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

Acknowledgements

Thank you

Our sincere thanks goes to the specialist palliative care staff who made this report possible by completing the survey.

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Coordinating Centre

Commissioned by

Published on behalf of the End of Life Care Board for Wales by

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1. Background and rationale

The population of Wales is growing but it is also aging. In 2016 over 21% of the Welsh population was aged 65 and over. This will rise to almost 25% by 2026 and reach in excess of 28% by 2036. [1]

As health often declines with age,[2] health and social care services will need to adapt to meet the changing demand of a growing older population.[3] The provision of high quality care is therefore an important topic for care providers and commissioners in Wales. This may be particularly important in areas where the older population will be greatest. In Powys for example, those aged 65 plus are expected to account for 37.8% of the population by 2036. [1]

There are over 22,217 older adult resident care home places in Wales. [4] The most recent Census (2011) showed 76.5% of care home residents in Wales were aged 65 plus and four in 10 residents (44.9%) were age 85 or over,[5] a group likely to be more vulnerable to conditions requiring high levels of support.[2]

The proportion of the population dying in care homes is growing.[6] Sixteen percent of all deaths registered in Wales during 2016 took place in a care home[7] yet, this figure does not acknowledge those residents who received palliative and end of life care in a care home before being transferred to another setting, such as hospital, and dying there. With such a high proportion of deaths that occur in Wales taking place in a care home, the provision of high quality end of life care in this setting is a topic of great importance.

Whilst work has been undertaken to better understand specialist palliative care service activity through the annual Minimum Data Set (MDS) survey,[I] little is known about the support delivered in the care home setting. This report therefore aims to increase understanding of how specialist palliative care services support adult care homes in Wales.

[I] '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] England: NCPC [Accessed 22nd August 2017] Available at: http://www.ncpc.org.uk/minimum-data-set

2. **Summary of findings and recommendations**

Through the survey, Specialist Palliative Care (SPC) providers working in the community conveyed their commitment to their work with care home residents and staff. The majority reported positive working relationships with care homes, yet some recognised that the network of homes they support could be more extensive. Providers acknowledged challenges to delivering SPC in the care home setting and offered constructive suggestions for ways to meet them.

a) Service characteristics

The nine services represented in this report were located in six of the seven Local Health Boards (LHB) and all had been running for ten or more years. Two thirds of the survey population described themselves as a hospice, the remaining third identified as a Specialist Palliative Care Unit.

Five providers said they were commissioned to provide services in the community generally. The same five services were specifically commissioned to provide support to care homes. Some respondents explained that lack of specification of care homes in their contacts and agreements was irrelevant and that support was willingly given and driven by patient need. However, some expressed a desire for dedicated resources for targeted work with care homes.

b) Service delivery

The scope of the services were wide-ranging including education, training, clinical, practical, social, emotional, psychological and spiritual support.   Some respondents described services delivered by multi-disciplinary staff teams.

All nine providers offered clinical support to care homes, including telephone advice. Routine and emergency visits were provided by more than half of respondents.

Formal education and training was offered to care homes/staff by seven of the nine services. This included sessions to support forward care planning and decision-making, disease specific training, symptom control, syringe driver use, grief, loss and bereavement. A menu of communications-related training was also delivered.

All nine providers offered informal training with a high level of crossover with the formal subjects listed above. Providers described their informal teaching as 'ad hoc', 'needs led' and 'practice related'. An informal approach was thought to reduce barriers to education for the high turnover care home workforce.

c) Recording and reporting

The majority of providers used multiple recording methods to document their clinical work. This included paper records held by care homes and hospices and digital records, with over half using the Cancer Network Information System Cymru (CaNISC).

Lack of a standardised approach to recording amongst providers and in some cases, the absence of available data, meant it was not possible to clearly quantify the number of care homes supported or the level of support given to staff and residents. The availability of data on care home residents' place of death was also affected.

d) Challenges and facilitators

The high turnover of care staff and staffing levels were seen as a major challenge impacting on the ability of care homes to release staff to attend education and training. This was thought by some to impact on care home staff competency. SPC staff shortages were also cited as a challenge. It was suggested that fully staffed SPC teams including a funded administration role and staff with specific responsibility for working with care homes would facilitate better support.

Increased funding was most frequently cited as an enabler to high quality support to care homes and residents. Longer term grants that offer time to support the building of relationships before requiring outputs was suggested. A gentler, more informal approach by SPC staff was also thought to more effectively engage care home staff.

Lack of funding/commissioning of services was thought by some to affect the regularity and consistency of education and training delivery. Accessible education and training was thought to facilitate relationship building and help overcome some of the identified challenges.

e) Survey outcomes

Whilst there were limitations to the quantitative data, providers written accounts helped to identify differences in data capture relating to support to care homes and residents. Their free text contributions have enhanced our understanding of SPC support in the care homes in Wales and highlighted the challenges and potential facilitators of high quality support in the care home setting from a SPC provider perspective.

f) Recommendations

Recommendations cannot be inferred from the data given by the small sample of Welsh providers alone. However, the themes identified in the Welsh data echo and add weight to the results of a much larger sample of SPC providers in England which were gathered concurrently through the same survey.[8] The following recommendations should therefore be considered in the Welsh policy, commissioning and service context:

• 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.

3. **Methods**

a) Sampling strategy and participating service characteristics

We sought to survey a purposive sample of 31 Welsh providers 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 23% (seven).

