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Results of a national survey of support to adult care homes in England: A specialist palliative care provider perspective.

FINAL REPORT August 2017



Public Health
England



Acknowledgements

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Thank you to the following for data analysis support

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Thank you to the following for comments on the text

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Anita Hayes
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Thank you to the individuals and teams who generously shared their time, experiences and perspectives for the purpose of this report. Thanks to your participation, we have the first detailed look at the provision of specialist palliative care in care homes in England.

Coordinating Centre

Marie Curie Palliative Care Research Centre, Cardiff.

Commissioned by

The National End of Life Care Intelligence Network, Public Health England.

Published by

The National Council for Palliative Care. The National Council for Palliative Care (NCPC) was one of the partners producing this report. On 1 July, NCPC merged with Hospice UK to create a new body supporting hospice and palliative care. NCPC job titles correct at the time of writing.

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1. Foreword

England is now classified as an aged society with over 15% of the population aged 65 years and older. By 2035 it will be classified as super aged with more than 20% of the population aged 65 years and older.⁽¹⁾ The past few decades have witnessed increased life expectancy for the population with the result that more people die at a much older age often following a period of increasing physical and/or mental frailty. In 1963, 9% of males and 18% of females died aged 85 years or older and in 2014, this was 30% and 48% respectively.⁽²⁾ The numbers of people dying and age at which they die will continue to increase significantly over the next two decades.⁽³⁾

Care homes, both residential and nursing, play a critical role in the delivery of care towards the end of life for many, predominantly older, people. In 2005 16% (76,977) of people died in a care home but this has increased to 22% (101,203) in 2014. An even higher proportion will receive some of their care in care homes before death as approximately a third of people (28,892) living in care homes die elsewhere, mainly in hospital. There is significant variation by Clinical Commissioning Group across England in the proportion of people aged 75 years and older who die in care homes varying from 10% to 43%.

The causes of death of people who die in care homes also differ from those who die in other locations with 62% of people having some form of dementia mentioned on their death certificate compared with only 14% of those who die in hospital. A study of 2,444 deaths in care homes in southern England suggested that almost half of people who die in care homes do so after a period of slow dwindling decline and just over a quarter had a specific terminal condition.⁽⁴⁾ Care homes therefore provide end of life care to a significant proportion of the population who are also especially vulnerable.

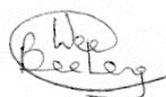
This report is the first study at a national level of specialist palliative care support to care homes. It combines quantitative and qualitative approaches to give an extraordinary insight into the challenges faced by care homes and specialist palliative care services supporting them to provide high quality end of life care. It is also packed full of examples of good practice and truly moving quotes and vignettes illustrating the strong desire to provide good care at the end of life to people nearing the end of life in care homes. Importantly, this report adds another important piece of evidence to help drive forward the Ambitions for Palliative and End of Life Care: A national framework for local action, in particular the second ambition: each person gets fair access to care.

Public Health England commissioned this report with research carried out by the Marie Curie Palliative Care Research Centre at Cardiff University to better understand the nature and extent of specialist palliative care support provided to care homes. The steering group included representatives from NHS, The National Council for Palliative Care and Hospice UK together with PHE.

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2. Background and rationale

This report aims to increase understanding of how specialist palliative care services support adult care homes in England.

There are over 450,000 care home places in England.⁽⁵⁾ The care home resident population is ageing⁽⁶⁾ and the prevalence of complex healthcare needs and frailty amongst this group is increasing.⁽⁷⁾

It is estimated that that over 21% of all deaths in England take place in a care home⁽⁸⁾ and that those resident in a care home account for between 19 and 25% of all deaths in England.⁽⁹⁾

Whilst work has been undertaken to better understand specialist palliative care service activity through the annual Minimum Data Set (MDS) survey,¹ little is known about the support offered in the care home setting.

'The physical environment of different settings, including hospitals and care homes, can have a direct impact on the experience of care for people at the end of life and on the memories of their carers and families. Central to this is the importance of providing settings in which dignity and respect are facilitated.'

(Department of Health, 2008)⁽¹⁰⁾

¹ The Minimum Data Set for Specialist Palliative Care Services was collected by the National Council for Palliative Care on a yearly basis, with the aim of providing an accurate picture of hospice and specialist palliative care service activity. Further information can be found at: NCPC (2017) Minimum Data Set [Online] Available at: <http://www.ncpc.org.uk/minimum-data-set> (Accessed 28th June 2017).

3. Summary of findings and recommendations

Respondents came across as committed and passionate about their work in the care home setting. The constant thread running through their accounts was the willingness and professional imperative to provide and support the delivery of compassionate care to residents.

All but a few reported positive relationships with the homes they supported. They acknowledged challenges to delivering Specialist Palliative Care (SPC) in care homes and offered constructive suggestions for ways to meet them.

Almost three quarters of the survey population described their service as a hospice. Around a quarter identified as a Specialist Palliative Care Unit. Services covered from one to five Clinical Commissioning Groups areas and the vast majority had been running for 10 or more years.

A wide range of services was described and many examples of work undertaken by multi-disciplinary teams and/or in close collaboration with other service providers were given. Many providers had formal, ongoing relationships with care homes whilst others were more informal. Some services actively targeted support at care homes. Collaboration and positive relationships were shown to be important factors in the successful delivery of training and clinical care in this setting.

Almost all respondents said they had an agreement or contract to supply SPC services in the community generally. Fewer were specifically commissioned to supply SPC services to care homes. Some providers explained that lack of specification of care homes/residents in contracts and agreements was irrelevant and that support was willingly given and driven by patient need.

Around half of those specifically commissioned to provide services to care homes/residents said they provided clinical support. A similar number delivered education and training, with many providing a combination of both.

Lack of a standardised approach to recording among providers and the fact that in many cases they were unable to identify individuals as a care home resident, meant it was not possible to clearly quantify the level of support delivered. The availability of data on care home residents' place of death was also affected.

Data from those who had Key Performance Indicators (KPIs) for services to care homes/residents showed that outputs such as the number of referrals or visits were the most prevalent form of performance measure described. KPIs, which focused on outcomes (measurable change as a result of the service intervention), were less frequently reported. Despite the increased focus in healthcare on the involvement of patients and carers in the assessment of care, patient and carer reported outcomes were rarely mentioned. One example of best practice did however emphasise the importance of evidence-based practice and gave a description of how care and service provision had been influenced by feedback from bereaved family members.

The high turnover of care staff, clinical staff and managers in residential and nursing homes was seen as a major challenge that inhibits support to care homes and residents. Staff turnover and staffing levels were thought to impact on the ability of care homes to release staff to attend education and training, and also to affect the retention of knowledge and skills, the ability to maintain a consistent quality of care and the creation of a stable learning environment. However, some respondents acknowledged that training is an investment in individuals and therefore transferable to other care sites. Improved pay and conditions to reflect the responsibility and value of care and nursing roles in care homes was suggested as a way to improve staff retention.

The requirement of staff to attend training in their own time rather than work time, and care home managers attitudes to training were thought to be a barrier to learning. Proposed ways to improve the prioritisation and uptake of training included providing funding for additional staff to cover those on training, the development of SPC core competencies for care home staff and the specification of these competencies in care home contracts.

Associated with this was the suggestion that there should be greater collaboration between Clinical Commissioning Groups, Local Authorities, and regulatory bodies.

It was proposed that a longer-term strategic approach to funding and increased commissioning of dedicated SPC clinical staff and educators to work with care homes, would help to improve the continuity and sustainability of support.

Provision of GP support was thought by some to be a factor affecting the delivery of timely and appropriate care to residents. A focus on GP education, the development of positive relationships, and more effective ways of allocating and contracting GPs to care homes were suggested as ways to strengthen their support.

Language barriers and cultural differences were cited by many as a challenge. This included English being spoken as a second language by care home staff and the implications of different cultural beliefs around death and dying for Advance Care Planning.

Whilst there were some limitations to the quantitative data, providers written accounts helped to identify weaknesses in data capture relating to care home residents. The richness of their free text contributions have provided a valuable snapshot of SPC support in the care home setting in England. In particular, it has enhanced our understanding of the challenges and potential enablers to providing support from a SPC provider perspective. These perspectives have influenced the development of the following recommendations:

- SPC Providers should combine to assess the feasibility of establishing a unified approach to data capture that will enable the level of support delivered to care homes and residents to be quantified, reported and understood.
- Commissioners should target SPC funding and support to care homes and residents through specification of this care setting in contracts and agreements where appropriate.
- Commissioners and providers should review SPC service performance measures to ensure, where appropriate, patient and carer reported outcomes are included.
- SPC providers, commissioners and care homes should work together to increase awareness and attainment of core competencies. They should determine the best way to deliver education and training to meet the needs of care home staff considering local challenges.
- Clinical Commissioning Groups and Local Authorities should consider their role as commissioners of services in encouraging care homes to engage with SPC education and training. This could include working together and with care home owners and managers to explore the viability of improving care home engagement with SPC training through the specification of mandatory core competencies in contracts and agreements.
- Further research is needed with care home staff to examine their perspectives on the challenges and enablers to providing SPC support in the care home setting.

4. Methods

a) Sampling strategy and participating service characteristics

We sought to survey a purposive sample of 326 providers in England who were registered with the National Council for Palliative Care (NCPC) as being providers of community-based specialist palliative care support.

The sample was identified from a database of SPC services held by NCPC for administering the Minimum Data Set (MDS) survey for Specialist Palliative Care Services. The response rate for this cohort was 27% (88).¹¹

Targeting only those historically registered may have excluded new or unknown services. The survey was therefore publicised more widely through websites and social media to try to reach this audience. This resulted in an additional 20 responses: 14 hospital teams previously thought to deliver inpatient services only and six providers who were formerly unknown.

Due consideration was given to the inclusion of an ambulance service that completed the survey. Their contributions have been included in the report due to the nature of educational support they give to care home staff. One response was excluded and two were retracted by providers. The total number of responses was therefore 108.

b) Inclusion criteria and consent to participate

Specialist palliative care providers that work directly with care homes in the community were invited to complete the survey, those that did not work directly with care homes in the community were excluded.

Participation in the survey was voluntary with respondents able to choose not to answer some or any of the survey questions. By participating in the survey, service providers agreed that their responses, including anonymised extracts of text, could be shared through this report.

c) Definitions

Care home: The definitions used to describe the two main types of care home in this report combine the terminology used by the Care Quality Commission (CQC) and understood in community practice.⁽¹¹⁾ These are:

- Nursing home (Care home with nursing)
- Residential home (Care home without nursing).

Survey Participants: Throughout the report the terms service providers, respondents and survey population are used to describe those who participated in the survey.

Palliative Care: The World Health Organisation has defined palliative care as follows: Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a

¹¹ The individual provider identification numbers held on the MDS database did not take into account recent structural changes where services had merged/integrated. The return rate would be higher if these changes were taken into account.

support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families; enhances quality of life and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications. Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions.⁽¹²⁾

d) Data capture

Primary data were captured through an online survey, which was developed and administered using the Bristol Online Survey tool (BOS). The survey was open for a total of 62 days between November 2016 and January 2017.

Completed questionnaires generated quantifiable information about the support that specialist palliative care providers offer to care homes. Some survey questions were categorical, allowing respondents to choose an answer from a list of predefined answers, e.g. whether they had or had not been commissioned to provide SPC support to care homes. Other questions invited free text responses, allowing providers to give free text accounts such as a description of their relationship with the care homes they support.

e) Data transfer, analysis and presentation

All valid survey responses were downloaded from BOS in Excel format and were then labelled with a response number. The response data were then split into two separate files by data type: qualitative data, quantitative data.

