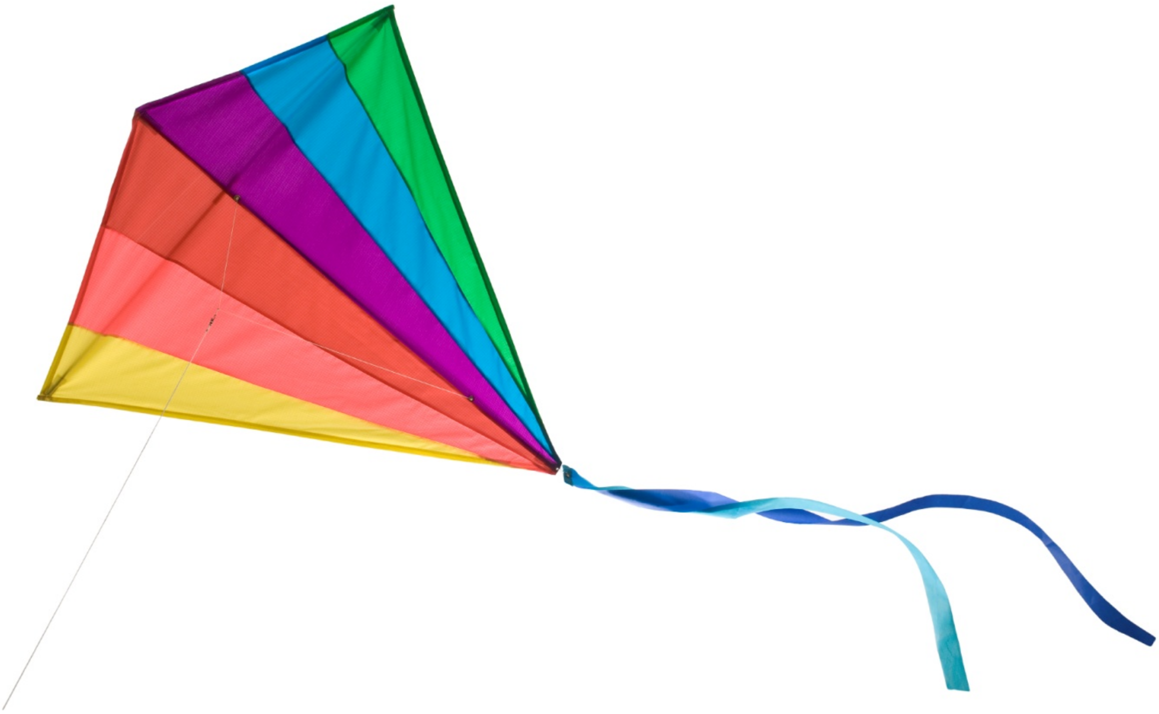


National Survey of Patient Activity Data for Specialist Palliative Care Services

MDS Bereavement Support Report for the year 2013-2014

About the National Council for Palliative Care

The National Council for Palliative Care (NCPC) is the umbrella charity for all those who are involved in providing, commissioning and using palliative care and hospice services in England, Wales & Northern Ireland. NCPC promotes the extension and improvement of palliative care services for all people with life threatening and life-limiting conditions and promotes palliative care in health and social care settings across all sectors to government, national and local policy makers. For further information or to subscribe to NCPC to receive publications free of charge and reduced rates at conferences visit **www.ncpc.org.uk**

About The National End of Life Care Intelligence Network

The National End of Life Care Strategy, published in 2008, pledged to commission a National End of Life Care Intelligence Network (NEoLCIN) to improve the collection and analysis of national data about end of life care for adults in England.

This is with the aim of helping the NHS and its partners commission and deliver high quality end of life care in a way that makes the most efficient use of resources and responds to the wishes of dying people and their families. NEoLCIN plays a vital role in supporting the comprehensive implementation of the strategy. On 1st April 2013 NEoLCIN became part of Public Health England, an executive agency of the Department of Health.

The NEoLCIN website is **www.endoflifecare-intelligence.org.uk**
Public Health England's website is **www.gov.uk/phe**

About Hospice UK

Hospice UK is the national charity for hospice care. We champion and support the work of more than 220 member organisations that provide hospice care across the UK, so that they can deliver the highest quality care to people with terminal or life-limiting conditions and support their families.

Hospice UK supports the breadth, dynamism and flexibility of modern hospice care, by: influencing Government and decision makers; improving quality of care through the sharing of good practice; and providing resources, training, education and grant programmes.

We work collaboratively with our members to support their vital work and to create a stronger voice for hospice care in the UK. We also support the development of hospice and palliative care worldwide. Hospice UK's website is **www.hospiceuk.org**

Bereavement Support MDS report 2013/14

Contents

Key findings

- Women are more likely to access Bereavement Support than men, and the proportion of women accessing Bereavement Support has increased over time
- Incomplete data capture on age and ethnicity makes it difficult to assess any other characteristics of people who access Bereavement Support
- There are no clear trends in the length of support or the type of contact offered by Bereavement Support services

Definition

A Bereavement Support service is provided to relatives, partners and carers of a deceased person and may include individual counselling, home visits, and group activities. Although similar emotional and psychosocial support is often provided to carers of people who are close to death, this dataset records after the death.

Bereavement Support services are organised with varying degrees of formality. Some are provided quite informally or integrated into the general pattern of services, while others have routine referral, assessment and discharge procedures. Services are encouraged to develop procedures to ensure that this important aspect of their workload is recorded.

Note on figures: where possible, the number of organisations providing each data item in each year is given in parentheses on each graph. Different organisations return MDS data from year to year, and so any historical trends presented here are subject to the caveat that the profile of services responding may be different from year to year.

Not all services report on all items of data; consequently the total number of people accessing a service varies from section to section of the report. Throughout the report, where services have provided clearly anomalous data, they have been excluded from the analysis.

All tables referenced are available in the accompanying annex document.

To help interpret graphs that show quartiles, it may be useful to think of it as: 25% of services are below the blue line, 25% of services are above the red line, and 50% of services sit between the blue and red lines.