Targeting only those historically registered with NCPC may have excluded new or unknown services. The survey was therefore publicised more widely through Marie Curie, the Wales Cancer Research Centre, NCPC, Hospice UK and the End of Life Board websites, social media and networks to try to reach a wider audience. This resulted in an additional two responses. The total number of responses was therefore nine.

b) Inclusion criteria and consent to participate

We invited SPC providers that work directly with care homes in the community to complete the survey. All responses met this criterion. No responses were excluded or retracted.

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.[9] 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 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.[10]

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 and 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 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.[11]

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. Due to the small sample size, the number of observations have been reported only as percentages may mislead the reader. An account of missing data is provided throughout the report.

4. **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 their service: Specialist Palliative Care Unit (SPCU) or Hospice.

All nine survey respondents (100%) answered this question. Six respondents described their service as a Hospice and three described their service as an SPCU.
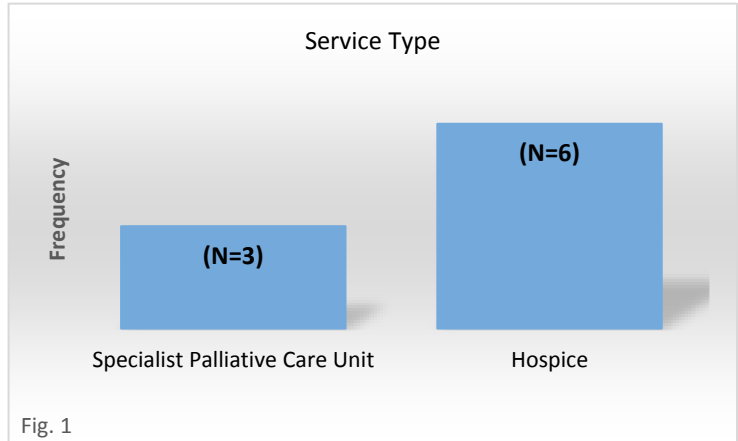
Fig. 1

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

As this survey on SPC 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.

Eight survey respondents answered this question. Seven said the 2015/16 MDS survey had been completed for their service.
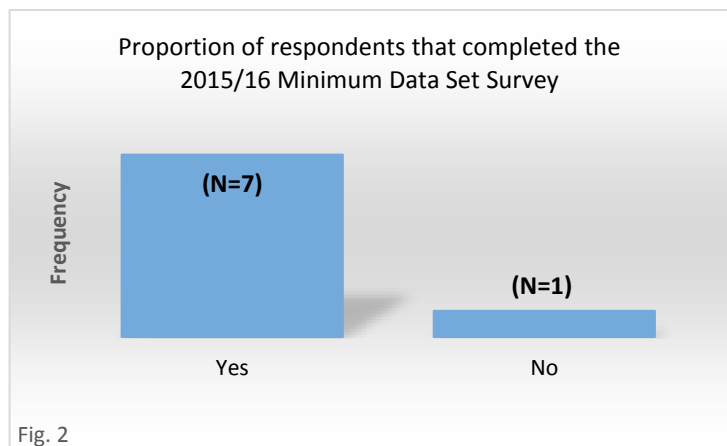
Fig. 2

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.

All respondents stated that their service had been running for 10 years or more.
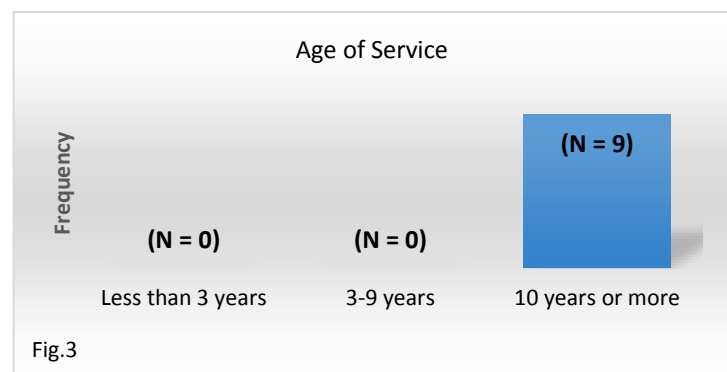
Fig.3

d) Service description

We asked providers to give a description of the general services they deliver. All nine gave a description in the free text box provided.

Respondents described a wide range of services, which are shown in the word cloud below. The descriptions showed that services delivery often relied on multi-disciplinary teams including clinicians, nurses, physiotherapist, occupational therapist, social workers and counsellors. Some service descriptions were broad. E.g. *'inpatient care, day centre, community support'.* Others were more specific, listing up to 15 difference service components. Respondent four described an impressive range of services delivered by a team of professionals in the hospice and wider community setting:

'The Community Specialist Palliative Care Team provides palliative care expertise to people with advanced and progressive conditions […], supporting them at home, and in the community hospitals, aiming to deliver the right care, in a place which is in accordance with the patient's preference for place of care, according to need and not limited by diagnosis.'

(Respondent eight)

'Consultant-led community support in patients normal place of residence, e.g. own home, nursing/residential home, supported living etc.   Day centre based on site at the hospice with range of group programmes and one-to-one support delivered by multi-disciplinary team.   Nurse-led outpatient service. Hospice at Home for overnight care and day respite. SPC support to two hospitals, bereavement support for relatives of both deceased previously known to the hospice and those not known to the hospice within the local community, including care for children. Befriender service, formal and informal education services for other healthcare professionals […]'.

e) Service coverage by area

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

Nine respondents answered this question. All said their service sits within one LHB boundary. No respondents stated they worked in a CCG, which suggests none work across LHB boundaries or Welsh/English borders. The services represented in this report are located in six of the seven Health Boards.

f) 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.

