followed** when I am dying.
- Not that I can think of.

4 Do you have any particular end of life needs due to your culture or identity?

Where	Group B BSL	Group B HoH	Group C BSL	Group C HoH
Yes	2		11	2
No	1		7	6

a. If yes, what are they?

- Lip speaker so far but may deteriorate- living will must be used
- I need someone who has sign language skills and to understand deaf culture.
- I am a Catholic and would like communication with a priest consideration of deafness
- I am a Catholic and would want to see a priest
- Yes I need a BSL interpreter. If I put into a care home or wherever, I might need a BSL interpreter if any problems. Other times, I can lip-read.
- Being gay I would simply like my family and friends (and me) to be treated with respect. Also being hard of hearing, I need staff to be able to understand how best to communicate with me and to be able to understand how my hearing aids and streaming aids work!
- I want to go home, to hospice/ hospital and receive treatment/health support or care by people who can sign or are Deaf aware
- used BSL for communicate
- a signer or to be there for a support
- my religion - have a funeral (Janazah) the next day or so in a mosque with prayers around family and close relatives also a prayer depending on the time (5 times a day prayers)
- BSL user. If in hospice with BSL also visual relaxation not music

- Signer in hospital. Hospice where people can sign + understand deaf culture. BSL and SSE. Visual support
- If any problem with my health, I need a BSL interpreter, a nurse, woman nurse, not man.
- Yes, I want to make sure my religious beliefs are followed (Islam). I also want to be aware of what is happening, if possible, via sign language interpreter or staff that can sign.
- I am deaf, so I would like to be somewhere where people can communicate with me properly, maybe a care home for deaf and Deaf people.

COMMENTS

NHS Hospitals don't have hospice 'End of Life' services offered to those who want and need holistic care. WHY?

There need be homes for the deaf in north east - too many elderly are being left in care home with no communication and their health deteriorated rapidly! It's hard enough to put hearing people into care home and it would be 10x harder for deaf people due lack of communication / understanding of their culture and their needs aren't being met they will end up very isolated and it affects their mental health wellbeing. Where's their equality access to the service??

I would expect there to be someone who is able to provide BSL communication for my family members. I would not like there to be communication with interpreters only. If the staff themselves could not be trained in BSL, **I would expect the NHS to provide training to interpreters about end of life care and then book these specialist interpreters only.** This is because interpreters can be quite professional and cold, due to the nature of their job. I would expect staff to have Deaf awareness training. I have heard stories of deaf people being treat as if they are aggressive and non-compliant in hospices/care homes due to feeling like no one can communication with them. Another important factor is visiting times. **Deaf people cannot have their family ring them. If this is an issue an alternative could be video calls to their families.** NHS could provide tablets to Deaf people in end of life care to help them speak to family.

I am glad Deaflink are carrying out this research. I only hope it does help towards making positive changes instead of being put to one side having ticked an NHS box on some audit

I would like died in South Africa because I grew up in South Africa and there is beautiful view

Current service not looking good for deaf BSL users, always struggle every day to be understood. Don't make end of life a problem for us too.

Teach communication and how to improve confidence etc. It’s good, need deaf awareness all over really. Don’t want (Deaf patients) to become isolated, and nothing to do then become decline quickly not fair. Families pay a lot money to care homes, they are not cheap, really expensive. A lot of people force to sell their home for sale, to pay a lot to care home and quickly money go down to finish. Awful and frustrating.

Never mentioned to my family as I am not yet old 80 or 90, not yet. Not looking into the future yet, never thought. I need to prepare for my future, I never thought about this.

PROFESSIONAL OBSERVATION

As part of the research we spoke to a number of interpreters who have experience of supporting BSL users through the 'End of Life' stage. We felt that this gave a different, and useful, perspective of patients and family's needs at the End of Life stage. These are some of the examples they identified – some very good working practices and some that raise some issues.

"I have, as an interpreter, had the unfortunate situation of conveying to many deaf people that they have a terminal illness or work with them as a result of them having a terminal illness. Reactions have varied considerably from hysterics, shock, non-reactive or dismissive to name a few. The support they receive I believe is influenced by this initial reaction. The health care professionals are so very reliant on us as interpreters to gauge how the patient acknowledges this information. I always ask to recap and reiterate what has just been said explaining and expanding on the options very explicitly. I do, without doubt, believe that **familiar** interpreters should be used during this time as it gives people reassurance and comfort that they know someone they can trust. Many deaf patients receive this information on their own, without family present or have no family.