Response rate

115 of 246 Bereavement Support services returned MDS data in 2013/14 representing a 47% response rate, down from 49% in the previous MDS reporting year.

This is consistently the section of the MDS with the poorest response rate, due to a number of possible factors:

- we believe the data is often held separately to patient data and so the form may not reach the person who should complete the return when it is often sent to a contact who is better able to complete the forms for other settings;
- the data asked for is not useful data for the sector so services see limited value in returning it;
- bereavement services in hospitals are held on our database but may not provide the kind of support we ask about here. If they provide logistical support around funeral arrangements and signpost on to counselling services not specifically associated with specialist palliative care then the majority of their work is not captured by the MDS form and so they may not return it.

Discussions are underway with Public Health England, Cruse Bereavement Care, the Childhood Bereavement Network, and the Association of Bereavement Coordinators as to how bereavement data could be captured more accurately and on a larger scale. In the meantime, NCPC would welcome feedback on how to improve response rates and capture a more complete picture of the work being done to support bereaved people.

Table 7a: response rates by type of organisation and type of management, 2008-2014

	Hospice			Hospital			Clinic			Community	
Year	Managed by NHS	Managed by Independent	Management not recorded	Managed by NHS	Managed by Independent	Management not recorded	Managed by NHS	Managed by Independent	Management not recorded	Managed by NHS	Total services responding
2008/09	18	83	21	11	1				1	2	137
2009/10	16	90	15	8		1				1	131
2010/11	16	93	16	8						1	134
2011/12	13	109		7						1	130
2012/13	9	106		10	1		1	1			128
2013/14	9	93		11	1		1				115

Number of service users

There has been a slight decrease over time in the mean number of people seen per service, which is likely to be due to the decrease in response rates from larger services (as shown by the variation in the 3rd quartile of the data).

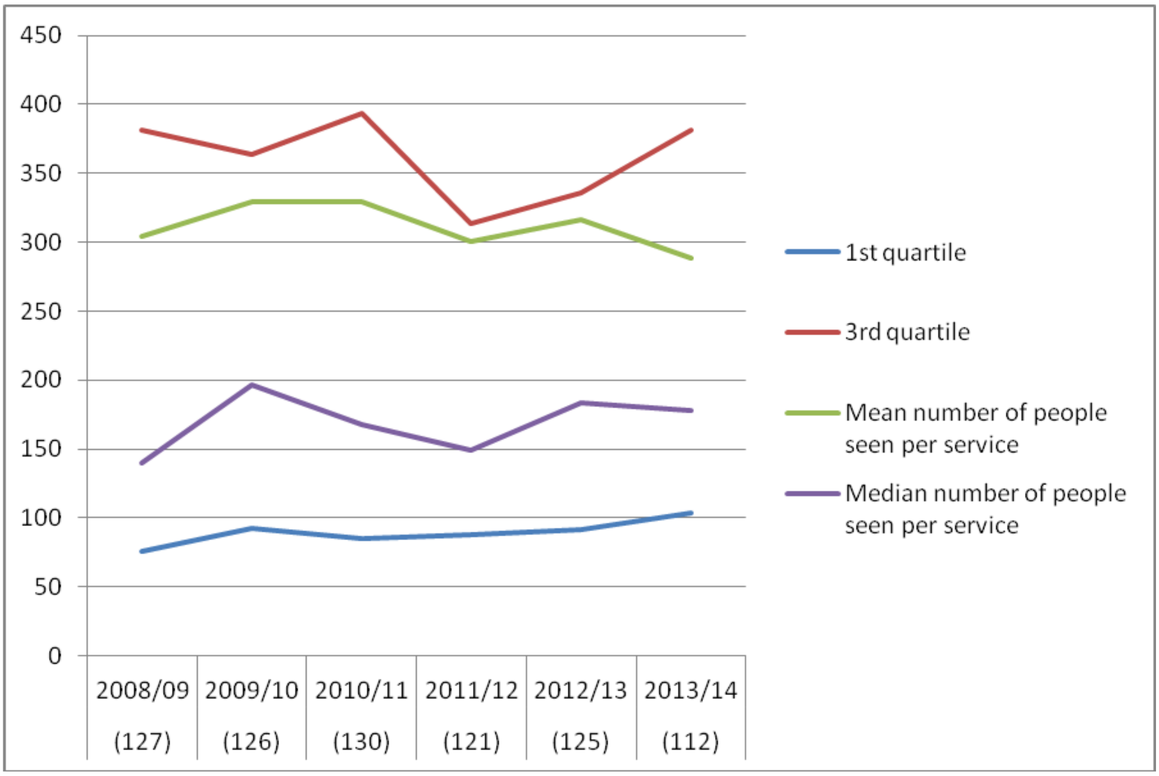


Figure 7.1: changes in the range of size of Bereavement Support services over time (Table 96)