Seven of the nine total survey population 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 showed that at least one provider included bereaved family members supported along with inpatient and outpatient data. These figures were not broken down, so the individual patient data could not be extracted. The recording of data by inpatient and outpatient status suggests in some cases individuals may be double counted.

Provider six (see text box) did not answer the question but explained they could not separate out individual patient data as some teams recorded interventions rather than individuals.

> *'Not defined - some services measure number of interventions not individuals due to group activities [….'*
>
> (Respondent six)

> *'820 people used one or more of our services. We do not separate out specialist from non-specialist. These figures would include people who just received an equipment loan, as well as people who had long term night respite or CNS input.'*
>
> (Respondent two)

For the reasons stated above, we were unable to identify the number of individual patients seen in the specified timeframe.

[II] There are 207 CCGs in England which are clinically led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area. Further information can be found at: NHS Clinical Commissioners (2017) *About CCGs* [Online] London: NHS Clinical Commissioners [Accessed 29th August 2017] Available at: https://www.nhscc.org/ccgs/
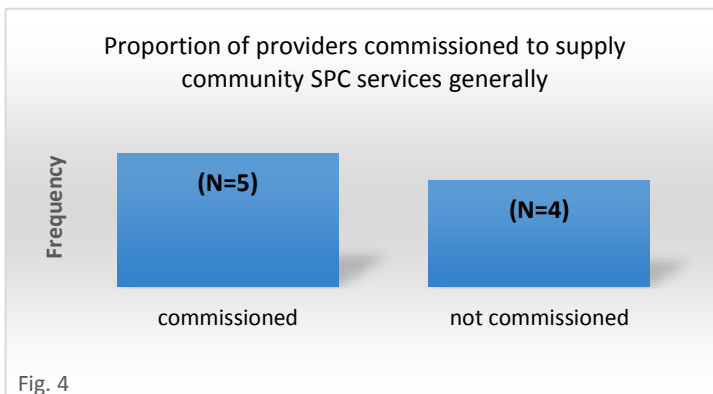
5. Commissioning

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

a) 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 LHBs or Local Authorities (LAs) to deliver general SPC services.

All nine providers answered this question. Five said they had an agreement or contract to supply general SPC services. Four did not.

Proportion of providers commissioned to supply community SPC services generally

Frequency

(N=5) commissioned

(N=4) not commissioned

Fig. 4

b) 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.

All five providers who previously said they were commissioned to supply general SPC services answered this question and said they were commissioned to supply some kind of SPC service to care homes. All five said they were commissioned to provide clinical support and three were commissioned to provide education/training. One provider chose the 'other' category.

The free text information given by respondent four in relation to this question shows the range of ways providers are contracted to supply SPC support in the community and to care homes specifically:

Proportion of providers specifically commissioned to supply SPC services to care homes

Frequency

(N=5) commissioned

(N=4) not commissioned

Fig. 5
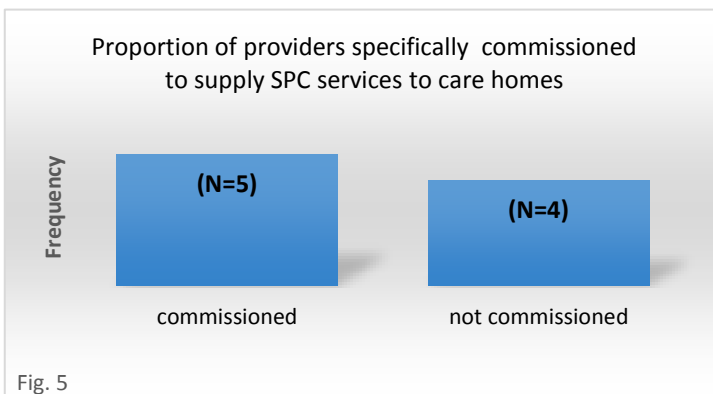
> *'Patients in a care home are treated the same way as a patient residing in their own home. They have access to all the same community services, for example the day centre'*
>
> (Respondent seven)

'We have a Service Level Agreement with a Health Board which effectively funds less than 20% of our whole service and has no specific requirement regarding our input to care homes.   In a separate agreement, we have been commissioned by the same Health Board to provide Hospice at Home services across a county borough council area. In further separate agreements we have been specifically commissioned by another Health Board to provide education and training in SPC to all care homes in their area. We are also commissioned by a Workforce Development Team to deliver training days to Health and Social care Workers.'

Although almost half of the sample (four respondents) said they were not specifically commissioned to supply services to care homes, they used free text to explain that in spite of this fact, support is willingly given and driven by patient need. Respondent three wrote:

'Our service is entirely an NHS service […] there are no activities that are specifically commissioned. We are expected to provide SPC service to patients in our hospitals and community (within catchment) including any Nursing Home and Care Home residents. Referrals are accepted for patients with specialist palliative care needs, and a diagnosis that will significantly shorten their lives or where death is considered to be likely within days or weeks. […]'

'Care home work is not specifically commissioned. However our one CNS works in the community and this includes a service to care homes for about 25 percent of the county. All other support is either grant funded or GP cluster funded (Advance Care Planning projects) or funded by the charity (training sessions). We received a […] grant from the Welsh Government, via the Health Board, for education around the new 'care decisions' documentation - this has included nursing homes as well as hospital, community and hospice staff. The Health Board also pay us to provide verification of expected death training to Registered Nurses. '

(Respondent two)

Respondent two explained they were actively seeking grants to provide more support to care homes: *'This will not be CNS type support, but more practically based 'end of life care' support.'* Which suggests they have identified a need for targeted end of life support for care homes in their area.