Qualitative data were uploaded to NVivo 11 software that supports the organisation and analysis of unstructured/qualitative data. Content Analysis enabled the data to be analysed and described. The catalogued data were read line by line and relevant data were isolated, interpreted and allocated codes or categories that were as near as possible to the free text material provided. Where appropriate, the counting of frequencies of coded categories/data units enabled the data to be quantified and reported.⁽¹³⁾

Extracts of free text survey responses are included in the report to add context to the discussion and convey the tone and language used by providers. To assist the reader, some grammatical corrections have been made however, this has been undertaken with caution to ensure the meaning of the text has not been altered.

Quantitative data were uploaded to SPSS 23 software that supports the statistical analysis of data. Descriptive statistics were used to describe quantitative data. In order to improve transparency both percentages and number of observations available for each question were presented. Percentages have been rounded to nearest whole number which means that in some cases, the sum of the percentages may not add up to 100. The effect of outliers was mitigated by reporting medians and inter quartile ranges alongside the means. Account of missing data is provided throughout. The data tables are shown in Appendix 1.

5. Participating service characteristics

This section describes the characteristics of the services that participated in the survey.

a) Type of service

We asked providers which of the following two options best described the respondents service: Specialist Palliative Care Unit (SPCU) or Hospice.

One hundred and five of 108 survey respondents (97%) answered this question. The majority, 72 respondents (69%), described their service as a Hospice and 33 (31%) described their service as an SPCU.

Three respondents (3%) did not answer this question, this could be because their service does not fit either category description. For example in a later section, respondent 67 who did not answer this question wrote: *'We are a Community Palliative Care Team [...].'* This suggests there was a limitation to this question. If repeated in future, an 'other' free text option added to this question would allow the creation of alternative categories.

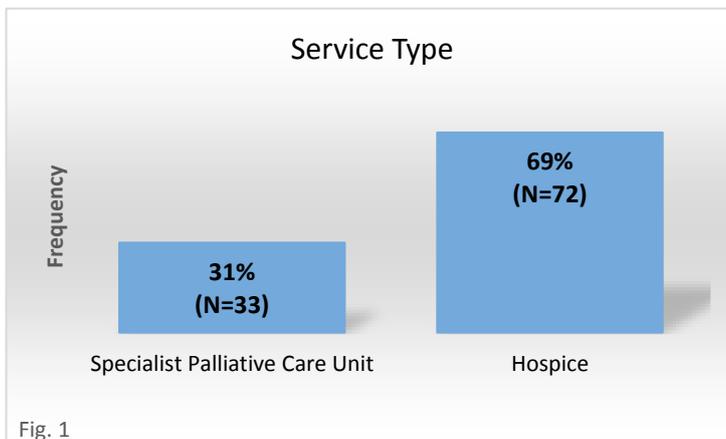


Fig. 1

I work for a Community Foundation NHS Trust not a specialist palliative care unit or hospice. We have provided direct clinical care support and education/training support to all nursing and residential homes within [our area] since the Specialist Palliative Care Service inception [...].'

(Respondent 2)

b) Completion status for 2015/16 Minimum Data Set survey

As this survey on support to care homes aimed to expand on information gathered about other care settings through the annual MDS survey, we were interested to find out what proportion of services had completed it in 2015/16.

One hundred and six of 108 survey respondents (96%) answered this question. Almost three quarters, 76 respondents (72%), said the 2015/16 MDS survey had been completed for their service.

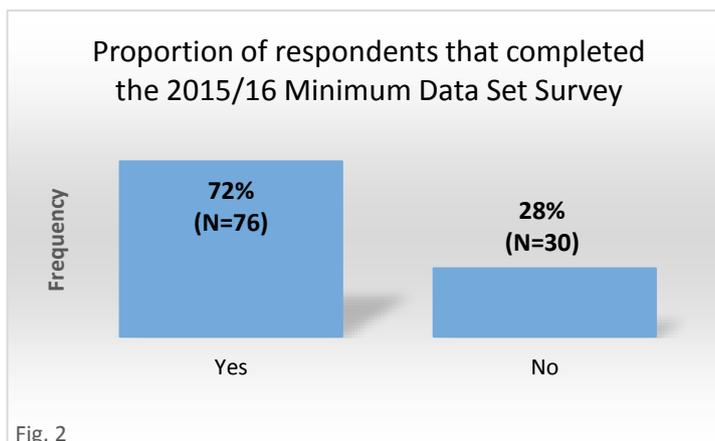


Fig. 2

c) Age of service

To get an idea of how established the services represented in this report are, we asked how long they had been running. We gave the choice of three options: Less than three years, three to nine years, 10 years or more.

One hundred and six of 108 survey respondents (98%) answered this question. The vast majority, 95 respondents (90%) said their service had been running for 10 or more years. Only three (3%) had been running for three years or less and eight (8%) for three to nine years.

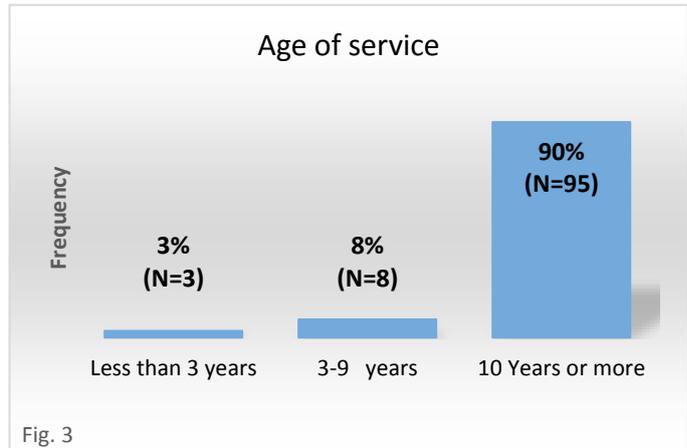


Fig. 3

d) Service description

We asked providers to give a description of the services they deliver. Ninety-nine of 108 total survey population (92%) gave a description in the free text box provided.

A word frequency search showed that 'community' was the third most frequently used word after 'care' and 'support'. Respondents described a wide range of services, which are shown in the word cloud below.

The descriptions showed that many of the services were provided by multi-disciplinary teams. The extract from respondent 32 shown in the text box is an example of the impressive range of professionals that make up some of the services represented in this report.

'The team provides specialist palliative care for patients and their family in their own homes, community hospitals and care homes. This is a multi-disciplinary service with clinical nurse specialist, specialist dietitian, physiotherapist, occupational therapist and social worker as well as sessions from a palliative medicine consultant. The team provides a 7 day service and SPC advice over the telephone is available for out of hours provision. We also have an end of life care team who support formal and clinically based education, including a facilitator for care homes who works directly with care home staff.'

(Respondent 32)



e) Number of individual patients who received SPC support

To get an idea of the number of patients who benefited from the services represented in this report during a one-year period, we asked how many individual patients they had supported between 1st April 2015 and the 31st March 2016.

'We are unable to give this data accurately, as data is recorded per team and the same patient may be involved with different teams at the same time.'

(Respondent 25)

Eighty-six of 108 total survey population (80%)

answered this question. However, the data highlighted differences in recording practices which meant that while some were able to provide patient only data, others were not. Free text information provided showed that some of the figures given included family members supported and others included children who received specialist palliative care. For the most part, these figures were not broken down, so the individual adult patient data could not be extracted.

Some providers supplied referral figures which means that individual patients referred to different teams within a service are counted multiple times. Similarly, some said they could not separate out individual patient data as each team within their service records patient data separately, again meaning potential duplication of numbers. Consequently we were unable to find out the number of individual patients seen in the specified timeframe.

Recommendation

SPC Providers should combine to assess the feasibility of establishing a unified approach to data capture that will enable the number of individual patients seen and the level of support delivered to be quantified, reported and understood.

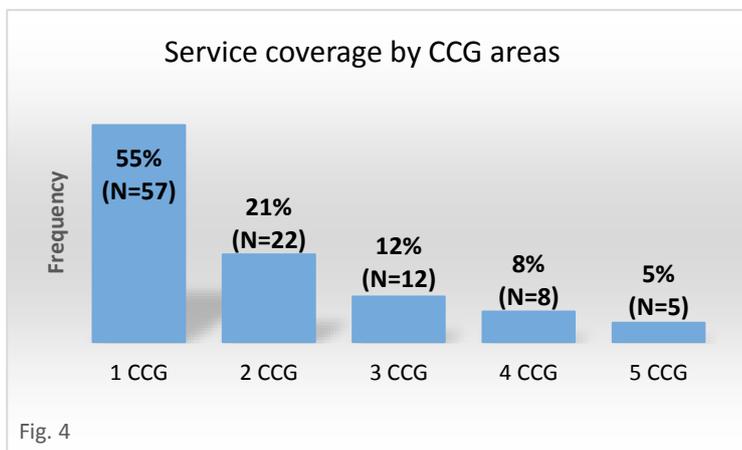
6. Commissioning

This section describes the commissioning arrangements of the services who participated in the survey.

a) Service coverage by Clinical Commissioning Groups

We were interested to know about the geographic area covered by the services who took part in the survey. We asked within which Clinical Commissioning Groups (CCGs) or Local Health Boards (LHBs) the services sit.ⁱⁱⁱ

One hundred and four of 108 total survey population (97%) answered this question.^{iv} Over half, 57 respondents (55%), said their service sits within one CCG boundary. 22 services (21%) sit within two CCGs and 12 services (12%) sit within three. 13 respondents (13%) said they cover an even wider area of four and five CCGs.



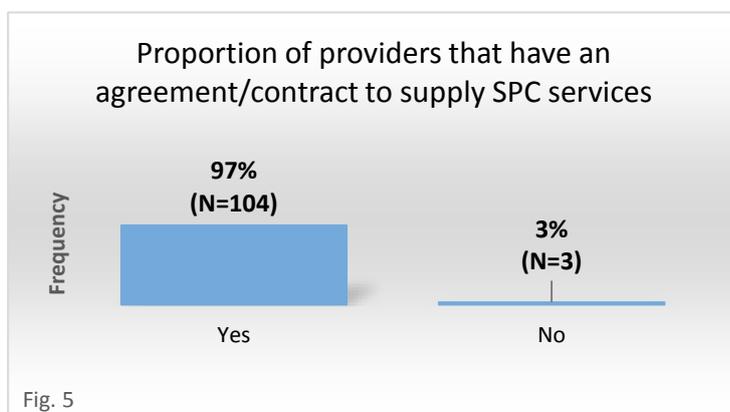
One service said that they operate across English/Welsh borders sitting in one CCG and one LHB. They are represented in the one CCG category in the graph.

b) General SPC service commissioning

We were interested to know what proportion of service providers who responded to the survey were commissioned to deliver SPC services in the community generally, as well as specifically for care homes.

We asked if the service providers had an agreement or contract with CCGs, LHBs or Local Authorities (LAs) to deliver general SPC services.

One hundred and seven of 108 total survey population (99%) answered this question. The vast majority, 104 respondents (97%) said they had an agreement or contract to supply general SPC services. Three (3%) did not.



ⁱⁱⁱ There are seven LHBs in Wales responsible for planning and securing the delivery of primary, community, secondary and specialist services in their area. Further information can be found at: NHS Wales (2017) *Our Services* [Online] Available at: <http://www.wales.nhs.uk/ourservices> (Accessed 21st June 2017).

^{iv} The CCG service coverage for the ambulance service discussed in section 4a was high due to the nature of the service and has not been included in the data.

c) Care home specific SPC commissioning

We asked what type of support providers were commissioned to supply to care homes, giving a choice of four options: Clinical support, education and training, other or none. Respondents could choose multiple options.

One hundred and two of the 104 providers (98%) who previously said they are commissioned to supply general SPC services answered this question.

Seventy-three of the 102 respondents (72%) who answered this question said they were commissioned to supply some kind of SPC services to care homes however, 29 (28%) were not.