Age of service users

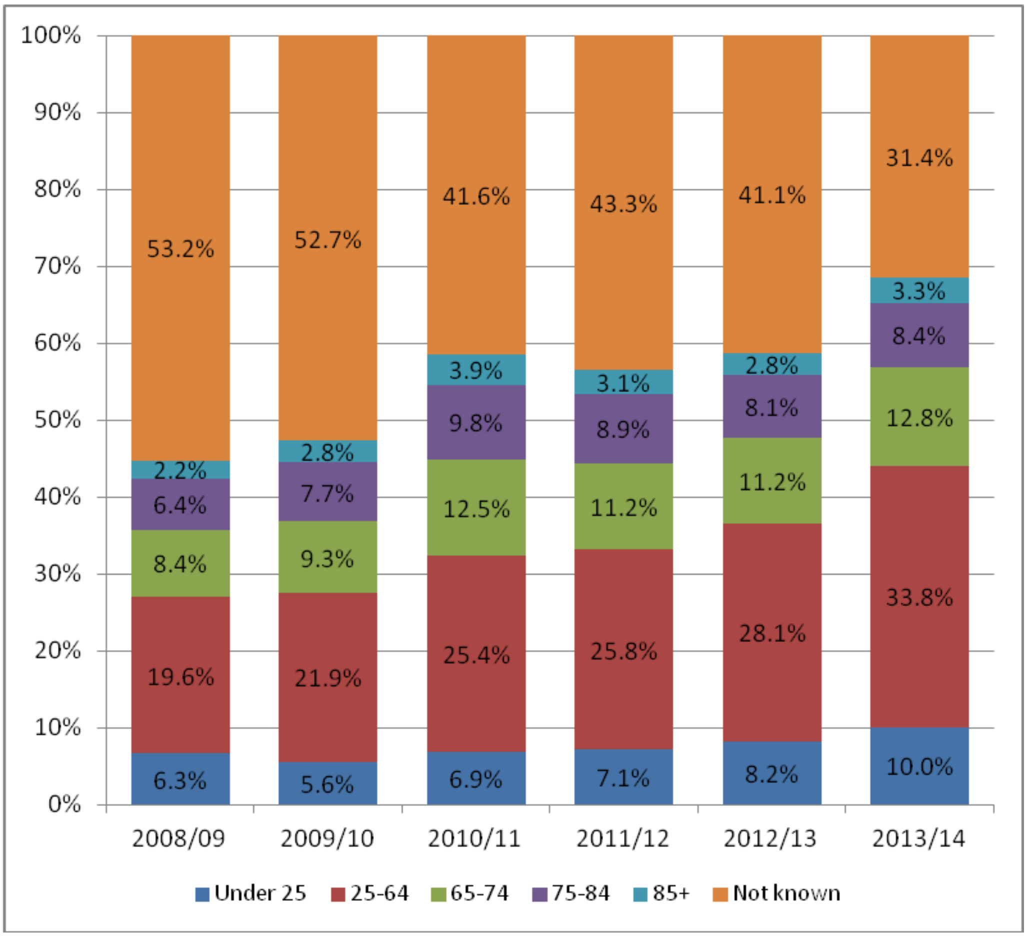


Figure 7.2: proportion of different age groups accessing Bereavement Support services, 2008-2014 (Table 97)

The apparent improvement in data quality is in fact due to services who historically record very little demographic data not submitting returns in 2013/14, rather than a general improvement in data quality across the sector. Consequently it is hard to make a judgement on whether the demographics of those accessing Bereavement Support are shifting or not; however, it does seem as though there is a proportionate increase in younger people making use of these services.

Sex

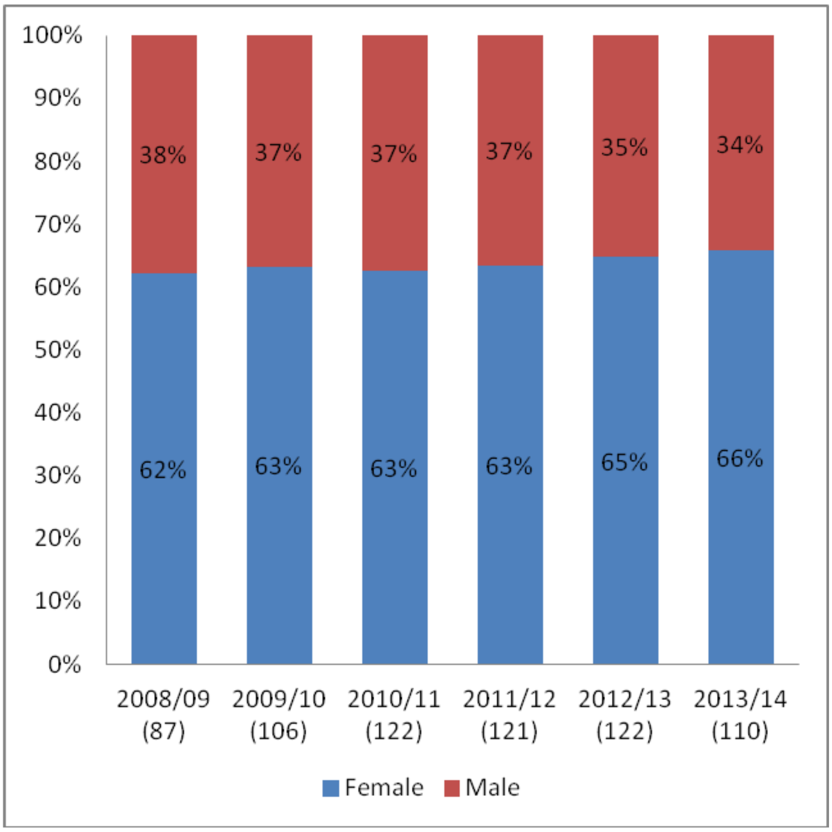


Figure 7.3: proportion of men and women accessing Bereavement Support services, 2008-2014 (Table 98)

A clear majority of Bereavement Support clients are female, with the proportion of men accessing this service decreasing slightly over time.

Case study: encouraging men to access bereavement support

Services submitting MDS data that suggested the profile of their patients differed from the average were asked to submit case studies, to give some idea of what actions they take to make sure their services are accessible to as many people as possible.

Macmillan Specialist Palliative Care Team North East Lincolnshire

As a team we work with patients and families to provide holistic care pre- and post-bereavement. Men who access bereavement counselling are generally familiar with the team prior to bereavement.

The team routinely makes contact following bereavement to pass on condolences and offer assistance with immediate difficulties, at which point formal bereavement support is offered.

Referrals to the Macmillan Specialist Palliative Care Social Worker follow in cases where there are complex bereavement needs and the man indicates a willingness to access formal bereavement counselling.

Counselling takes a person centred approach with sessions agreed with the bereaved enabling individuals to progress at a comfortable pace. One man stated ‘bereavement sessions helped me to cope again.’ As counselling progresses the frequency of sessions is reviewed and sessions cease when they are no longer needed.

The Macmillan social worker also facilitates a Social Bereavement Group for men and women finding it difficult coming to terms with the death of their life partner. Members state ‘meetings are natural, we feel normal. When we were part of a couple we supported each other, as individuals in a group we support each other. We share our feelings, experiences and lots of laughter.’