Place of care and support targeted at care homes may be considered an important factor for service commissioners to take into account, as figures published in October 2017 show that between 10% and 22.6% of all deaths across the 22 local authorities in Wales occur in a care home, with a Welsh average of just over 16% [7]. Whilst a proportion of residents who die in care homes will require generalist rather that specialist palliative care, high mortality in this setting may warrant an exploration of the appropriateness of resource targeting through specific mention of place of care in commissioning.

c) Contracts and agreements for SPC services for care homes

We asked what type of contracts or agreements providers had for the services they were 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.

All five of the survey respondents who previously said they were commissioned to supply SPC services to care homes answered this question.

'Not specified' was most frequently reported with three respondents choosing this option. 'Service level agreement' and 'block contract' were each chosen by one respondent. 'other' was chosen twice.

Fig. 6
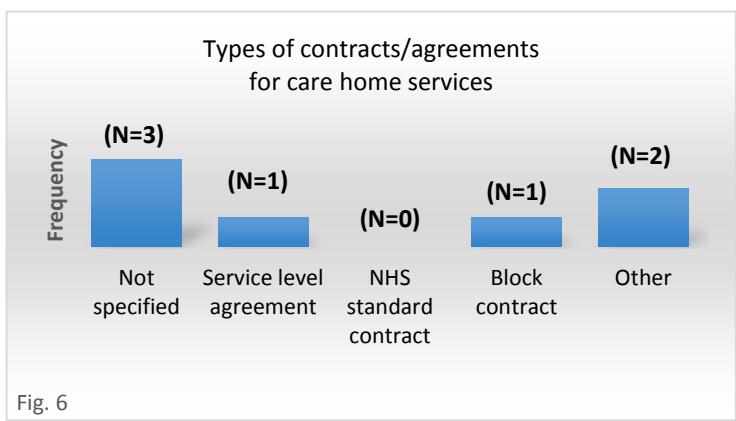
The two providers who chose the 'other' category used the free text box provided to describe the other type of contract/agreement they had to provide SPC support to care homes. Both described contracts that were made possible through End of Life Board funding. For example, Respondent four wrote:

*'The work with one Health Board is a specific contract resulting from funding via the End of Life Care Board for training in care homes. The work we undertake in another Health Board with care homes is not reflected as part of the Service Level Agreement.'*

d) 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. [III] The total survey population of nine answered this question. Two said that they did have KPIs for the services they provided to care homes. Seven said they did not.

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

Fig. 7
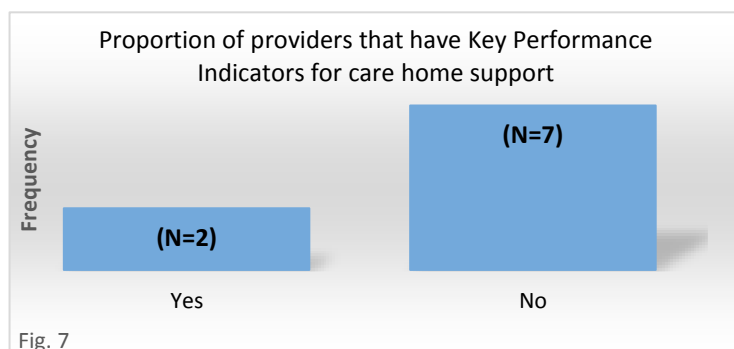
e) Example KPIs for SPC services in care homes

We asked providers to give examples of their KPIs for the services they deliver to care homes and residents. Both the providers who said they had KPIs for care home support gave examples.

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

'Outputs' which are concerned with what is delivered, e.g. number of referrals, number of patients seen, were most prevalent with seven references.

'Outcomes' which focus on measurable change due to the service intervention, e.g. patients able to die in their preferred place of death, were mentioned five times and included patient reported outcomes.

This shows a reasonable balance of type of performance measures, which is positive, as literature suggest outcomes reporting in SPC may still be in its infancy. [(12)] However, the

'Percentage of patients achieving their preferred place of death per year, significant improvement in physical symptoms reported, use of the Integrated Care Pathway for end of life care, Percentage of people seen contacted two days of initial urgent referral, percentage of people seen contacted five days of initial routine referral, percentage of people polled rating their experience as good or excellent, percentage of internal audits completed annually and percentage of compliance with submission of reports to Palliative Care Implementation Group and the National Council for Palliative Care.'

(Respondent seven)

[III] 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)?* UK: Advanced Performance Institute [Online] [Accessed 21st June 2017]. Available at: https://www.ap-institute.com/what-is-a-key-performance-indicator

data is very limited due to the small sample size and caution should be taken when interpreting these findings.

One of the respondents said that KPIs for their work in one health board were yet to be finally agreed and that they maintain their own KPIs for the work in another health board. This suggests that KPIs for SPC services are not standardised.

f) Number of care homes supported

To get an idea of providers care home workload, we asked them how many care homes they support. Seven of the nine total survey population answered this question.

The data showed the minimum number of care homes being supported was 10 and the maximum 50. The average number supported was 22 and the median was 15. However, caution should be used when interpreting this data as two of the respondents said the figures quoted were approximate.

Free text information from the two providers who did not answer the question showed they did not know the number of homes supported by their service. For example, Respondent eight wrote: *'To all those in the area we cover - sorry not sure of numbers.'* It was not clear if the information gap was due to a lack of data held by the individuals completing the survey or knowledge gaps at service level.

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

All nine providers answered this question and said they provided clinical support. Each said they offered telephone support, six said they carried out routine visits and five said they provided emergency visits.

The data showed that five respondents offered a combination of routine visits and emergency visits with telephone advice.