Fifty-seven of the 102 respondents (56%) said they provide clinical support and 51 (50%) said they deliver education and/or training. 12 (12%) indicated that they provided 'other' services.

Forty respondents (39%) said they provided a combination of clinical support and education/training. A full breakdown of the combinations of types of SPC services commissioned can be seen in Appendix 1, Table 8.

Although 28% of the sample (29 respondents) said they are not commissioned to supply services to care homes, eight providers used free text to explain that lack of specification of care homes in contracts and agreements was irrelevant and support was willingly given and driven by patient need. Respondent 79 wrote:

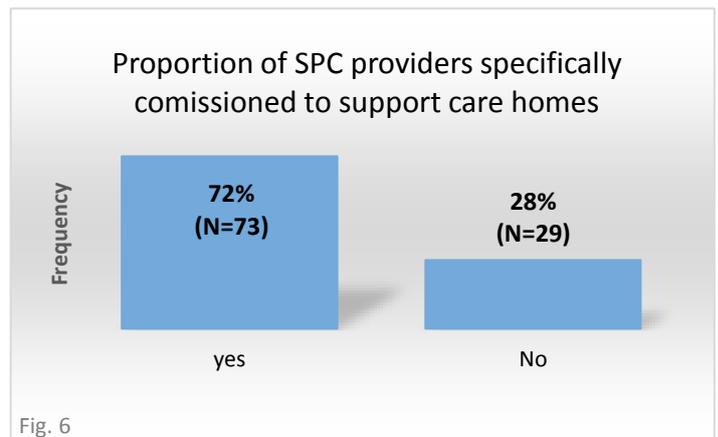


Fig. 6

'[...] Our Service Level Agreement with [the] CCG is not specific in relation to what care and support is provided and in what environment. As a Hospice, we would support the patients and families irrespective of whether it was funded/commissioned or not.'

(Respondent 45)

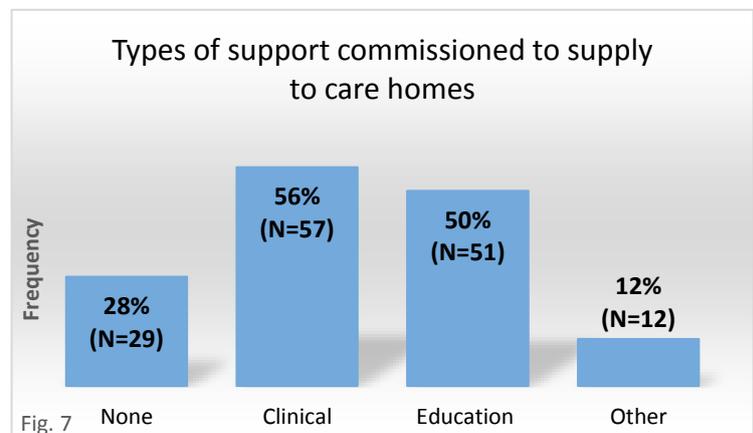


Fig. 7

'There is no specific clause in the contract that we have to provide community palliative care services to nursing homes. However we believe our remit is to provide palliative care support/services to the community and that includes care homes.'

The extracts from respondents 79 above and 21 (see text box) suggest the ethos of person-centred care, where the needs of the individual person are met by providing more flexible services that meet people's needs rather than the needs of a service,⁽¹⁴⁾ is becoming increasingly embedded in SPC practice. This may be reflected in limited mention of care homes in SPC commissioning.

A point to consider however, is that between 19% and 25% of all deaths in England are of care home residents.⁽¹⁵⁾ Whilst a proportion of residents who die in care homes will require generalist rather than specialist palliative care, the high mortality rate in this setting suggests that in relation to care homes, place of care may be considered an important factor for service commissioners. Further exploration of the significance and appropriateness of specific mention of place of care in commissioning would therefore be beneficial.

Recommendation

Commissioners should target SPC funding and support to care homes and residents through specification of this care setting in contracts and agreements where appropriate.

'The contract with the CCG is very 'woolly'. It is not known what level of input we should give.'

(Respondent 1)

'There is no specific contract to provide care to patients in care homes. The patients in care homes are treated the same as if they are in their own home, i.e. they are referred to our service based on need. The hospice will provide care and support to patients in care homes that meet the hospice referral criteria. [...].'

(Respondent 21)

d) Description of 'other' SPC services commissioned to supply to care homes.

Whilst only 12 of the 102 survey respondents who said they are commissioned to supply SPC services specifically to care homes chose the 'other' service option, 24 (24%) used the free text box to give a description of the 'other' support they are commissioned to provide to care homes.

Eight responses were excluded, as they described clinical support or education/training, options they had already chosen from the category list. From the remaining 16 responses, six 'other' categories were found.

Four respondents described their 'advice service' where they offer SPC advice to care home staff and in some cases also GPs. Two respondents mentioned 'practice development support' and two wrote of their participation in a 'care home forum' with one explaining this is to update care home managers of local and national developments. 'Advance Care Planning', 'bereavement support' and 'social work support' were each described as an 'other' option by one respondent.

As mentioned previously, eight providers used the free text box to explain that their service supports care homes, although they are not specifically mentioned in their contract or agreement.

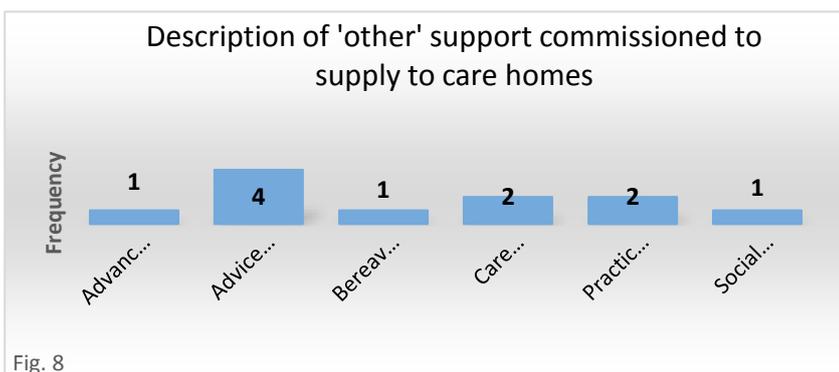


Fig. 8

'The support we provide within nursing and residential care homes is only a partly commissioned service within the block contracts we have with our CCGs. So all services provided by the care home team are not fully funded by the local CCGs, but also rely on our own income generation streams provided by our fundraising team.'

(Respondent 28)

e) Contracts and agreements for SPC services to care homes

We asked what type of contracts or agreements providers are commissioned to supply to care homes, giving a choice of five options: Service level agreement, NHS standard contract, block contract, other or not specified. Respondents could choose multiple options.

Sixty-nine of the 73 survey respondents (95%) who previously said they are commissioned to supply SPC services to care homes answered this question.

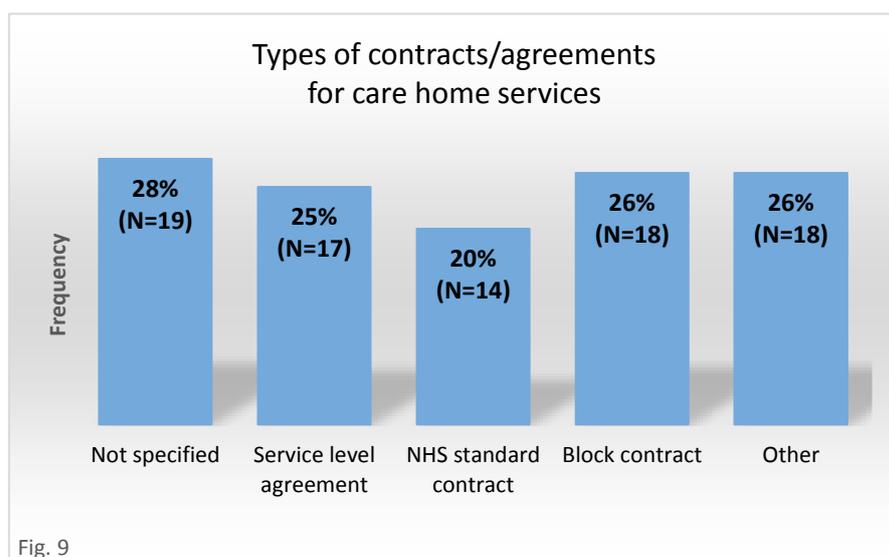


Fig. 9

'Not specified' was most frequently reported with 19 respondents (28%) choosing this option. 'Block contract' and 'other' categories each were chosen by 18 respondents (26%). This was closely followed by 'service level agreements' with 17 responses (24%). NHS contract was least prevalent with 14 providers (20%) choosing this option.

Three respondents chose 'not specified' as well as one or more other categories which suggests the specification of care homes in contracts is variable in their area.

See Appendix 1, table 11 for a breakdown of contracts/agreement combinations.

f) Description of 'other' contracts and agreements for SPC services to care homes

Despite the fact that only 18 respondents previously chose the 'other' option, 29 of the 87 respondents who answered the question on contract types (33%) gave information in the 'other' free text box.

'We only receive part-funding from the CCG, therefore the services we provide to support care home residents and staff is partly commissioned by us, the hospice.'

(Respondent 62)

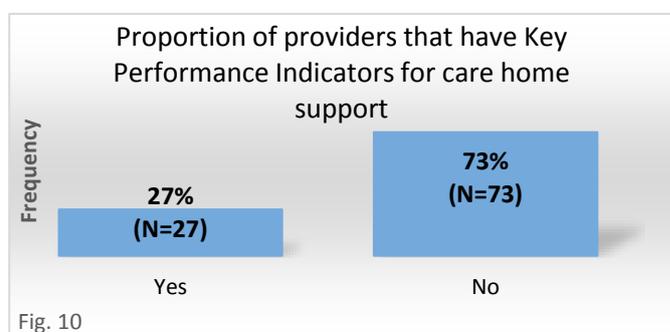
Three 'other' options were listed, 'Joint commissioning/dual funding' being the most frequent with five references. 'CCG service specification' was mentioned three times and 'non-recurrent funding' once.

Five respondents used the free text box to explain that they are not specifically commissioned to provide support to care homes. Three had previously made a similar comment, meaning in total, 10 respondents drew attention to non-specification of place of care in commissioning.

g) Key Performance Indicators for SPC services in care homes

We wanted to learn more about if and how providers measure their performance in relation to the support they give to care homes and residents.

We asked providers if they had Key Performance Indicators (KPIs) for their work with care homes. ^v Ninety-nine of the 108 total survey population (92%) answered this question. Twenty-seven of them (27%) said that they do have KPIs for the services they provide to care homes. Almost three quarters (73 respondents/73%) said they did not.



^v KPIs are metrics focused on key dimensions of performance used to measure how well organisations/services are performing against their strategic goals and objectives. More information can be found at: Advanced Performance Institute (2017) *What is a Key Performance Indicator (KPI)?* [Online] Available at: <https://www.ap-institute.com/what-is-a-key-performance-indicator> (Accessed 21st June 2017).

h) Example KPIs for SPC services in care homes

We asked providers to give examples of their KPIs for the services they deliver to care homes and residents. 35 providers answered this question, eight more than the 27 who said they had KPIs for care home support.

Analysis of the data resulted in three performance indicator themes being coded: 'Activities', 'Outputs' and 'Outcomes'.

'Activities' which relate to what services do, e.g. to provide clinical support or education, were least cited with 14 references.

'Outputs' which are concerned with what is delivered, e.g. number of referrals, number of visits, number of telephone calls, were found to be the most prevalent form of KPI with 31 references.