Case study: encouraging men to access bereavement support

Services submitting MDS data that suggested the profile of their patients differed from the average were asked to submit case studies, to give some idea of what actions they take to make sure their services are accessible to as many people as possible.

Bolton Hospice

Our service offers support not counselling. We have a Bereavement Support Co-ordinator (who happens also be the Chaplain) and currently ten volunteer supporters. Within a month of the death of someone within our service, next of kin and other family or friends who are known to the hospice receive a card from the Hospice to offer condolence and to give contact details along with a slip about the service and upcoming dates for the two groups we run.

About three months after the death the bereaved are invited to a Time of Remembrance ‘Service’ (for want of a better word) and they are offered the facilities of the service again in the invitation letter, and then at the back of the ‘Service’ booklet. The two groups meet monthly: one session is held in the afternoon for those over 60 years old, the other in the evening for anyone. We also offer one to one sessions and sessions for families, whoever the bereaved see as their family.

We make no special provision for men but have men in both groups and men attend one to one, although more women actually contact the service and take up provision. As with all Bereavement Services we offer a service for all and will see anyone with a connection to a patient in our system. I, The Bereavement Support Co-ordinator, am a man and that may assure other men. Men tend to come to sessions for a shorter time, find emotions difficult but all those who have attended have left feeling stronger, although this is a generalisation. Our mission statement:

“We allow the bereaved the space, time and opportunity to tell their story as many times as they need, without judgement and without pre-conceptions. We give the bereaved the opportunity to be heard and to give a voice to their grief.”

Ethnicity

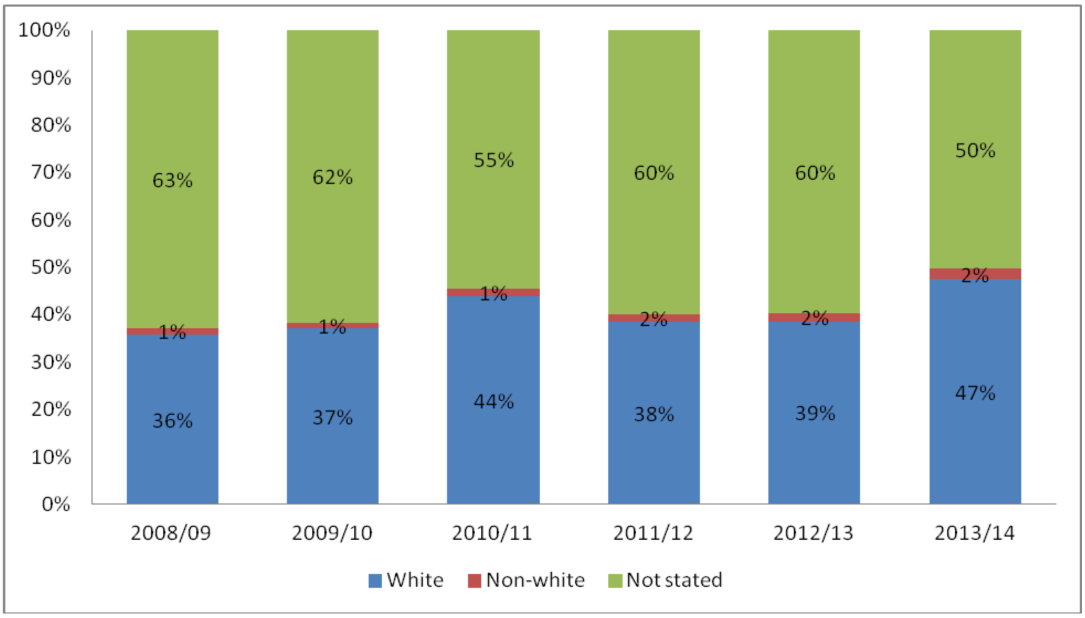
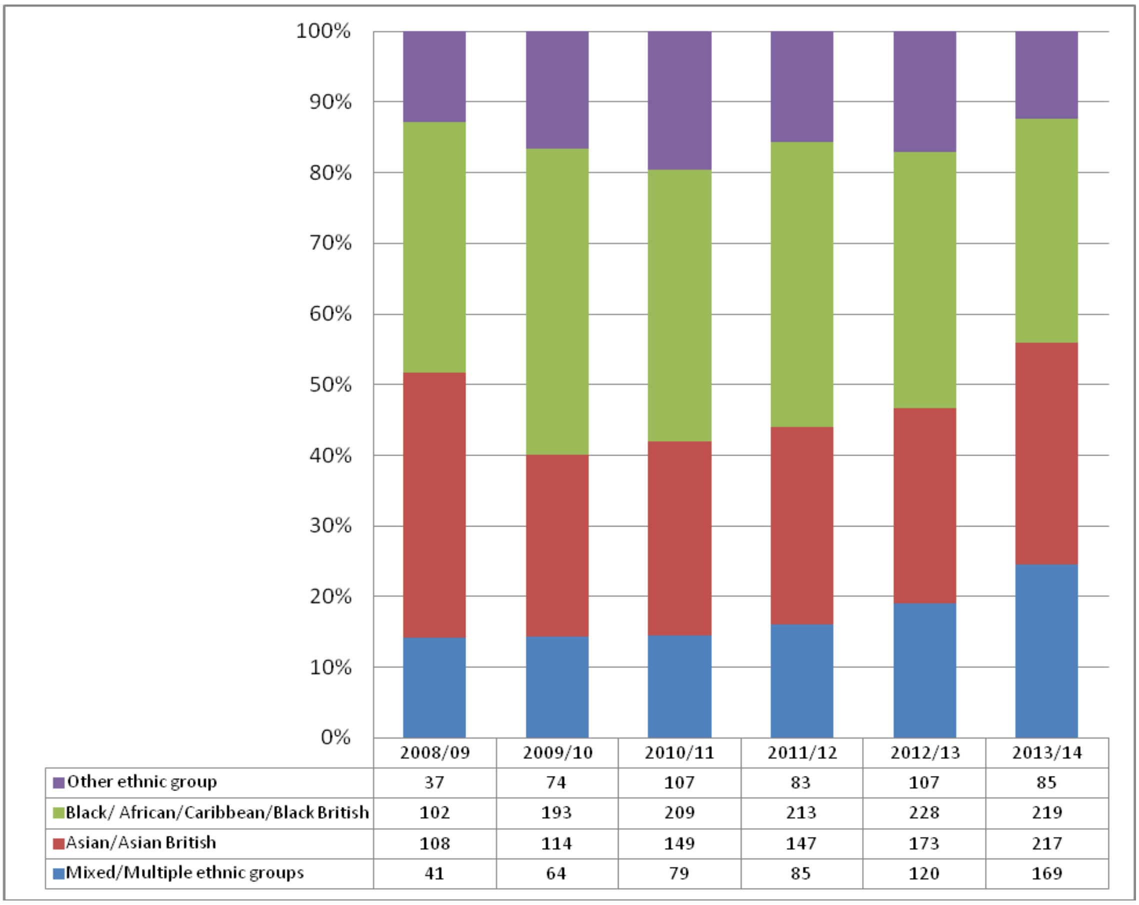