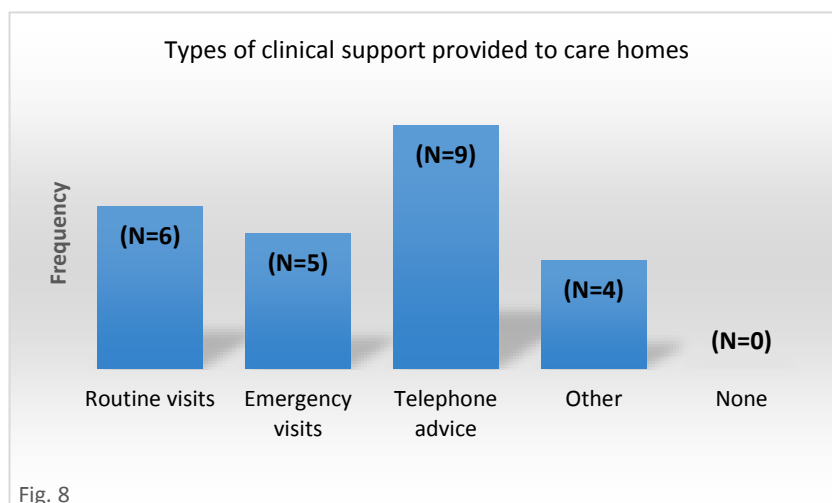The 'other' option was chosen by four respondents. Their free text

Fig. 8

descriptions identified the following as 'other' options: education, training and placements, out of hours, Hospice at Home service, specialist clinical support for complex palliative care needs/symptom control. The creation of additional categories should therefore be considered if the survey is repeated in the future.

b) Recording clinical support to care homes/residents

We asked providers what information they record about the clinical support they give to care homes and residents. The nine total survey population answered this question.

The data showed that SPC staff were recording information about contacts with patients and the support offered in up to five places. In total, seven reporting tools were identified. These included digital systems such as Cancer Network Information System Cymru (CaNISC), the Welsh Clinical Portal (WCP) and care home in-house systems. Staff contributed to paper records held by care homes and hospices as well as individual patient paper case notes and district nurse records.

> *'All SPC clinical records are contained within Health Board paper and electronic case notes. In addition, team members will document summaries within District Nurse paper case notes and within the paper case notes maintained by nursing home staff within the homes. Record keeping for all patients (whether in their own homes or in a care home) is similar.'*
>
> (Respondent three)

Just one respondent said they used paper records only and two used only digital.

In total, seven of the nine respondents mentioned digital records. Six specifically named CaNISC. Respondent nine (see text box) explained that CaNISC had enabled data sharing among SPC providers but that care home and primary care staff did not have access to the system. The data showed that five of the nine providers used multiple recording methods. This in part may reflect the restricted access to CaNISC by non-SPC staff as well as the use of different recording tools for different purposes. For example, respondent seven explained that they recorded all face-to-

> *'The hospice maintains electronic records (on CaNISC) of the reason for the visit; details of the clinical support provided and patient plans. Care home patients are not listed separately but integrated in our community records. CaNISC information is available to all other SPC services across Wales but is not accessible to care home staff or primary care. Staff will input separately onto care home systems to support communication with care home staff'*
>
> (Respondent four)

face contacts on CaNISC whilst both face-to-face and telephone contacts were recorded in the hand written hospice notes.

Comments on the type of clinical information recorded highlighted six different activities which are shown in the word cloud below.

care plans   Support provided
clinical support   telephone conctact
face-to-face contact
reason for visit

c) 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. Two of the nine total survey population were able to say how many patients on their caseload were care home residents. Of the two responses given, one reported a care home resident caseload of 50. The other provided a care home resident referral figure of 53 and gave a free text comment that suggested their recording practices for community patients may prevent identification of care home residents beyond the point of referral: *'53 new referrals. Continuing - unknown as integrated with community patients.'*

Free text comments from those who did not answer the question showed that most either did not have the information: *'We do not have this information I am afraid'* or did not have access to it at the time of completing the survey: *'unable to provide due to no access to figures at present'*.

Just one provider supplied a breakdown by type of care home. Of the 50 care home residents supported by Respondent seven, 40 were resident at a nursing home and 10 lived in a residential home. Respondent four said the type of care home is not captured in their referral figures.

d) 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. Only two out of a possible nine respondents provided an answer to this question. These were the same providers that answered the previous question.

One respondent stated their service supported 50 deaths. Of these, 41 took place in their usual place of residence, eight were in hospital and one in a hospice. The other respondent stated that 44 deaths were supported by their service in the given period and that all of the patients died in their usual place of residence.

7. Education and training

100% of respondents said they delivered some kind of 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 they provide. By amalgamating the available data, we can see that the nine total survey population said they delivered some kind of education or training to care homes.

Respondent four explained the joined- up, collaborative approach taken to the delivery of education and training in their area:

'As the preferred provider of SPC in [our area], [the hospice] has extensive experience in both clinical and educational input to the 12 homes across the borough. Staff have honorary contracts with [the health board], work closely with [their] Safeguarding and Governance Nurse and are members of the [...] Palliative Care Strategy Group, including the education work stream, ensuring that care education is delivered in a coordinated manner and links closely with national and local health board strategy'.

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, the nine total survey population answered this question. Seven said they provided formal training to care homes, two did not.

All seven of the respondents who said they offered formal education or training gave a description. See the word cloud and table 1 for a list of education/training types and coding frequency.