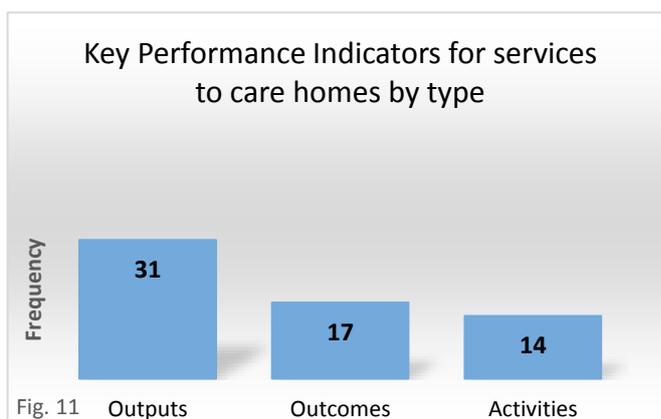
'Outcomes' which focus on measurable change due to the service intervention, e.g. Reduction in unplanned hospital admissions, patients able to receive preferred choice of care and preferred place of death, were mentioned almost half as much as outputs with 17 references. This may be because there is an assumed relationship between the two, with outputs being used as a proxy measure for outcomes. For example, one might assume that discussion with patients about Advance Care Planning and the number and the proportion of completed Advance Care Plans where patient wishes are recorded, might translate into the patient achieving preferred choice of care and preferred place of death.

Whilst literature suggest outcomes reporting in SPC may still be in its infancy,⁽¹⁶⁾ it is noteworthy that analysis of the outcomes data showed that patient and family reported outcomes was referenced just three times.

NHS England Statutory guidance on patient and public involvement in the commissioning of health services maintains that patients and carers should be involved in a meaningful way in assessment of care as well as its design.⁽¹⁷⁾ The lack of mention of such reporting may warrant further investigation.

Recommendation

Commissioners and providers review SPC service performance measures to ensure, where appropriate, patient and carer reported outcomes are included.



'70 within catchment area - infinite number possible with Gold Standards Framework Care Home programme, as homes can be out of catchment.'

(Respondent 46)

'Difficult to quantify as individual care homes, but we do provide bespoke training if requested and care homes in our locality are encouraged to use the hospice as a point of contact for guidance, which in turn at some point may generate visits.'

(Respondent 106)

'Outcomes have not historically been included in the range of data collected about SPC, but our view is that commissioners should, over time, adopt assessment measures (both process and outcome), in collaboration and discussion with providers, so that the most accurate 'tools' are used to both reflect the activity that has been commissioned locally and to measure the value and impact of SPC (not

i) Number of care homes supported

To get an idea of providers care home workload, we asked them how many care homes they support. Seventy-eight of the 108 total survey population (72%) answered this question.

The data showed the range of number of care homes supported by respondents' services was wide with between four and 294 being cited. The average number of care homes supported was 51, the median was 35. However caution should be used when interpreting this data due to the limitations described below.

Free text information provided by respondents showed that some supplied the number of all care homes that could potentially be supported by their service, while others gave the number they were actually supporting. Some made distinctions between the number of homes supported through their educational and clinical support roles, which means there may be some double counting.

To mitigate these limitations in the future, a one year past time frame should be given so that the numbers actually supported in that period can be counted and relevant data supplied.

'We use an electronic database called SystemOne. This is also used by many GP practices and is used by our local community nursing service [...]. Details of initial referral are stored, as well as ongoing records of clinical assessments and treatment plans for each patient. Details of every visit and phone call are recorded. We are able to produce reports detailing the number of visits and phone calls made regarding care home residents.'

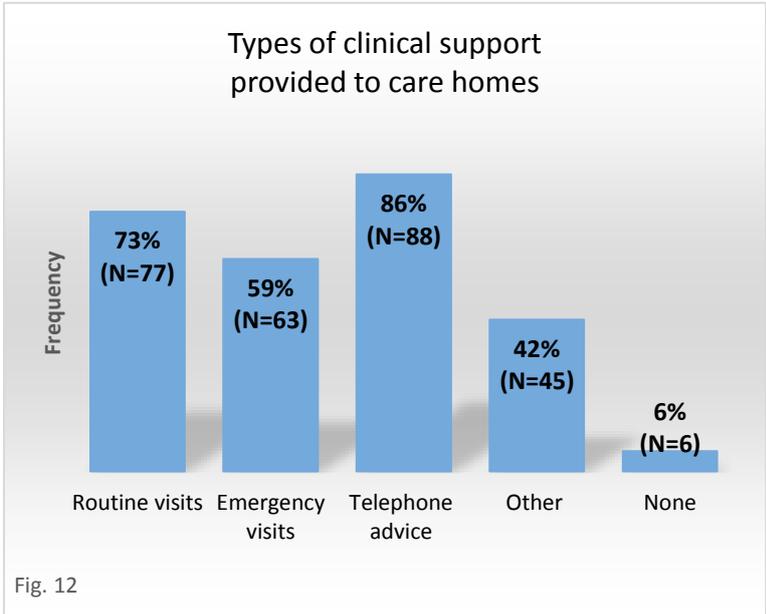
7. Clinical support

This section describes the clinical support provided to care homes and residents by the services who participated in the survey.

a) Types of clinical support provided to care homes/residents

We asked what type of clinical support was supplied to care homes giving a choice of five options: Routine visits, emergency visits, telephone advice, other or none. Respondents could choose multiple options.

One hundred and six of the 108 total survey population (98%) answered this question, 88 of whom (86%) said they provided telephone support. Seventy-seven (73%) said they provided routine visits and 63 (59%) emergency visits. The 'other' option was chosen by 45 respondents (42%). Just six respondents (6%) said they provided no clinical support in care homes.



The data showed that 52 respondents (49%) offered a combination of routine visits and emergency visits with telephone advice. See Appendix 1, Table 17 for a full breakdown of the combinations of types of clinical support provided to care homes.

b) 'Other' clinical support provided to care homes/residents

Forty of the 45 respondents that previously chose the 'other' option provided free text information on the other clinical support they deliver.

Analysis of the data showed that education and training was most frequently cited with 16 references. Three respondents used the free text box to comment on the use of language in the survey regarding 'emergency' visits. Respondent 10 for example wrote: *'We don't use the terms routine or emergency [...].'* The other two respondents described 'urgent' visits setting them apart from emergency visits. Seven respondents described the provision of 'domiciliary/home visits' on request. These unscheduled visits could be considered different to routine and emergency visits. The creation of additional categories should therefore be considered if the survey is repeated in the future. A list of the 'other' clinical services identified and their coding frequency is shown in the table 1.

Table 1: Types of 'other' clinical support provided to care homes

	Frequency
Education/training	16
Domiciliary/home visits	7
Patient assessment/review	4
Symptom control	4
Hospice at home	4
In-patient service	4
Day services	3
Syringe driver support	2

c) Recording clinical support to care homes/residents

We asked providers what information they record about the clinical support supplied to care homes and residents. One hundred of the 108 total survey population (93%) answered this question.

As demonstrated by respondent 21's commentary below, recording appears to be an integral part of SPC work with services being required to use multiple recording methods:

'The clinical details are recorded in the hospice care plans and clinical notes. The visits are recorded in the patients care home care plan to be shared with other health care providers. Assessment summaries are sent to GPs and other relevant health care practitioners in the form of a clinical letter. Visits are recorded on the hospice database.'

'[...] in the home there are a variety of methods that the Hospice nurses use to record their intervention for each patient. Often they use the paper records that are in the care home, sometimes they have temporary access to the home's electronic system.'

(Respondent 100)

The majority of respondents mentioned digital records. Clinical software SystemOne was frequently referred to. Some providers drew attention to the fact that digital health record systems had enabled data sharing, allowing GPs and other health care practitioners to access patient data. The sharing of records between a hospice and health trust was also mentioned.

In some cases, providers said remote out of hours access to patient/carer information had been made possible through the use of digital records and platforms.

Whilst some providers use larger health care recording systems, others described in-house databases and systems. Some had recently gone 'paper light' or were in the process of implementing digital systems.

Many said they record information in care home records (paper and digital) with some saying they do this if needed or if the record is available. A number of providers commented on the need to extract information and duplicate records for care homes as there is no electronic data sharing or shared record between SPC providers and care homes.

Free text comments on the type of clinical information recorded highlighted 25 different activities which are shown in the word cloud below.



d) Number of care home residents supported

To get an idea of the number of care home residents who were supported by the services represented in this report during a one-year period, we asked how many individual patients on their caseload between 1st April 2015 and the 31st March 2016 were care home residents. We also asked them to break down the figures between residential and nursing homes.

The data available was limited, as only 52 of the 108 total survey population (48%) answered the question. Some providers could not supply the overall total. Some gave partial information on patients supported in each setting. Free text comments from a number of providers mentioned that nursing home data is separated, but that residential home data is not, which explains the difficulties of some in reporting by setting. Missing data were not imputed and the figures quoted reflect the available data.

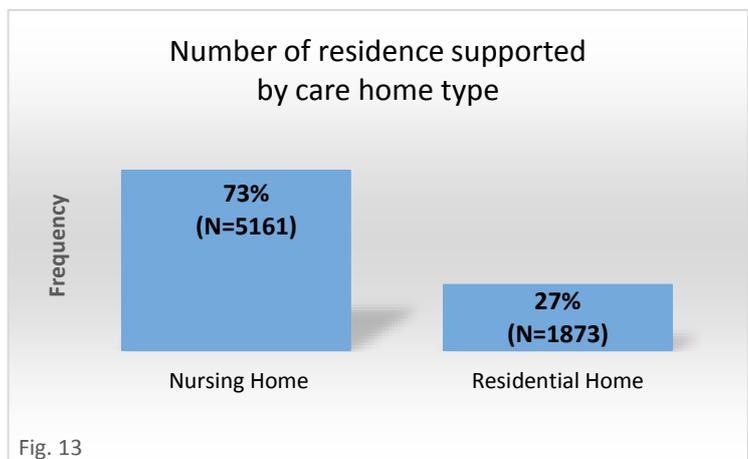


Fig. 13

'[...] our database does not distinguish between patient's home and care home.'
(Respondent 36)

The range of the total number of care home residents supported was large, with between two and 3180 care home residents supported in the specified period. The average was 230 the median was 113.

'Unable to provide this information as referrals are not differentiated between place of residence.'
(Respondent 47)

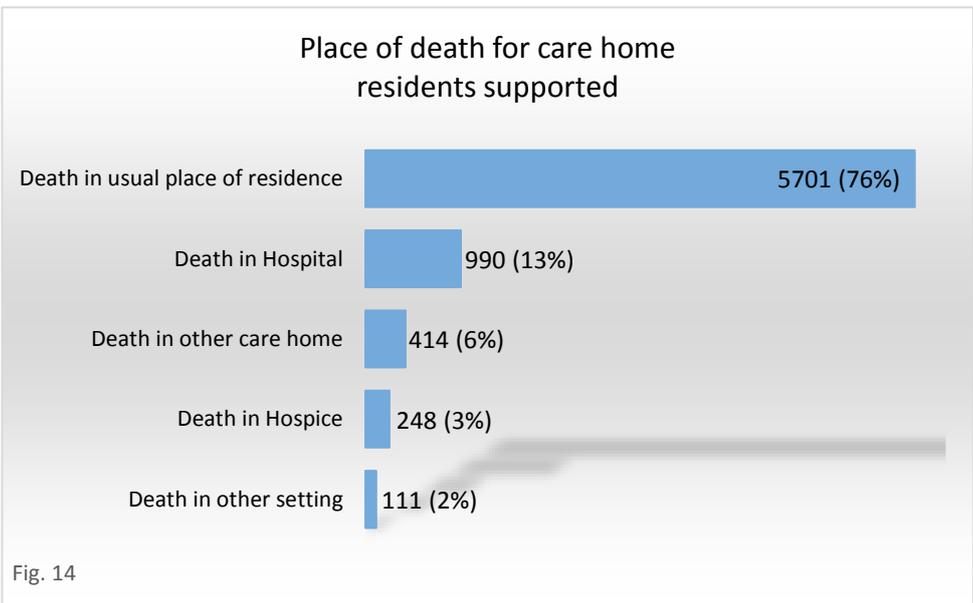
A total of 11,955 patients were identified by the respondents, yet only 7,034 were categorised as being a resident at either a nursing home or residential home without nursing. As shown in the graph, of the 7,034 patients that were categorised by place of residence, 73% (5,161) were shown to reside at a nursing home and 27% (1873) lived at a residential home. This indicates that approximately three out of four people supported in the given period were nursing home residents.