Figure 7.4: proportions of people accessing Bereavement Support services reported as white, BAME and not recorded, 2008-2014 (Table 99)

As Bereavement Support is the setting with by far the highest proportion of unrecorded ethnicity, it has commensurately low levels of recorded access for people of BAME origin. It is difficult to compare provision with prospective need, although we will look further into how this may be done using census data on the BAME population aged over 65 as a proxy measure for need.



	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
🟪 Other ethnic group	37	74	107	83	107	85
🟩 Black/ African/Caribbean/Black British	102	193	209	213	228	219
🟥 Asian/Asian British	108	114	149	147	173	217
🟦 Mixed/Multiple ethnic groups	41	64	79	85	120	169

Figure 7.5: people accessing Bereavement Support services from grouped BAME categories, 2008-2014 (Table 100)

Contacts

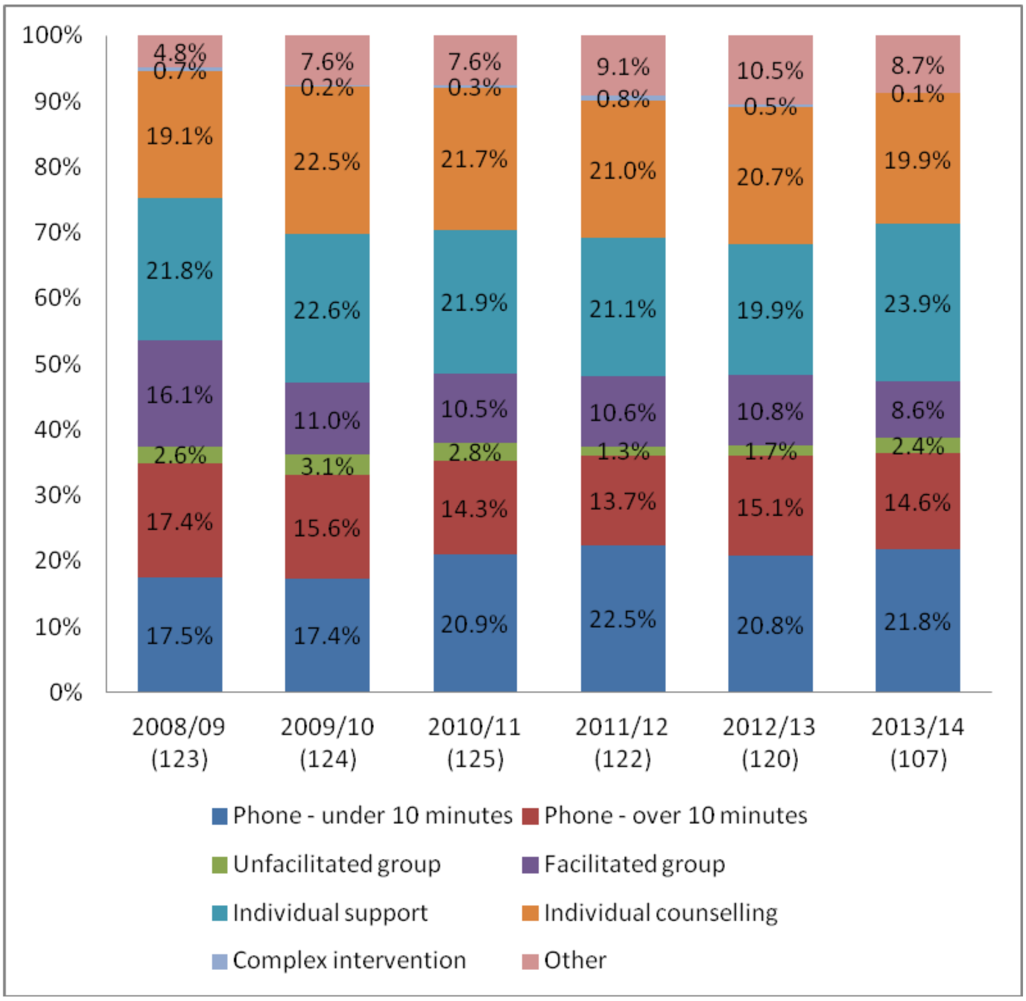


Figure 7.6: types of contacts recorded by Bereavement Support services, 2008-2014 (Table 101)

Overall, shorter phone calls and individual support (provided by a volunteer or other person, not necessarily a trained counsellor) are increasing, while facilitated groups are decreasing. Complex interventions have dropped significantly in 2013/14.