Some examples:
About 5 years ago, an elderly deaf man, widower, living alone, unable to recover from broken arm, dementia but able to communicate and understand quite well. He gave up in a way but still looked forward to seeing people. He was put on the Liverpool Care Pathway as end of life care. He was told they could do no more for him and that he would die. He just shrugged his shoulders. It was horrid for him, he was basically starved and given no fluids until he died. Each time I attended at the request of nurses/doctors he asked for a drink as he so desperately wanted one. There was always a drink at the other side of the room which he could not reach (part of the plan). I could not deny him this drink. He asked every time. I explained to him each time. Family had agreed to the plan and they did most of communication with health care professionals. He had no control or decision making at the end of his life. It took several weeks for him to die. Hearing family with one other deaf member, **familiar** interpreters used occasionally.

Approximately 2 years ago. Elderly deaf woman, widow, living in supported housing. Fell and fractured hip. Very limited eyesight and early dementia. Her preferred Interpreter was present during initial admission and diagnosis. She was told, via interpreter, the options available. Her hearing family also present and they had very limited BSL skills. She decided not to accept surgery. She would therefore not recover. Had capacity to make that decision. Her condition deteriorated as did her mental state. Staff were very conscious about ensuring she understood everything as far as possible during her stay until her death. They called interpreters in almost on a daily basis but towards the end she was unable to communicate all. **But she was given the chance to**. She stated that she had had a good life and accepted her pending death.

Elderly man given terminal diagnosis and 18 month prognosis. GP very proactive in his long term care and clear that she would support him to die at home as he wished. This was decided very early on after his diagnosis. He was very informed with decisions about his care with GP, consultant and nurse specialist. Regular reviews of care. Always with **familiar** interpreters. Macmillan nurses involved later through his illness who offered excellent support and he accepted or declined treatments after considering the options available to him. His family very much involved also and became a family discussion most times with the final decision being his. He died peacefully at home after four and a half years and I believe had a very dignified end of life care because it was well planned, guided and he was kept informed of every single step along the way. Deaf family, involved with **familiar** interpreters throughout.

Elderly man, fell and was not able to recover. Early dementia, Parkinson’s disease and other conditions that prevented him from recovery. Excellent communication with himself, family and hospital team. Very forthright discussions and realistic in expectations all discussed with him but he was limited in his ability to respond appropriately so family ultimately had to make many of the decisions. Treatment invariably withdrawn as no realistic chance of recovery. Deaf family, involved with preferred interpreters throughout.

Deaf woman, I attended of my own free will at the hospital where she was as no interpreters had been arranged even though she had been in hospital for over one week. She told me she had cancer but she said no more, only that her family did not want anyone to know. I felt it was taken completely out of her hands. She appeared very frightened. I sat with her for a while. I never saw her again. I have been told since that her family decided everything for her. Interpreters were rarely used during her illness, and that was decided by family when interpreters would attend, not her. Deaf family wrote messages to doctors and withheld info from her. She could not stand up to them.

RECOMMENDATIONS

End of life never easy, can't meet everyone's needs or be everything to everyone. However the experiences of D/deaf BSL users are that they have anxieties and concerns about what they are going to experience, based upon their knowledge of what has happened before to others such as isolation, needs ignored, dying lonely and no-one to speak to. This is a significant factor in their desire to die at home – where they will be supported and communicated with.

> *"Current service not looking good for deaf BSL users, always struggle every day to be understood. Don't make end of life a problem for us too."*

This research has identified the following key areas:

1 IDENTIFY THE AND INFORMATION AND COMMUNICATION NEEDS OF PATIENT AND FAMILY

1.1 **Implement accessible information standards** – Ask, Record, Flag, Share and take Action. If this was followed the majority of recommendations would be met.

1.2 **Consider Communication**. A GP asked a grieving widow to go to surgery to offer apology that they couldn't communicate with her when her husband was dying. GP did not book an interpreter.

1.3 **Take responsibility.** A hearing mother and deaf son, she has dementia and is struggling to understand him and he to understand her. Their contact is reduced and it is impacting on their relationship.

1.4 **Stop assuming.** If a BSL user says 'I can lip read' or 'I can speak' you still need to think about what they can hear, communication is a two way process.

1.5 **Check if the deaf person is in the loop?** Do not assume that the D/deaf patient is informed or has understood what is being said and done. Who's perspective is it?

2 USE A COMMUNICATION PROFESSIONAL

2.1 **Use Professional Qualified Interpreter** – many interpreter provider agencies use level 6 (and in some cases not even level 6). This is not a qualified interpreter, there is training beyond the academic level 6 qualification.

2.2 **Use a Preferred or familiar interpreter.** Not only will the BSL user be more comfortable and confident about the information being given but the interpreter will know if the BSL user is not following or understanding the conversation. They will clarify that both parties have the right information. They will respond in a professional manner when delivering difficult information.