'The clinical support provided is documented via the patient electronic record. At present, we can identify nursing home visits however, residential care home visits are recorded as usual place of residence.'
(Respondent 52)

The data is somewhat limited by the amount of missing data and caution should be applied when interpreting these results. Free text information supplied by the respondents suggests that the high level of 'don't know' and missing responses may reflect providers recording habits. For example, factors such as the ability to identify nursing home residents more easily may influence the results. As previously proposed, future work focused on the recording and reporting of data may prove valuable in getting a better understanding of support offered to the care home community.

e) Care home resident place of death

To get an idea of the number of care home residents' deaths supported by the services represented in this report during a one-year period, we asked how many deaths supported between 1st April 2015 and the 31st March 2016 were of care home residents. We also asked them to break down the figures into place of death giving five options: Usual place of residence, other care home, hospital, hospice or other setting.



As with the previous question, the data availability was limited. Fifty-two of the 108 total survey population (48%) answered this question. Some participants could not provide the overall total and some participants only supplied some of the answers on specific place of death. Missing data were not imputed and the figures quoted reflect the available data.

In total, 7,464 deaths were reported. Albeit the data is not complete, hence there might be an underestimation of the number of deaths recorded, the data offers a good description of place of death over a one year period with 5701 deaths (76%) occurring at the patients usual place of residence and 990 deaths (13 %) in hospital.

As with the previous section, due to the limitations caused by the amount of missing data, caution should be applied when interpreting these results.

As before, free text information supplied by the respondents suggests the high level of 'don't know' and missing responses may reflect providers recording habits. Some examples of free text comments are shown in the quote boxes above. Commentary from respondent eight suggests that service providers may be willing to review and update their recording practices:

'185 - nursing home deaths only - residential home patients are counted as "home" for referral and death data.'

(Respondent 17)

'We cannot give this figure because we also provide a verification of death service out of hours for the locality and all these are recorded as part of our activity - and it would be too much work to lift them out of the total numbers.'

(Respondent 11)

'Unable to extract the data of the exact number of patients who were resident in a care/residential home under our care. [...] We will review our data capture going forward to enable extraction of identification of patients in care homes and their achievement or not of preferred place of death.'

Recommendation

Due to the data limitations, future work focused on the recording and reporting of data relating to support to care home residents is again recommended. SPC Providers should combine to assess the feasibility of establishing a unified approach to data capture that will enable the level of support delivered to care homes and residents to be quantified, reported and understood.

8. Education and training

84% of providers delivered education or training to care homes

This section describes the education and training delivered to care homes by the services who participated in the survey.

We were interested to know what proportion of the survey population provided education and/or training to care homes and so asked about the type of formal and informal education and training that was provided. By amalgamating the available data, we can see that 91 of the 108 total survey population (84%) said they delivered some kind of education or training to care homes. Further information about the formal and informal training provided follows.

a) Provision of formal SPC education and training

We asked providers if they supplied formal education to care homes, 104 of the 108 total survey population (96%) answered this question. Three quarters (78 respondents), said they provide formal training to care homes, 26 (25%) did not.

Some providers explained that their entire remit is education. Free text comments described some of the difficulties they had delivering training to care home staff. For example, respondent 25 wrote:

'Getting staff to formal sessions can be a challenge and we have had a large number of failures to attend. A member of the education team going to the care home for updates has been more effective although not sustainable.'

See section 9c for more information on education and training challenges.

b) Number of care home staff formally educated/trained

We asked providers how many care home staff they had formally educated/trained in a one-year period between 1st April 2015 and the 31st March 2016. Of the 78 survey respondents who previously said they provide formal education/training to care homes, 61 (78%) answered this question. The range of number of staff formally trained was between six and 1450. The average was 223 people the median was 120.

c) Description of the formal SPC education and training provided

We asked providers to describe the formal training that they delivered. Eighty of the 108 total survey population (74%) gave a description.

Fifty types of formal training were identified. Communication training, often focused on difficult/sensitive conversations, was most frequently reported with 53 references. Sage and Thyme communication skills training was frequently mentioned.

Other commonly listed subjects included syringe driver training (41 references), symptom control (37 references), Advance Care Planning (27 references) and recognition/verification of death or dying (27 references). See Table 2 for a list of the most frequently coded types of formal education and training.

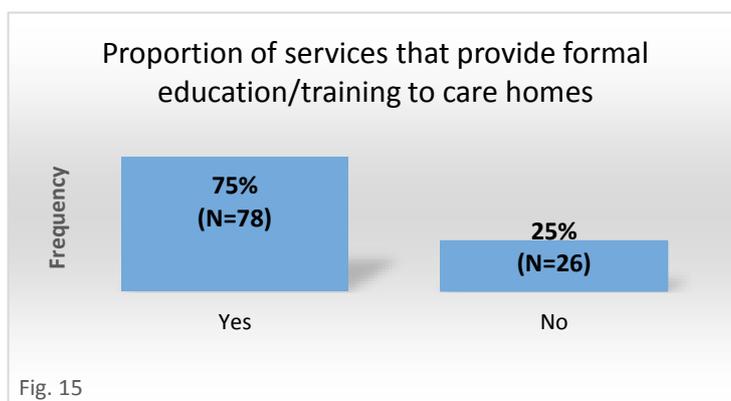


Table 2: Most frequently coded types of formal education/training*

Training provided	Frequency
Communication	53
Syringe driver	41
Symptom control/management	37
Advance Care Planning	27
Recognition/verification of death or dying	27
Grief, loss and bereavement /compassion/dignity and respect	22
Principles of end of life care	16
Six Steps/ABC	14
Dementia awareness	11
Spiritual and psychological care	10
Nutrition and hydration at end of life	7
Holistic Assessment	4
Mental Health Act/ Deprivation of Liberty Safeguards (DoLS)/ Mental capacity assessment/ Best interest decision-making	3
Managing breathlessness	3

*Coding frequency of 3 or more.

d) Provision of informal SPC education and training

We asked providers if they supplied informal education to care homes, 103 of the 108 total survey population (95%) answered this question. The vast majority, 91 respondents (88%), said they provided informal education and/or training to care homes, just 12 respondents (12%) did not.

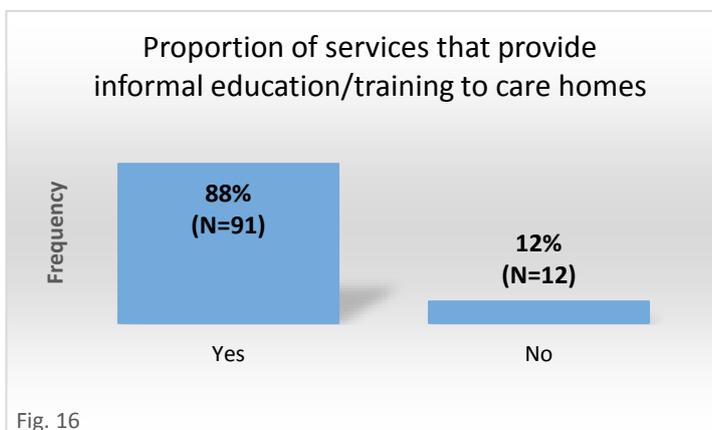


Fig. 16

e) Number of care home staff informally educated/trained

We asked providers how many care home staff they had informally educated/trained in a one year period between 1st April 2015 and the 31st March 2016. Of the 91 survey respondents that said they provided informal education/training to care homes, 38 (42%) answered this question. The range of number of staff informally trained was between three and 419. The average was 69, the median was 50. Some respondents said they did not record this type of information due to the informal nature of the education/training support.

f) Description of the informal SPC education and training provided

We asked providers to describe the informal training that they delivered. 90 of the 108 total survey population (83%) gave a description.

Respondents described informal education as 'on the job teaching' and 'learning by doing'. Respondent 61 described 'situated learning' that occurred during clinical review and the giving of advice for patients.

In total, 28 types of informal training were identified. Symptom control (33 references) and syringe driver training (20 references) were the most frequently coded types of informal training also featured high on the list of formal education and training.

A list showing the most frequently coded types of informal education and training provided is shown in Table 3.

'Informal education and training takes place during a schedule visit to a patient. It is difficult to quantify how often, numbers of staff supported or number of hours delivered. The informality of interaction facilitates care home staff to ask questions and discuss patients without constraint. CNSs consider this to be part of the work they do on a day to day basis.'

(Respondent 8)

'[...] our role is often informal, e.g. palliative care register meetings are all an education opportunity. [...]'

(Respondent 51)

Table 3 : Most frequently coded types of informal education/training*

	Frequency
1. Symptom control/management	33
2. Syringe driver	20
3. Recognition of dying	15
4. Advance Care Planning	13
5. Reflective/Debrief sessions	11
6. Bereavement support/difficult conversations	5
7. Communication skills	4
8. Oral care	3
9. Anticipatory medication	3

*Coding frequency of 3 or more.

9. Collaborative working and best practice

This section describes working relationships between SPC providers and care homes from a participating service perspective. It outlines the challenges and enablers to the delivery of SPC to care homes/residents and gives examples of best practice shared by providers through the survey.

a) Care home relationship rating

We asked providers to rate their working relationships with their care home community. We gave a choice of five options ranging from very good to very poor. One hundred and four of the 108 total survey population (96%) answered this question.

The relationship rating was predominantly positive with 86 providers (83%) saying they had either a good or very good working relationship with their care home community. A further 14 (13%) rated their relationship as satisfactory. In total four respondents (4%) gave a

'We have an excellent relationship with the homes but this has taken years to establish.'

(Respondent 87)

negative relationship rating of poor or very poor.

Care home relationship rating

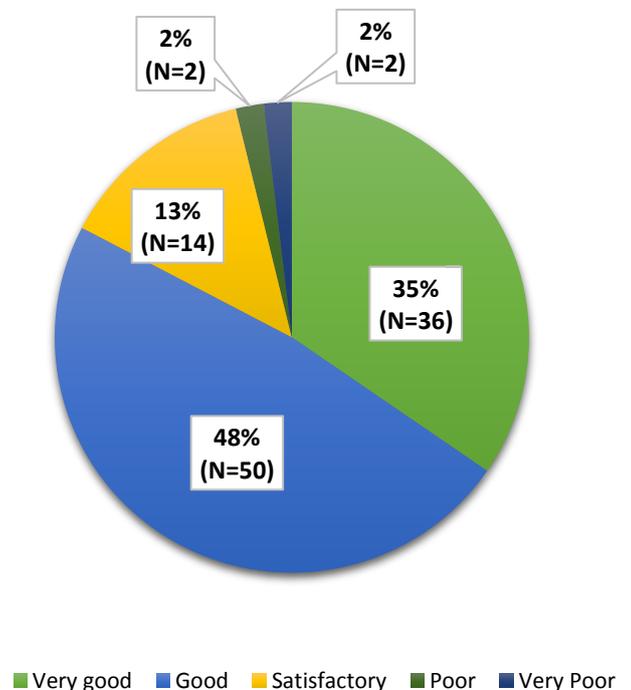


Fig. 17

b) Description of working relationships with care homes

Providers were invited to describe their relationship with their care home community, 95 of the 108 total survey population (88%) took this opportunity.