Length of support

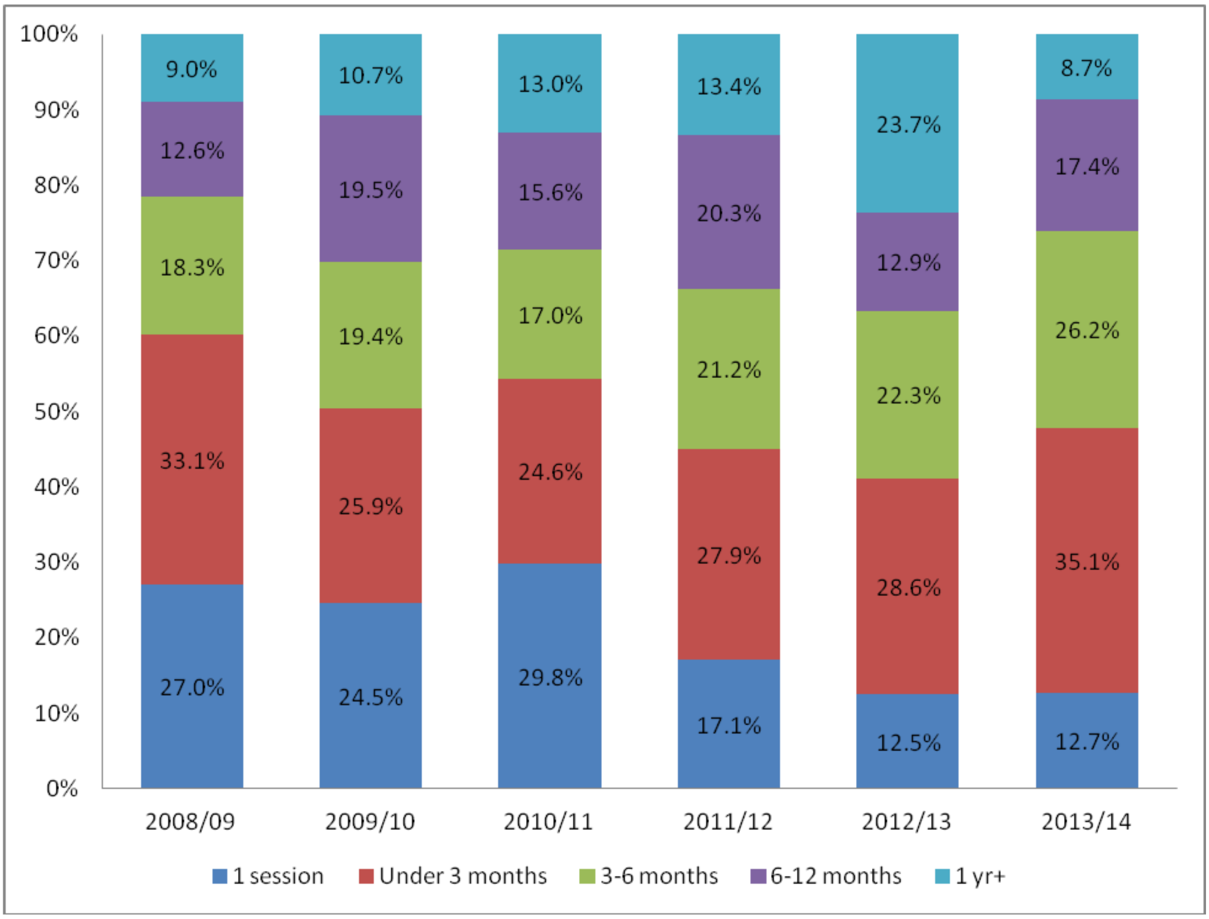


Figure 7.7: length of support recorded by Bereavement Support services, 2008-2014 (Table 102)

There is a large amount of variation in the recorded length of support data, reflecting both the data quality of submissions received and the changes in services responding from year to year. Consequently, it is difficult to make any judgements about trends in this area.

Diagnosis of deceased

Data is collected on the diagnosis of the deceased relative or friend whose loss has catalysed the service user to seek bereavement support. The data collected in the MDS on diagnosis of deceased shows the majority of people who access bereavement support that is allied with specialist palliative care have lost someone to cancer, as might be expected given the prevalence of people with cancer seen across all other MDS settings. We will cease to collect this data in the future, as there is no evidence that the diagnosis of the deceased has any impact on the length of support required, the type of support required, or the likelihood that someone will seek bereavement support.

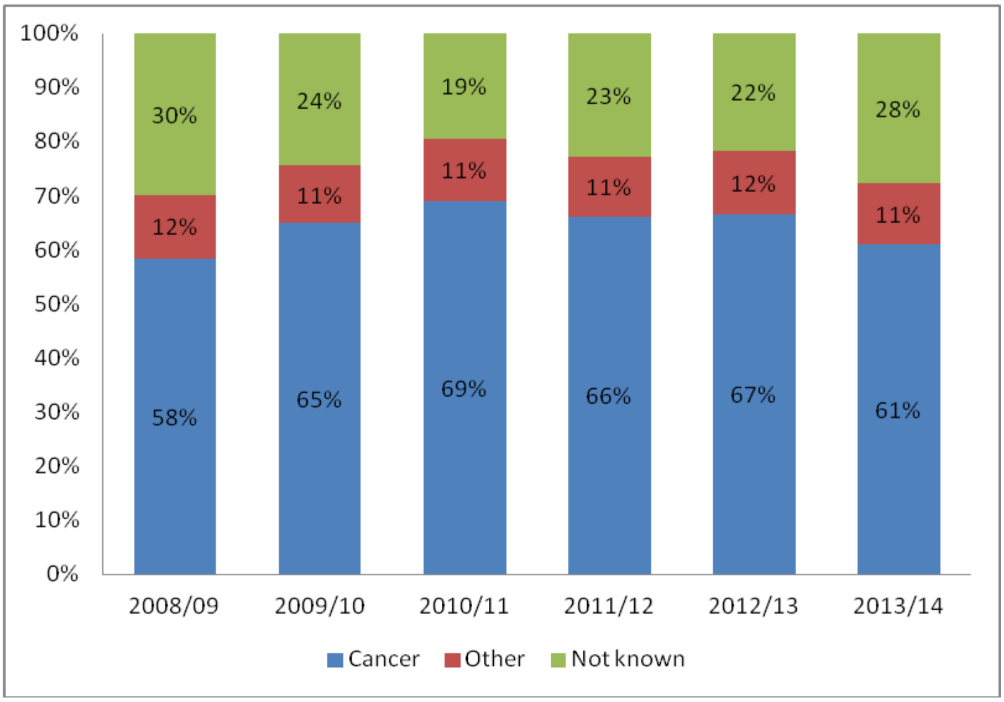


Figure 7.8: diagnosis of deceased relative or friend reported by Bereavement Support clients, 2008-2014 (Table 103)