Proportion of services that provide formal education/training to care homes

Frequency

(N=7)　　　(N=2)

Yes　　　No

Fig. 9
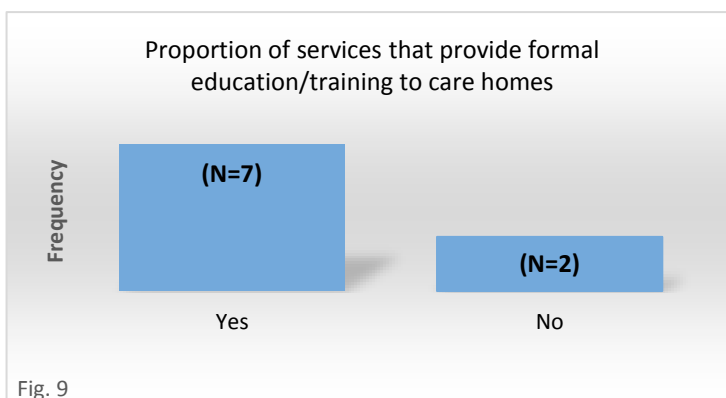
Some providers focused on one topic such as care decisions document training whilst others offered multiple courses. An introduction to the principles and practice of palliative care was offered by two providers. One being part of a broader five day course.

Disease/illness specific training was offered by two providers. One gave an extensive list including understanding cancer, motor neurone disease, heart failure, chronic pulmonary disease and renal failure. Both providers offered dementia awareness training.

Three providers delivered communication training. The subject matter included having difficult conversations, dealing with difficult situations, breaking bad news and responding to distress. One provider explained that their communications training was reflective, based on learners own experiences of dealing with difficult questions.

Four respondents said they offered symptom management training. One offered training on comfort measures in relation to hydration, bladder and bowels. Their portfolio also included syringe driver training for registered

nurses and training on recognising the deteriorating patient, which was available to registered nurses and other staff.

Four providers offered training to support forward care planning and decision-making. Advance Care Planning, care decisions tool/documentation/guidance and do not resuscitate decisions (DNACPR) were specifically mentioned. Respondent five explained that care home staff *'[…] sometimes find it difficult to maintain competency for Care Decisions Document use due to not using regularly and high staff turnover'*.

One provider said they offered staff training on care after death, bereavement, personal wellbeing and resilience.

One respondent said they provided bespoke training based on the needs identified by the care home on request. Another said they offered a practice placement with the hospice team.

Three respondents said they supplied accredited training or training that linked to accredited courses. Qualification Credit Framework (QCF) training (unspecified) and foundation level Sage and Thyme Communication Skills were mentioned.

Respondent two commented on their approach to care home staff training: *'[…] we take an opportunistic approach - grabbing any chance to have input.   However, we do offer a specific three session programme via the local Social Care Workforce Development Programme […].'*
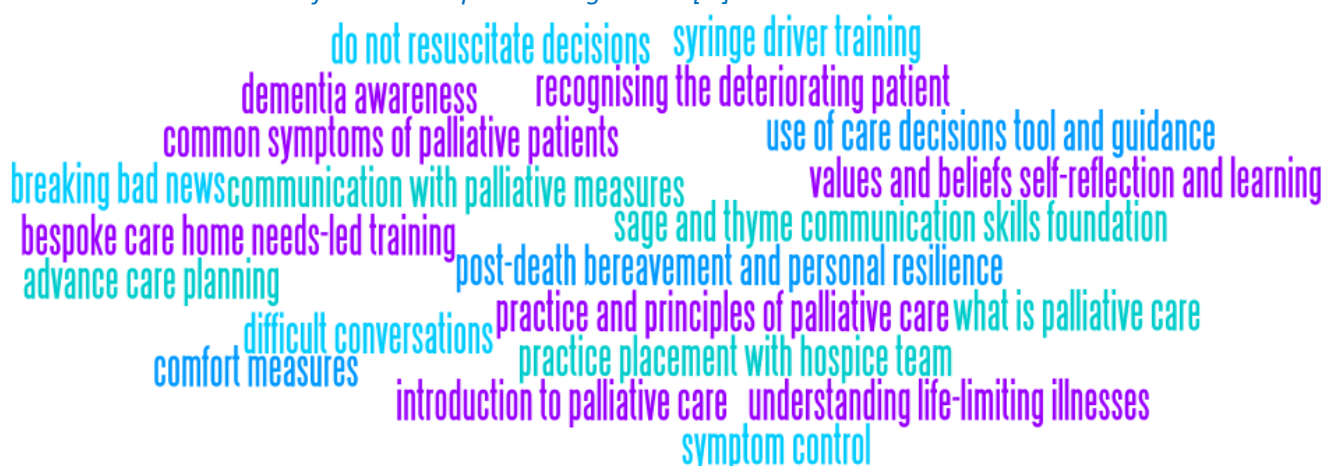
Table 1 : Formal education/training coding frequency by type

Training provided	Coding frequency
Disease/illness specific	8
Communication	5
Advance Care Planning	4
Care decisions tool/documentation/guidance	4
Symptom control/management	4
Introduction to palliative care	2
Comfort measures	1
Do not resuscitate decisions	1
Grief, loss and bereavement	1
Recognition of deterioration	1
Syringe driver	1

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.

All seven survey respondents who previously said they provide formal education/training answered this question. However, three said they either did not have this information or

> *'We do not specifically record this, but I would estimate 80 - 90 at various formal educational events.'*
>
> (Respondent two)

were unsure of the figure. A fourth said they had estimated the given figure as such data wasn't captured by their service. Due to these data limitations, caution should be used when interpreting the following findings.