Most respondents described having a positive working relationships with care home managers and other staff. Although three made the point that this had taken a number of years to establish.

Three providers described an 'ad hoc' service to care homes where no formal ongoing relationship had been established, another (Respondent 79) described a positive but passive relationship: *'Good when we are approached by the care home. At present we do not actively approach nursing homes to provide support.'*

Others described the importance of care home forums in helping to develop relationships. For example, respondent 53 wrote: *'We have access via the council to the Care Home Forum and can discuss new developments or problems in a positive learning environment.'*

Some providers expressed the view that care home staff felt comfortable and confident in accessing advice and support services. The availability of 24/7 advice was thought to be a contributing factor.

Good communication links between care homes and education facilitators was thought to be important for positive relationships. Having a named person on both sides was believed to help achieve this.

One provider stated that it was impossible to build up continuous relationships with care homes as their service covered a vast area. Other factors that were effecting the quality of relationship with care homes were mostly associated with staff turnover and knowledge retention. This is discussed in more detail in the following sections.

'Well established, mutually respected relationship. We work intensely with a few homes at one time, as is their educational and clinical need. End of life care champions are established and once confident, our educational and mentoring input is minimal. The homes contacting us as and when they need us. The facilitator maintaining links with the champions and managers. [...].'

(Respondent 100)

'We have noticed care homes are caring for more complex residents. Staff turnover in our local care homes remains high.'

(Respondent 62)

c) Challenges and barriers to providing SPC support to care homes

We asked providers to tell us what they believed were the main challenges and barriers to providing clinical support, education/training or other support to care homes. One hundred of the 108 total survey population (93%) answered this question. A table showing the most frequently coded items is shown at the end of this section.

Staff Turnover

Coding of the free text showed that ‘Staff turnover’ was most frequently mentioned as a challenge to supporting care homes (67 references). This included the turnover of care staff and clinical staff in residential and nursing homes. Some respondents specifically mentioned the frequent changes in care home managers.

Staff turnover and ‘staffing levels/shortages’ (20 references) were thought to be key factors impeding care home staff ability to be ‘released to attend education and training’ (40 references).

Staff turnover was thought to also impact on the ‘retention of knowledge, skills and competencies’ in care homes (18 references). Providers said the transient workforce made it difficult to create a stable learning environment and that: *[...] Continually changing staff, especially Home Managers, makes sustainability of a consistently good standard of end of life care very difficult to achieve [...]* (Respondent 93). Difficulties in maintaining staff competency in using syringe drivers due to occasional use was also mentioned.

Some providers described low morale among care home staff as a barrier. Respondent 93 wrote:

[...] Poor morale amongst managers and all levels of staff - areas of concern raised in the safety and confidential environment of the teaching room, describe consistently working with poor staffing levels and the frustration caused by being unable to practice the standards they would like. Poor care of staff themselves.’

Funding

‘Funding’ was thought to be a challenge by many (27 references), with a number of providers mentioning the lack of funding/commissioning for education and training which meant some provide it ‘if they can’. Respondent 65 believed lack of education commissioning meant that the coverage of education was ‘patchy’ and ‘inconsistent’.

‘The ever changing nature of the care home workforce means that staff education and upskilling is a challenge, as staff gain skills and then are lost to other employment sectors. Staffing levels in care homes also make it extremely difficult for staff to be released for training which makes the traditional model of staff education in a taught session extremely difficult. This requires a more flexible and creative approach which some find challenging e.g. using technology as a solution.’

(Respondent 89)

‘Resources and investment - ongoing funding to recruit staff to deliver training, but guaranteed funding and investment to ensure education roles are sustained. We have managed funded facilitator posts [...] They work really hard with different professionals and achieve such a lot through delivering training, to enhance the delivery of end of life care. However, once the funding has finished, most of this good work falls away as there is no one providing the motivation, enthusiasm and ongoing support and advice to embed and sustain new practice.’

(Respondent 101)

Some perceived care homes to be reluctant to pay for formal education. Respondent 94 wrote of a *'conflict around charging for formal training.'* Respondent 23 wrote of the training challenges care home managers face: *'In nursing and care homes there is a huge turnover of staff, so it is hard for owners to know who to invest in, because what has been learnt will move on with that staff member [...].'*

Providers said that financial restrictions meant that care homes did not pay staff to attend training and so they had to attend in their own time.

Time

Time was thought to be a barrier, specifically 'lack of study time for care home staff' (12 References) and 'lack of time for SPC staff to provide education and training' to care home staff (8 References).

Attitudes

Lack of recognition of the importance of palliative and end of life training by managers and lack of commitment to training from care home staff generally were also recognised challenges. These factors were thought by some to be reflected in the lack of staff motivation to participate in training as well as their poor attendance.

'High staff turnover means we cannot build on training already given, as the new staff need to start from scratch. Language and cultural differences can be a challenge. Some staff state in their own culture they do not talk to the patients about dying and decisions are made by the relatives. This is contrary to our teaching and confidentiality requirements.'

(Respondent 6)

Developing relationships with care home staff and 'engaging care home owners' were cited as obstacles to collaborative working by some (7 references). Lack of care home manager buy-in was also mentioned. 'Care home culture' was another challenge (7 references). Provider comments included the view that some care homes are reluctant to change working practices or take a proactive approach to planning and the delivery of care.

Language and cultural differences

'Language and cultural differences' were cited by many as a challenge (15 references). Two factors were dominant: Language barriers due to English being spoken as a second language by care home staff, and the implications of different cultural beliefs around death and dying on Advance Care Planning. Respondent 52 wrote: *'[...] Cultural barriers in end of life care - for example many cultures struggle with Advance Care Planning [...].'*

GP support

The 'provision of appropriate GP support' was thought by some to be a barrier to providing timely appropriate care to care home residents (7 references). Issues with out of hours GP support and multiple GPs visiting individual care homes were specifically mentioned as problematic.

'Variable GP support to care homes. Multiple GPs covering one care home which leads to less pre planning. Out of Hours GPs tend to send care home patients directly to hospital. Not all boroughs use Electronic Palliative Care Co-ordination Systems.'

(Respondent 94)

A list of the most frequently coded challenges to providing SPC support to care homes is shown in Table 4.

Recommendation

As the challenges described are those perceived by SPC service providers, further research is needed with care home staff to examine their perspectives on this subject.

Table 4: Most frequently coded challenges/barriers to providing SPC support to care homes.*

Challenge	Coding Frequency
Care home staff turnover	67
Releasing care home staff to take part in Education/training	40
Lack of funding	27
Care home staffing levels/shortages	20
Care home staff knowledge, skills and competency retention	18
Care home staff language and cultural differences	15
Lack of study time for care home staff	12
Developing, Managing and sustaining relationships	10
Lack of time for SPC staff to train/educate care home staff	8
Engaging care home owners	7
Care home culture	7
Provision of appropriate GP support	7
Building relationships	7
Care home staff commitment to training	7
Creating a stable learning environment	6
Poor attendance at training	6

*Coding frequency of six or more.

d) Care home SPC support enablers

We asked providers to tell us how the challenges and barriers they had identified could be reduced or resolved. 91 of the 108 total survey population (84%) answered this question. See Table 5 at the end of this section for a list of the most frequently coded enablers.

Funding

'Increased funding' was most frequently coded as an enabler (20 references). The dominant theme here was around more funding and commissioning to pay for dedicated SPC staff to work with care homes, particularly in relation to the provision of education and training.

Providers said a different approach to funding could help improve continuity of support. Suggestions included having a 'joined up strategy and funding', 'centralised' and 'longer-term' funding.

One respondent said a commissioned system of lending and support from the district nursing teams may be helpful in supporting care homes with equipment costs for syringe drivers which care homes are reluctant to absorb.

Making funds available to care homes to pay for additional staff to cover those on training was thought to be a way to increase their support and engagement with education and training. Proposals for ways to incentivise care home staff to attend training included: giving staff paid time away from work to develop and train, and the implementation of pay structures that reflect qualifications.

Improved pay and conditions to better reflect the responsibility and value of care and nursing roles in care homes was also thought to be a way to reduce staff turnover.

'Dedicated support achieves positive outcomes not only for patients and their family but for staff also. Care Home staff value support in assisting them to 'get it right' they become confident and often flourish [...].'

(Respondent 51)

'Greater recognition and long term investment by CCGs is needed to ensure education within palliative and end of life care is sustained so that everyone in the community is able to access the best level of palliative and end of life care irrespective of where they are being cared for.'

(Respondent 101)

'Hospices could be commissioned to provide core end of life care training to care home staff both qualified and unqualified. Care Homes could be incentivised to send staff on training courses. This could include payment to care homes to provide back fill for released staff. It could also be a Kite Mark to demonstrate that the care home has a high percentage of appropriately trained staff from a recognised training organisation.'

(Respondent 8)

Some providers believed that the attainment of knowledge, skills and qualifications in palliative and end of life care could not only improve quality of care but also care home staff retention and morale. Describing the potential positive impact of education, respondent 100 wrote:

'No education is ever wasted and the staff carry that education with them, often to another care home, spreading the awareness of the need for education. If staff receive education, it helps them feel valued, respected and effective in their practice, affecting staff morale, the care home atmosphere and staff retention. This all impacts on the quality of care given. Education can affect the efficiency of the care given, maximising the staff resource [...].'

Mandatory core competencies

It was proposed that agreement amongst palliative care providers on the core components of training needed by staff to deliver appropriate SPC support to care home residents would be helpful.

'Mandatory education/training' was often put forward as a solution to the challenges around uptake of education and training in care homes (12 references). Specifying a minimum end of life education/training requirement in service specifications, contracts and inspection criteria

was thought to be a good way of encouraging care home owners/managers to prioritise end of life training. Respondent 46 wrote:

'The CCG/Care Quality Commission could perhaps insist, via some form of service level agreement/contract that attendance to such training is essential and that care homes are not allowed to advertise they provide end of life care if their staff have not received the correct training to do so.'

(Respondent 47)

'Increased use of quality control measures e.g. contractual arrangements through commissioned places and Care Quality Commission inspection reporting to compel care home owners to ensure at least a fundamental level of competence amongst their staff.'

Increased collaboration

A number of comments on 'cross-organisational collaboration' related to how joint agreements or approaches to commissioning/contracting of services could improve education/training take-up (15 references). These included partnership working between SPC providers and local authorities who commission care home places to encourage amendments in contractual arrangements, and joint agreements between Local Authorities and commissioners regarding the content of care home contracts. Other proposed collaborations included: SPC educators in a given area taking a unified approach to education/training instead of working in isolation, and improved collaborative working between NHS and care home staff. Support to help care homes connect and learn from each other was also mentioned.

There was some emphasis on approaches that could facilitate improved GP support to care homes. Suggestions included: the development of positive relationships with GPs, a focus on educating GPs, working with commissioners to find new and more effective ways of allocating and contracting GPs to care homes.

Accessible training

The provision of 'accessible training' was coded 13 times. Ways in which providers thought SPC education and training could be made more accessible to care home staff included: adapting the content of training to the particular needs of care home staff (including adaptation of materials), visiting regularly to offer support, training all staff (qualified and unqualified), identifying key members of staff to be 'end of life champions' and cascade education and training to colleagues, offering practice-linked or on-the-job training, working one to one

with staff to meet individual learning needs where required and increased use of technology such as 'bite sized' downloadable education.