Data from VOICES[1] suggests that in fact, the likelihood someone will access bereavement support may be partially dependent on place of death, or rather that bereavement support is more likely to be offered in some settings than others. For example, looking at overall statistics from VOICES for the past three years, around two thirds of people say they did not access bereavement support and would not have wanted to, while 18% of people say they would have liked to access bereavement support but did not. Around 14% of people both wanted to and were able to access some form of bereavement support.

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[1] National survey of the bereaved (VOICES), ONS 2013.

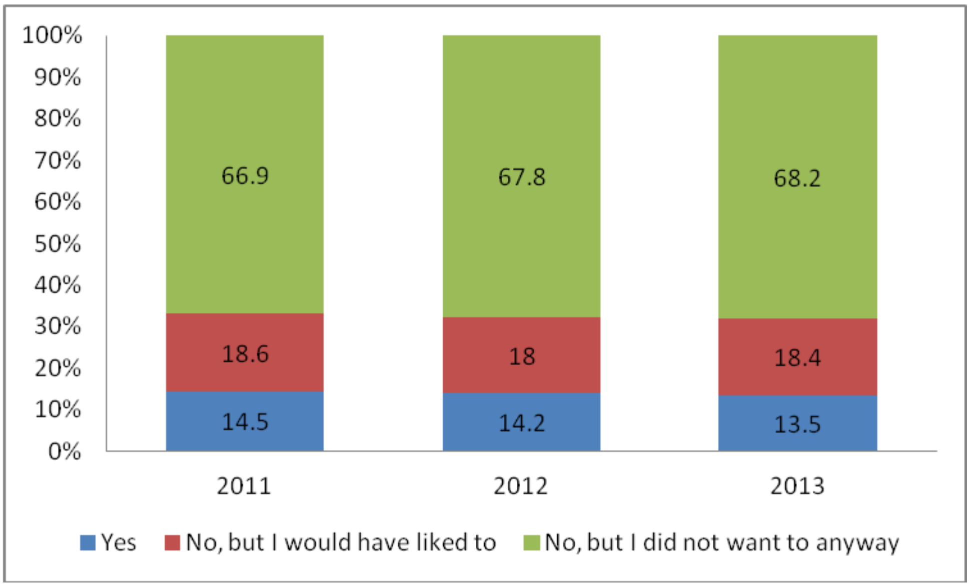

Figure 7.9: VOICES data across all settings: Q52. Since he/she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his/her illness and death? (Tick one only)

For example, looking at overall statistics from VOICES for the past three years, around two thirds of bereaved people say they did not access bereavement support and would not have wanted to, while 18% of people say they would have liked to access bereavement support but did not. Around 14% of people both wanted to and were able to access some form of bereavement support. Yet breaking this down to setting level, these percentages vary significantly.

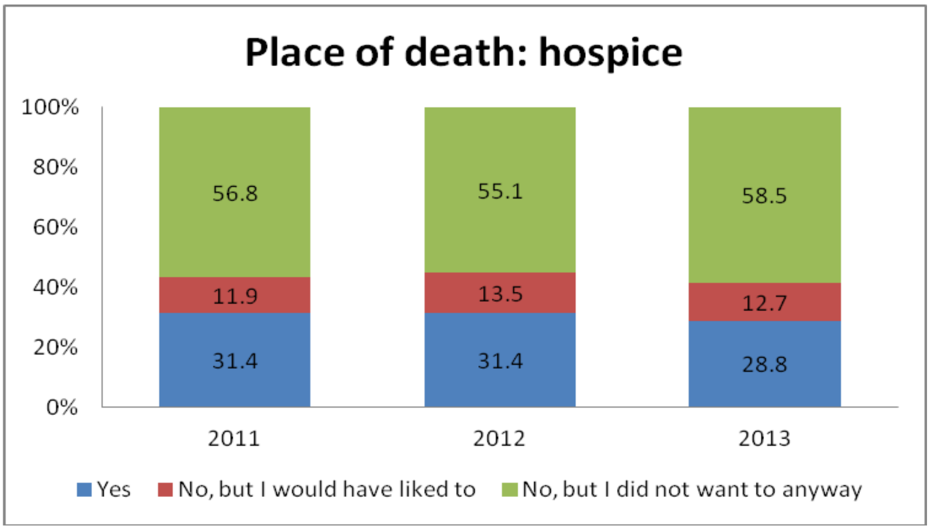

Figure 7.10: VOICES Q52 for hospice settings only: Q52. Since he/she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his/her illness and death? (Tick one only)

For people responding to VOICES who had had someone die in a hospice setting, 13% of people would have liked to access bereavement support but did not, compared with 18% of all bereaved people. For those who had had someone die in a hospice setting, almost 30% of respondents access bereavement support, compared with around 14% of all bereaved people. Does this mean that people who experience the death of someone close to them in a hospice situation are more likely to require bereavement support? Or does this mean that hospices are more proactive in offering bereavement support and so meet an unspoken need for more support?