Of the four respondents who did provide a figure, the range of number of staff formally trained was between 20 and 200. The average was 91 people, the median was 73.

c) Provision of informal SPC education and training

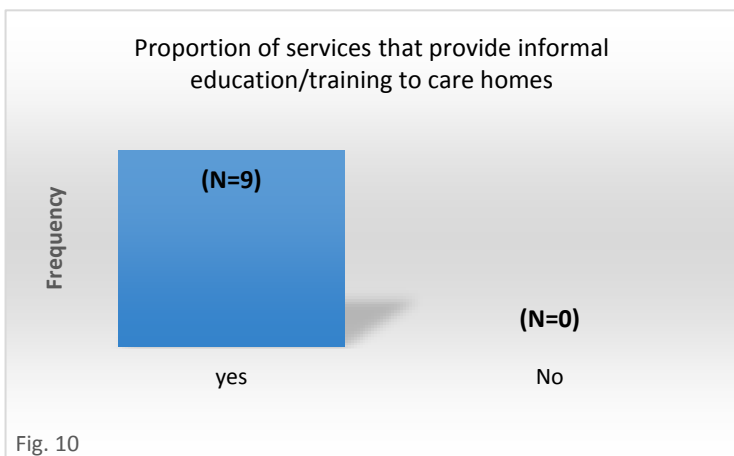We asked providers if they supplied informal education to care homes, the nine total survey population answered this question. All of whom said they provided informal education or training and offered a description.

Respondents described informal education as 'ad hoc', 'Needs-led' and 'practice-related'.

A number of approaches were used to deliver informal education/training. This included on-site support for practice-related training and support linked to individual residents. For example, telephone support was said to help facilitate decision-making (See text box).

Proportion of services that provide informal education/training to care homes

(N=9)   (N=0)

yes   No

Fig. 10

> *'Informal through telephone advice line for specific issues - often offering a sounding board for staff making decisions regarding maintaining care in the individuals usual place of residence.'*
>
> (Respondent six)

A learning zone, which included digital and paper resources had been used by respondent one however, they later stated that *'despite comprehensive advertising of learning zone, including individual nursing home packs and visits, this facility was not utilised by care home staff'*.

Respondent four described how their service reduced barriers to education in the care home setting through a 'formally informal', 'blended learning' approach:

> *'Recognising the difficulties that can be experienced by care homes in releasing staff to attend external courses and the problems inherent in delivering education to a high turnover workforce, we also deliver informal education using a blended learning approach based on four principles: 1. little but often, which facilitates regular attendance, accommodates a high turnover workforce and is "formally informal". 2. Focused on generic palliative care; communication skills; recognising dying; symptom management; care*

decisions tool and planning ahead. 3. Patient focussed and reflective. 4. Ownership by care home staff, link nurses identified in each home, learning objectives set by care home staff, "resource box" maintained by care home. We also host quarterly Link Nurse meetings for District Nurses, Hospital Nurses and care home staff as well as informal education delivered on a case by case basis.'

In total, nine types of informal training were identified. Advance Care Planning, Care decisions document/tool support and symptom management were each referenced twice. See table 2 below for a full informal education coding list.

Table 2 : Informal education/training coding frequency by type

Training provided	Coding frequency
Advance Care Planning	2
Care decisions tool/documentation	2
Symptom management	2
Resident/case specific	2
Communication	1
Syringe driver	1
Recognising dying	1
SPC support (general)	1
Supporting Six Steps Education Programme*	1

* The Six Steps Programme was mentioned in relation to informal training only. It was not discussed by any provider in relation to formal training.

d) 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.

All nine survey respondents who previously said they provide informal education/training answered this question. However, five said this information was either not recorded or that they did not have access to it at the time of completing the survey. Due to these data limitations, caution should be used when interpreting the following findings.

Of the four respondents who did provide a figure, the range of number of staff informally trained was between 20 and 50. The average was 34 people and the median was 33.

8. 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. The nine total survey population answered this question.

The relationship rating was predominantly positive with seven of the nine providers saying they had either a good or very good working relationship with their care home community. One rated their relationship as satisfactory and one gave a negative relationship rating of poor. No one chose the very poor option.

Care home relationship rating
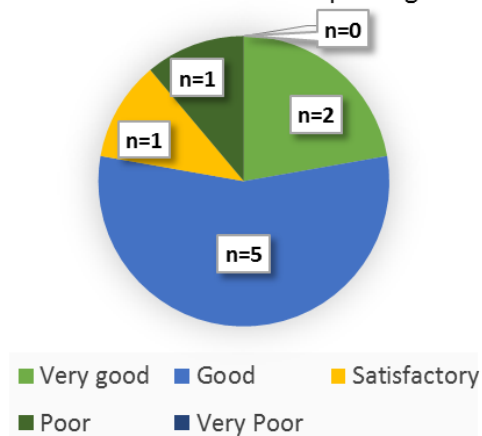
b) Description of working relationships with care homes

Providers were invited to describe their relationships with their care home community. Six of the nine total survey population took this opportunity.

Respondents described positive working relationships with care homes as well as some of the tensions and challenges.

Two respondents wrote about the importance of regular contact for the development and maintenance of relationships with care homes. Time was also thought to be a factor, with one respondent stating that relationships with care home staff had been built over a number of years.

Two providers recognised that whilst the relationships they had with care homes were good, the number of care homes they support could be greater. For example, Respondent six wrote: *'relationships are very good with a small number of care homes with whom we have regular contact but could be improved to cover more care homes'.*

Respondent two (see text box) was very complimentary about the attitudes and skills of some care home staff. This was balanced by comments about the potential tensions brought about by some care home staff attitudes to risk-taking and their perception of censure from families and outside agencies, particularly the NHS.