Locating education and training sessions in care homes was thought by several providers to be a way to make them accessible to staff. Describing 'situated learning' respondent 61 wrote: *'[it] works well. For example, going to the care home and working with the staff, or doing bespoke education sessions with the staff while 'at work' [...].'*

In contrast, respondent 104 wrote: *'[...] delivering in house education is difficult because people get called out of the session for various reasons. [...] I feel it is more successful to be able to bring staff out of the care home environment so that they are free from work interruptions.'*

Regulation and promotion of best practice
Some providers said there should be better regulation of care homes. For example, respondent 31 believed that the Care Quality Commission's approach to inspections could be improved: *'Better type of CQC inspections which encourage, rather than demoralise.'* Similarly suggesting an appreciative approach to change, providers proposed 'better recognition and promotion of good practice' in end of life care in care homes. Respondent eight suggested a 'kite mark' for those with a high percentage of appropriately trained staff.

'Through the sessions, staff come to realise that end of life care is everyone's remit and increases their confidence in providing such care - staff are sometimes demotivated at the start of the programme, but quickly become interested. Any disinterest at the second /third session is challenged privately, to see if there is a reason. This has highlighted things such as them feeling uncomfortable with death/dying and not understanding their role. These have then been addressed and a way forward found - 1:1 help for those with reading and writing difficulties, support from their peers if appropriate, resources on specific coloured paper - Staff often leave to go to another home, we then contact that home to offer continuation of the passport training.'

(Respondent 20)

As with the previous section on challenges, further research with care home staff to gain their perspective on enablers to providing SPC support in the care home setting is recommended.

Recommendations

As core competencies are now available through the new End of Life Care Core Skills Education and Training Framework,⁽¹⁸⁾ it is recommended that SPC providers, commissioners and care homes work together to increase awareness and attainment of core competencies. They should determine the best way to deliver education and training to meet the needs of care home staff considering local challenges.

Furthermore, Clinical Commissioning Groups and Local Authorities should consider their role as commissioners of services in encouraging care homes to engage with SPC education and training. This could include working together and with care home owners and managers to explore the viability of improving care home engagement with SPC training through the specification of mandatory core competencies in contracts and agreements.

Table 5: Most frequently coded enablers to providing SPC support to care homes*

Enabler	Coding Frequency
Increased funding	20
Cross-organisational collaboration	15
Mandatory education/training	13
Accessible training	13
Better recognition and promotion of good practice	9
Dedicated SPC staff to work in care homes	6

*Coding frequency of six or more.

e) Best practice in SPC support to care homes

We asked providers to share any known examples of best/innovative practice in SPC support to care homes. Seventy-two of the 108 total survey population (67%) took this opportunity.

Clinical support

Examples of best practice in clinical support were frequent. The provision of nurses specifically dedicated to care homes was often highlighted as good practice. These included generalist nurses and Clinical Nurse Specialists (CNSs). Having a named CNS in care homes was thought to facilitate continuity of care. Some providers mentioned that dedicated nurses had been commissioned by their CCG.

Some providers described teams working with local care homes to prevent admissions to hospital, complete Advance Care Plans and review medication. Having link nurses and hospice staff working 'alongside' care home staff was thought to work well.

Domiciliary visits by SPC Consultants were thought to help prevent unplanned hospital admissions. The role of GPs working in partnership with care homes to develop Advance Care Plans and refer patients to hospice services where needs are complex, was highlighted. Alignment of GP practices to individual care homes was thought to be important. One provider said they had embedded a GP home round in some care homes and that they believed this model should be expanded.

'[Our] CCG have commissioned a Supportive Care Team of specialist nurses to go into care homes and work directly with staff to support identification of people in the last few months of life, facilitate Advanced Care Planning and undertake monthly ward rounds with staff. The [...] team liaise closely with the Hospice and transfer of care between specialist and generalist is supported. For example, if a CNS has been seeing a patient with specialist needs which are controlled and the patient no longer needs SPC input, the CNS will notify the Supportive Care Team, who will monitor the patient in collaboration with the care home. Transfer of care dependent upon patient need is supported and supports good communication and sharing of patient information between teams.'

(Respondent 8)

For those admitted to hospital, having staff in Accident and Emergency (A&E) tasked with identifying them as care home residents was thought to speed up their discharge. Respondent 11 Wrote:

'[...] having a member of staff in A&E to work with their staff, to look at patients who are sent in from Nursing Homes - to try and turn them around as fast as possible and to target those individuals and their primary care teams around advanced care planning [...].'

Respondent 62 described the role their service played in supporting care home staff when Treatment Escalation Plans were not sent home with patients on discharge from hospital. They also mentioned helping staff to develop personalised care plans for patients following the withdrawal of the Liverpool Care Pathway.

Similar to the provision of dedicated nurses, establishing dedicated SPC beds in care homes was highlighted as best practice. Two providers commented on this. Respondent 40 wrote:

'We were funded [...] to specifically run a pilot with a care home. The hospice used the funding to commission four end of life care beds in a home. We assessed patients and supported them, their families and staff on a daily basis. Education was provided before and during the pilot. A key factor was having a CNS in the building most days. The staff and local GPs felt the care of all residents improved, not just the ones in the beds commissioned by the hospice.'

Respondent 116 suggested that a focus on general end of life care, rather than SPC may be considered best practice in the care home setting. Describing a service delivered by a range of professionals (a manager, senior educator, staff nurse educators and a healthcare assistant educator) experienced in working in care homes, it was said that the team demystified end of life care and reduce emergency admissions to hospital.

'Perhaps the most innovative aspect of the service is that it does not focus on SPC, but on end of life care that generic services such as care homes can provide [...].'

(Respondent 116)

Respondent 21 also highlighted their role in supporting 'generalist end of life care' in care homes. They wrote:

'Nursing and care homes require more support for generalised end of life care than the hospice can provide. The hospice provides a monthly 'catch-up' clinic in certain nursing homes - an opportunity for the staff to discuss patients with the Palliative Care Clinical Nurse Specialist when they visit.'

Respondent 93 gave an example of how SPC staff, with experience of working in care homes and an understanding of the challenges they face, can engender trust. They described a member of the team who was a CNS with 'significant expertise in nursing home and palliative care settings'. They went on to write:

'An in-depth understanding of the challenges faced by nursing home staff is a huge advantage in facilitating professional links and trust to underpin the education. [...] A lot of work forging links with nursing home managers and staff to find out what they needed has paid dividends.'

Reflective practice was thought to reap positive results. Respondent 61 said that post death reflection had helped to improve care.

Respondent 51 explained how 'invaluable' embedding a palliative care register in each care home had been in facilitating appropriate referrals and signposting to their service: *'[...] having patients on the radar so to speak reduces crisis calls and fosters emergency care planning and patient and family discussions re end of life early on in the disease trajectory [...].'*

Similarly, describing referral practices, respondent 47 explained that anyone could refer to their community end of life service via a 'single point of access' telephone number.

Respondent 62 explained their Hospice at Home service had an early referral access route for people with learning disabilities. This allowed time to develop a relationship with the individual and his/her companions in the home before they required care in their last weeks of life.^{vi} Hospice at Home services were highlighted as best practice by a further three respondents however, specific examples were not provided.

'[...] anyone can refer to the end of life services (patients, carers, GPs, health care professionals, social care professionals and the voluntary sector). [...] The service is available 24 hours a day, seven days a week. The purpose [...] is to provide streamlined access to all community end of life care services.'

(Respondent 47)

Respondent 94 said they were in the process of replicating a 'red bag system' in care homes in their area. They explained that the red bag contains, amongst other things, key information about a resident's health so that it can be transported with them on admission to hospital. The red bag system was developed by one of six enhanced health in care home vanguards, which are leading the development of new models of care that offer joined up health, care and rehabilitation services to older people.⁽¹⁹⁾

Social work support

Examples of social work best practice were limited. One respondent believed alignment of Social Workers with care homes to be good practice. Another gave a brief description of a case where care home staff had been helped to provide best care for a resident with a complex social history.

Care home forums

Six providers highlighted Care home forums as an excellent way to share best practice and other information with care home managers and staff. Care home forums were thought to be a good place to discuss safeguarding and safety issues. Respondent five wrote: *'The care home forum, run by the safeguarding team, is a monthly meeting where new updates are shared with care home managers and any issues can be aired.'* Regular forum meetings were thought to enable SPC providers to deliver ongoing training and encourage networking between care homes.

'Our Care Home Forum is well attended and we have outside experts presenting such as the Coroner and Medical Director.'

(Respondent 113)

^{vi} Hospice at Home services provide nursing and supportive care in the community in collaboration with other health and social care providers to enhance the quality of life of patients and support carers and families. More information can be found at: The National Association of Hospice at Home (2017) What is a hospice at home? [Online] Available at: <http://www.nahh.org.uk/about-hospice-care/what-is-hospice-at-home/> (Accessed 21st June 2017).

Training initiatives

Links between the delivery of education, training and practice have been made by providers throughout this report. As an example of best practice, respondent 118 explained how a 'theory practice gap' had been bridged by the delivery of the Six Steps programme (see text box).

'[...]In relation to our Six Steps programme, success has been strongly associated with the facilitator working alongside staff in care homes, bridging the theory practice gap and providing supportive practice development.'

(Respondent 118)

Two other providers mentioned the Six Steps programme. Respondent 18 described it as a whole organisation approach to best practice that encourages innovation. Respondent 23 gave a detailed overview of the Six Steps programme:

'The Six Steps to Success programme aims to enhance end of life care through facilitating organisational change and supporting staff to develop their roles around end of life care. End of life care champions within a care home are supported by the Education Facilitator to develop their knowledge, skills and confidence, and are encouraged to empower other staff members [...] to deliver high quality End of Life Care that encompasses the philosophy of Palliative Care. The programme is designed to be delivered over a set period of time and consists of nine half day workshops, with additional support and advice over this period. These will include an introduction workshop, one for each of the Six Steps of the national end of life care pathway, a dementia workshop and a concluding workshop. Each session will embrace individualised patient care and communication as key elements [...].'

They also commented on the outcomes: *'[...] most areas on a national level that are delivering the Six Steps are able to demonstrate its effectiveness. We have had some very positive outcomes and need further investment.'*

Three respondents gave the use of the Gold Standards Framework Care Home training programme as an example of best practice. Respondent 22 wrote: *'The Gold Standards Framework Care Home programme provides a structured programme to help care homes develop their systems/processes to provide good quality end of life care for residents, improve collaboration and reduce hospital admissions.'* They went on to mention however, that recruiting care homes could be a challenge due to the cost, as well as issues with staff turnover.

The Namaste technique/programme for people with Dementia was highlighted as good practice by three respondents. One was piloting the technique, another offered Namaste training to care home staff. Respondent 100, wrote a moving third person account of the potential benefits of the Namaste technique to people with Dementia and their loved-ones:

'[...] one of the carers had told a visiting wife about Namaste and the wife asked her more about it. She told her how she had massaged her husband's hands, helped him with drinks and little pieces of fruit, and sat and hummed to the music as she held his hands. The wife was visibly moved that someone had done this for the man that she loved and had cared for until her health had deteriorated so much that she could no longer do this. She spoke of her burden of guilt and helplessness and her loss which she shares with her family. It is a little thing to honour a human being in a small way but the results are huge.'

Respondent 74 believed best practice is rooted in evidence-based practice development. They wrote: *'[...] we need to provide a research based model of cultural change. This costs to implement but saves money and so is a cost effective model [...].'* They went on to explain the hospice had undertaken research that informed the development of a dedicated care home team and a tailor-made model of practice. The research included an audit of bereaved family members views on the end of life care provided to their loved one. This type of outcomes reporting was shown to be limited earlier in this report. In this instance, the feedback from family members was said to have helped staff to develop end of life care and improve care provision. Positive comments served to boost staff morale.