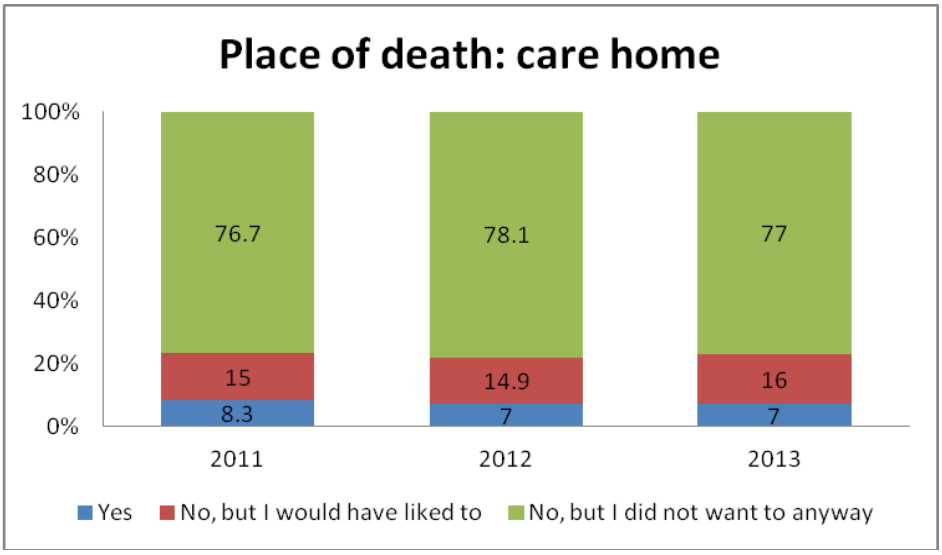

Figure 7.11: VOICES Q52 for care home settings only: Q52. Since he/she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his/her illness and death? (Tick one only)

Conversely, where the place of death was a care home, people are more likely to say they did not want to access bereavement support. Does this reflect the fact that those who die in care homes are likely to be older[2] and their deaths more expected, or does it reflect a lack of support available in this setting? It should be noted that the percentage of people wanting to access bereavement support but not doing so for deaths in care homes is not higher than the average across all respondents of 18%.

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[2] 67% of deaths in care homes in 2013 were people aged 85 or older. ONS Mortality Statistics, England and Wales, 2013.

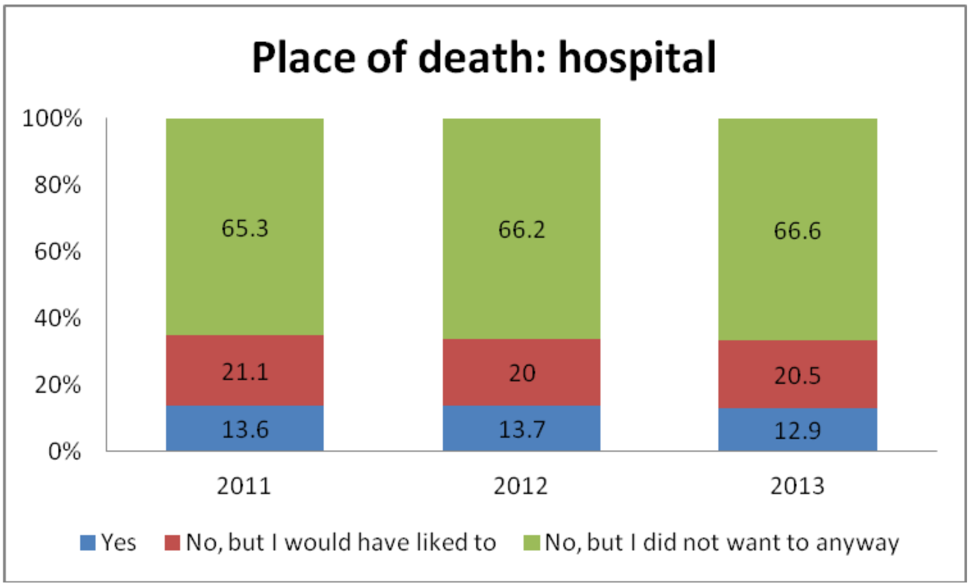

Figure 7.12: VOICES Q52 for hospital settings only: Q52. Since he/she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his/her illness and death? (Tick one only)

For deaths in hospital or at home, desire to access Bereavement Support was close to the average across all settings, with a higher proportion accessing Bereavement Support after a death at home and a higher proportion unable to access support they would have wanted after a death in hospital. The vast majority of Bereavement Support MDS returns come from hospices; the sample from hospitals is too small to make any valid comparisons between settings even with weighting.

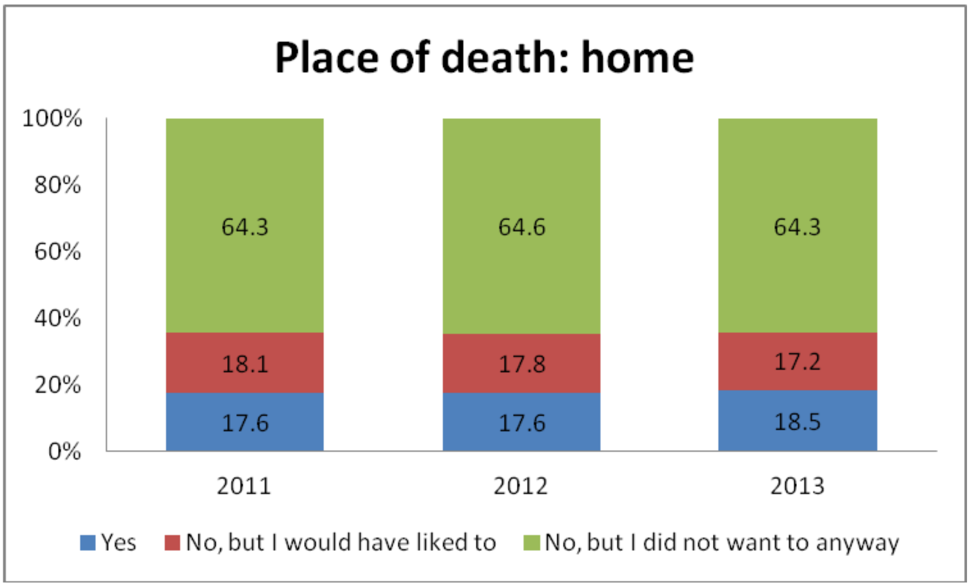

Figure 7.13: VOICES Q52 for home setting only: Q52. Since he/she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his/her illness and death? (Tick one only)