2.3 **Good practice/Law or Common decency?** – When delivering bad news and considering withdrawal of treatment this should never be delivered by family members acting as interpreters.

2.4 **Better systems to book interpreters.** Whether staff don't book them or the agencies can't provide them is unclear but the majority of interpreters are 'on call' for emergencies. Are the booking agencies available 24/07? What happens if the 'preferred interpreter' is not on that agencies books. In cases of emergency BSL users should be given the opportunity to book their interpreter and paid by the relevant organisation.

3 SOCIAL AND CULTURAL NEEDS

3.1 **It's not just about the medicine**. A person's access to health and social care services shouldn't be dependent upon hearing capacity. There are assumptions of level of understanding and an ignorance of deaf culture. On respondent said that their partner had a lymphoma in 2001 and later developed cancer in 2007, is terminology appropriate. There is a clear need for deaf awareness treatment throughout.

3.2 **Feedback.** Deaf people have never said that they've had problems? No complaints? How do you know without an impartial interpreter who will enable communication? Deaf people accommodating "I don't expect support", "I didn't think to ask". Some will say they know, but they don't and are too embarrassed to ask to have it explained. Time needs to be given to check understanding.

3.3 **Contact/Communication methods.** BSL users can't use the telephone. Many prefer using text as a high level of written English is not required. There are some things that are available that might help in an emergency - they can register their mobile for 999 calls to be accepted from their mobile. Next Generation Text (replacing speech to text) can be used but a lot of BSL users, especially the older ones are unaware of these services – they need to be advertised and promoted. Providing information in plain English. How can a BSL carer or patient can communicate with the next of kin during a hospital stay should be considered.

4 SUPPORT FOR CARERS

4.1 **Take time to understand an individual's circumstances.** Do not make assumptions - about the person's ability or understanding. Many BSL users have indicated they want to die at home, because they can communicate in their language and not feel isolated. "He wants just me" it's difficult for a carer to refuse to provide support to the patient or to admit that they need help when they are hearing, deafness will add another barrier to open communication. Is the carer saying 'let me do it, only I know how to look after them' or are they frightened that the professionals don't know what they're doing?

4.2 **Communicate with the next of kin/carer appropriately** – involve and include the family and respect the next of kin, communicate with them, not the distant family members.

4.3 **Ensure all options are explored and understood** – are people clear about what's available? How – nobody books interpreters! The interpreter who has worked for many years with terminally ill deaf patients/families stated that they had never heard a hospice being discussed.

4.4 **Educate and inform.** Many BSL users said they didn't have enough information. Some of them described situations where some knowledge and understanding about what to do in an emergency and how to recognise that it is an emergency would have helped greatly. The deaf woman, when concerned about her husband, would have contacted 999 and not tried to get an appointment with her GP. What information about first aid/health issues if someone is a carer is in BSL?

5 BEREAVEMENT SUPPORT

5.1 **Specialist support service**. As described earlier BSL users can become reliant upon their hearing partner or children and when that person dies the deaf person can be very vulnerable. Sensory support team cuts have taken away the formal support that was once provided to a bereaved BSL user and now they have to rely on others and this has potential for abuse.

5.2 **Accessible emotional support.** Newcastle talking therapies, Cruse etc. cannot be accessed by BSL users. Not only because a person needs to phone for an appointment (or find a friendly hearing person you trust and want to divulge that you need this service to) but because BSL users do not know the service and do not trust it. This will take several years of working within the deaf communities and getting positive testimony/approval.

DIVERSITY MONITORING

Gender

Female	24	Male	7

Age:

Under 18	**1**	18 - 24	**6**	25 - 34	**3**
35 - 44	**5**	45 - 54	**3**	55 - 64	**4**
65 - 74	**4**	75 - 84	**5**		

Sexuality?

Lesbian	**2**	Bisexual	**2**	Straight	**23**
Gay	**1**	Prefer not to answer	**1**		

Ethnic background

British	**26**	Chinese	**0**
Irish	**1**	White and Black Caribbean	**0**
Central/Eastern European	**0**	White and Black African	**1**
Indian	**0**	Other British Pakistani	**1**
Pakistani	**0**	Caribbean	**0**
Bangladeshi	**2**	African	**0**

Do you have a Disability?

Yes	**27**	No	**4**

What is the first part of your postcode? e.g. NE2

NE3 NE9 NE2 (2) NE7 NE12 SR1
NE23 (3) NE6 (3) NE29 NE1 SK10 SR8
NE22 NE4 NE33

Blind/Visually impaired	2
Homeless	0
Person with a Learning Disability	0
From a Black or minority ethnic community	3