A number of respondents accounts of education and training best practice included remarks on the speed at which it could be provided. Respondent 46 gave an example of how fast response to training needs can support quality of care to residents and reduce emergency admissions (see text box).

'The community and education teams have worked together if a care home is struggling to provide care for one of our patients because of lack of training. On several occasions, the education team have provided fast response to update / upskill staff to support clinical colleagues and prevent admission. On each occasion this was in response to nursing homes admitting residents with syringe pumps without the home having the resources / knowledge to manage this. Homes who have not previously invested in training their staff have been allowed a limited number of education sessions (usually 2) without charge before being encouraged to engage with our established programmes.'

(Respondent 46)

Technology

Technological innovation was highlighted by four providers. The specific examples of best practice given primarily focused on how technology can support learning. Respondent 41 said they had been piloting the delivery of virtual education to several care homes using telehealth technology. Respondent 87 described a web-based 'toolkit' that supports care home staff by providing information and up to date documentation. They wrote:

'We have been instrumental in developing an end of life toolkit on the internet which helps care homes identify suitable guidance and support on a variety of end of life subjects and also ensures that they have access to up to date documentation that is relevant to them and in use in their area. We have now added a learning portal to this resource which helps staff access education and training specifically tailored to their needs. The emphasis of this resource is to help save staff time by ensuring that they can access relevant and useful information and training easily. [...].'

Similarly highlighting technological innovation, one provider suggested looking at practice in Northern Ireland as an exemplar. Respondent 58 signposted to a knowledge-sharing network that is extensively used in Northern Ireland. They wrote: *'We anticipate the Project ECHO (Extension of Community Healthcare Outcomes) model will provide an innovative method of education delivery.'* This approach is said to utilise on-line video conferencing as a way to support the development of staff knowledge and skills in the care and management of residents with healthcare support needs.^{(20) & (21)}

Recommendation

Providers have shared many examples of challenges, enablers and best practice to inform future practice development. Further research is needed with care home staff to examine their perspectives on the challenges and enablers to providing SPC support in the care home setting.

10. Conclusion

The information and views shared through this report offer a snapshot of support in the care home setting in England. Although there were some limitations to the quantitative data, providers written accounts helped to identify weaknesses in data capture relating to care home residents. The richness of their free text contributions have in particular, enhanced our understanding of the challenges and potential enablers to the delivery of support from an SPC provider perspective.

Some of the identified challenges are not new and others, including the major issue of staff retention are endemic of a much wider problem in the health and social care sector. Providers written accounts described some of the ways they responded to locally identified challenges. Yet questions linger about what part commissioners can play in targeting support at care homes and encouraging them to engage with SPC education and training.

Despite all else, the constant thread running through the accounts is the willingness and professional imperative to enable and provide compassionate care. Their perspectives have influenced the development of the following recommendations for future work.

11. Recommendations

- SPC Providers should combine to assess the feasibility of establishing a unified approach to data capture that will enable the level of support delivered to care homes and residents to be quantified, reported and understood.
- Commissioners should target SPC funding and support to care homes and residents through specification of this care setting in contracts and agreements where appropriate.
- Commissioners and providers should review SPC service performance measures to ensure, where appropriate, patient and carer reported outcomes are included.
- SPC providers, commissioners and care homes should work together to increase awareness and attainment of core competencies. They should determine the best way to deliver education and training to meet the needs of care home staff considering local challenges.
- Clinical Commissioning Groups and Local Authorities should consider their role as commissioners of services in encouraging care homes to engage with SPC education and training. This could include working together and with care home owners and managers to explore the viability of improving care home engagement with SPC training through the specification of mandatory core competencies in contracts and agreements.
- Further research is needed with care home staff to examine their perspectives on the challenges and enablers to providing SPC support in the care home setting.

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13. Appendix 1: Data Tables

Table 1: Type of Service

	Frequency	Percentage
Specialist Palliative Care (SPCU)	33	31%
Hospice	72	69%
Total	105	100%

*Missing 3 (3%), (105/108).

Table 2: Number of respondents that completed 2015/16 Minimum Data Set survey

	Frequency	Percentage
Yes	76	72%
No	30	28%
Total	106	100%

*Missing 2 (2%), (106/108).

Table 3: Age of Service

	Frequency	Percentage
Less than 3 years	3	3%
years	8	8%
10 Years or more	95	90%
Total	106	101%

*Missing 2 (2%), (106/108). Percentage does not equal 100% due to rounding of figures to nearest whole number

Table 4: Service Coverage by Clinical Commissioning Group.

	Frequency	Percentage
1 CCG	57	55 %
2 CCG	22	21 %
3 CCG	12	12 %
4 CCG	8	8 %
5 CCG	5	5 %
Total	104	100%

*Missing 3 (3%), Excluded 1 (1%), (104/108). The CCG service coverage for the ambulance service discussed in section 4a was high due to the nature of the service and therefore has not been included. One organisation that sat across English/Welsh borders (1 CCG and 1 LHB) are represented in the 1 CCG category.

Table 5: Proportion of providers that have an agreement/contract with CCGs, LHBs or LAs for SPC services

	Frequency	Percentage
Yes	104	97 %
No	3	3 %
Total	107	100 %

*Missing 1 (1%), (107/108).

Table 6: Proportion of providers specifically commissioned to supply SPC services to care homes

	Frequency	Percentage
None	29	28%
Clinical/Education/Training/Other	73	72 %
Total	102	100 %

*Missing 2 (2%), (102/104).

Table 7: Types of support commissioned to supply to care homes

	Frequency	Percentage
None	29	28%
Clinical	57	56%
Education/Training	51	50%
Other	12	12%

*Missing 2 (2%), (102/104). Some providers chose multiple options so the total percentage exceeds 100%.

Table 8: Combinations of types of support commissioned to supply

	Frequency	Percentage
None	29	28%
Education/Training only	9	9%
Clinical only	15	15%
Other only	5	5%
Education/Training and Clinical	37	36%
Education/Training and Other	2	2%
Clinical and Other	2	2%
Education/Training, Clinical and Other	3	3%
Total	102	100%

*Missing 2 (2%), (102/104).

Table 9: Description of 'other' support commissioned to supply

	Frequency
Advance Care Planning	1
Advice service	4
Bereavement support	1
Care home forum	2
Practice Development support	2
Social Work Support	1

Table 10: Types of contracts/agreements for services to care homes

	Frequency	Percentage
Not specified	19	27%
Service level agreement	17	24%
NHS standard contract	14	20%
Block contract	18	26%
Other	18	26%
Total	86	123%

*Missing 4 (5%), (69/73). Some providers chose multiple options so the total percentage exceeds 100%

Table 11: Combinations of contracts/agreements for SPC support to care homes

	Frequency	Percentage
Service level agreement only	11	16%
NHS standard contract only	4	6%
Block contract only	12	17%
Other only	10	14%
Not specified only	16	23%
A service level agreement, NHS standard contract	4	6%
An NHS standard contract, other	3	4%
Any other combination of categories 1 to 5 above	9	13%
Total	69	99%

*Missing 4 (5%), (69/73). Percentage does not equal 100% due to rounding of figures to nearest whole number

Table 12: Description of 'other' type of contracts/agreements

	Frequency
CCG Service Specification	3
*Joint commissioned or dual funded	5
Non recurrent funding	1
Care home not specified	5

Table 13: Proportion of providers that have Key Performance Indicators for care home support

	Frequency	Percentage
Yes	27	27%
No	72	73%
Total	99	100%

*Missing 9 (8%), (99 /108).

Table 14: Key performance indicators for care homes by type

	Frequency
Outputs	31
Outcomes	17
Activities	14

Table 15: Number of Care homes supported

	N*	Minimum	Maximum	Mean	Median	Interquartile range
Number of care homes supported	78	4	294	51	294	21 – 74

*Missing 30 (28%), (78/108).

Table 16: Types of clinical support provided to care homes

	Frequency	Percentage
Routine Visits	77	73%
Emergency visits	63	59%
Telephone Advice	88	86%
Other	45	42%
None	6	6%

*Missing 2 (2%), (106/108).

Table 17: Combinations of clinical support provided to care homes

	Frequency	Percentage
None	6	6%
Routine Visits only	0	0%
Emergency Visits only	0	0%
Telephone Advice only	3	3%
Other only	6	6%
Routine and Emergency	1	1%
Routine and Telephone	17	16%
Routine, other	1	1%
Telephone advice, other	5	5%
Routine, emergency, Telephone	34	32%
Routine, Telephone, other	5	5%
Routine, Emergency, other	1	1%
Emergency, Telephone, other	9	8%
Routine, Emergency, Telephone, other	18	17%
Total	106	100%

*Missing 2 (2%), (106/108).

Table 18: Description of data available on the number of patients in care homes supported 1st April 2015 to 31st March 2016

	Total reported	Nursing Home	Residential Home
Available data	52 (48%)	42 (39%)	39 (36%)
Don't know	29 (27%)	17 (16%)	17 (16%)
Missing	21 (19%)	45 (42%)	48 (44%)

N/A	6 (6%)	4 (4%)	4 (4%)
Total	108	108	108

Table 19: Number of patients in nursing or residential homes supported 1st April 2015 to 1st March 2016

	Frequency	Minimum	Maximum	Mean	Median	Interquartile range
Care home patient caseload supported April 2015 – March 2016	52	2	3180	230	113	26 – 285
Number on caseload that were resident in nursing home	42	0	923	123	74	12 – 184
Number on caseload that were resident in residential home without nursing	39	0	304	48	19	9 - 63

* Missing data were not imputed. The figures above reflect the available data.

Table 20: Description of data availability on place of death for care home residents supported between 1st April 2015 and the 31st March 2016

	Total reported	Death in usual place of residence	Death in other care home	Death in hospital	Death in Hospice	Death in other setting
Available data	52 (49%)	48 (44%)	43 (39%)	43 (39%)	46 (42%)	43 (39%)
Don't know	28 (26%)	28 (26%)	30 (28%)	31 (28%)	27 (25%)	29 (27%)
Missing	24 (22%)	27 (25%)	30 (28%)	29 (27%)	30 (28%)	31 (28%)
N/A	4 (4%)	5 (5%)	5 (5%)	5 (5%)	5 (5%)	5 (5%)
Total	108	108	108	108	108	108

Table 21: Proportion of respondents that provide some kind of education/training to care homes

	Frequency	Percentage
Provides some kind of training	91	97%

*No missing as data amalgamated from responses to two questions, (91/108).

Table 22: Proportion of respondents that provide formal education/training to care homes

	Frequency	Percentage
Yes	78	75%
No	26	25%
Total	104	100 %

*Missing 4 (4%), (104/108).

Table 23: Number of staff formally educated/trained between 1st April 2015 and the 31st March 2016

	Frequency	Minimum	Maximum	Mean	Median	Interquartile range
Number of care home staff formally trained	61 (78%)	6	1450	233	120	50 - 300

* Missing data 5 (6%), N/A 1 (1%), Don't know 11 (14%), (61/ 78).

Table 24: Proportion of respondents that provide informal education/training to care homes

	Frequency	Percentage
Yes	91	88%
No	12	12%
Total	103	100%

*Missing data 5 (5%), (103/108).

Table 25: Number of care home staff informally educated/trained

	Frequency	Minimum	Maximum	Mean	Median	Interquartile range
Number of care home staff informally trained	38 (42%)	3	419	67	50	15 - 100

*Missing data 11 (13%), Don't know 42 (43%), (38/91).

Table 26: Care home relationship rating

	Frequency	Percentage
Very good	36	35%
Good	50	48%
Satisfactory	14	13%
Poor	2	2%
Very Poor	2	2%
Total	104	99%

*Missing data 4 (4%), (104/108). Total percentage does not equal 100% due to rounding of figures to nearest whole number.