> *'The relationships we have are good, but they are not yet very extensive. We have developed an interest in care home support through our training. We have been struck by the enormous amount of untapped talent and enthusiasm. We have also been very struck by the level of wariness some care homes show to the outside world. They seem very risk averse and scared of censure from families and in particular the NHS, who they seem to regard as having a regulatory role. E.g., ' I don't think we could do verification, the Health Board wouldn't let us'. They also seem isolated from other sectors and one another. We are keen to support them and improve their image.'*
>
> (Respondent two)

Respondent four highlighted how the desire to forge relationships could sometimes be one sided and that attitudes to palliative care held by senior care home staff could not only obstruct the development of positive working relationships, but also limit access to SPC support for their residents:

> *'Overall very good as the hospice has built up working relationships with staff over a number of years. However, inevitably, the relationship with some homes is better than others - there is one home on 'our patch' for example where senior staff have long-standing concerns re palliative care, which are rooted in their cultural background. Despite all attempts at discussion and education, the leadership has remained resistant to input and the number of referrals to SPC remain low.*

Free text comments from Respondent seven suggest that in some cases tensions in relationships can be due to disagreement between care home staff and SPC providers about the correct place of care for residents:

> *'Initially many residential homes offer to support patients/residents in their end of life care but when the resident reaches this point they refuse to support them despite CNS and DN input. This often results in the acute admission of the patient and death in hospital contrary to the patient's expressed preferred place of death.'*

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. The nine total survey population answered this question. See table 3 for a full list of coded challenges.

i. Resources

Coding of the free text showed that the challenges and barriers identified by the respondents primarily related to staffing, time and funding resource limitations for both care homes and SPC teams. The effect of these limitations as described by providers predominantly related to the provision of or engagement with education and training.

ii. Staffing and time

'Care home staff turnover' was most frequently mentioned as a challenge to supporting care homes (5 references). High staff turnover and 'care home staffing levels/shortages' (2 references) were thought to restrict opportunity for care home staff to attend training. 'Releasing care home staff for training' and 'insufficient study time for care home staff'were specifically mentioned as limiting factors. Respondent five expressed the view that the high turnover of care home staff had an effect on their competency and educational development.

SPC team staffing issues, including staff shortages and staff turnover, were thought to impact on the level and type of support offered to care homes. Respondent nine stated the SPC team had 'insufficient time'. Respondent three described the staffing challenges their service faced in more detail:

> *'I think that the main problems that we encountered were due to the transient nature of staff within the care home sector […].'*
>
> (Respondent one)

> *'Insufficient Specialist Palliative Care Team staff. We are working with depleted CNS numbers due to long-term sickness […] so we've have had to prioritise the clinical workload over activities such as education and audit […].'*

They went on to describe an inability to identify any suitably trained locums to cover long-term leave within budget, which had impacted on the staffing levels of the specialist palliative medicine team.

iii.   Funding

Four providers cited 'lack of funding/commissioning for care home education/training' as a challenge.

Respondent five commented on how lack of commissioning affected the delivery of education by their service: *'No commissioned services which affect regularity and consistency of educational development and training.'*
Respondent two explained how care home budget constraints had influenced how they delivered education/training:

> *'Through our Advance Care Planning projects we have learnt this: Budgets are tight. If you have ambitions to provide support for all, you must be prepared to do multiple short sessions to very small groups, on site. However, it is also enormously productive to get staff off site and meeting colleagues from other homes. The enthusiasm of individuals is critical for success and these might be quite junior people - repeated approaches, via different means might be needed.'*

iv.   Developing, managing and sustaining relationships

Providers made some comments about how care home culture, decision-making processes and communication pathways could be a barrier to support from SPC teams.

Respondent two wrote about difficulties engaging care homes, how successful engagement was sometimes 'hit and miss' and how even a low level pre-existing relationship such as having loaned equipment could make it easier to introduce other support.

> *'Sometimes we try for months to get a foot in the door and then for no apparent reason we succeed. It is a lot easier to introduce support to homes you already have a relationship with for some reason. E.g. Just having loaned a profiling bed or wheelchair or done a couple of CT sessions for a resident.'*
>
> (Respondent two)

Respondent one expressed the view that after successfully engaging care home managers, information about their SPC service was not cascaded to other staff within the home: *'Managers of care homes were fully informed and visited regarding what the hospice had to offer, but I don't believe this information was consistently disseminated.'*

Respondent four explained that centralised decision-making processes for large group homes restricted response to local issues. They also cited cultural differences as a challenge.

Table 3: challenges to providing SPC support to care homes coding frequency by type

Challenge	Coding frequency
Care home staff turnover	5
Lack of funding/commissioning for care home education/training	4
Care home staffing levels/shortages	2
Releasing care home staff to take part in education/training	2
Insufficient study time for care home staff	2
Insufficient time for SPC teams to deliver	2
SPC team staff levels/shortages	2
SPC team staff turnover	1
Lack of educational opportunity take-up by care home staff	1
Centralised decision-making by group care homes	1
Care home cultural differences	1
Engaging care homes	1
Cascading information within care homes	1

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. Eight of the nine total survey population answered this question. See table 4 for a list of coded enablers.

i. Funding

'Increased funding' was most frequently coded as an enabler (4 references). Respondent two described a need for substantial long-term funding and associated reporting schedules that support relationship development: *'We need large, long term financial grants that will provide enough time and resources to build relationships in small ways before 'outputs' are relentlessly pursued.'* Respondent six proposed improvements could be made through shared investment.

Other providers suggested commissioned SPC services and funded education/training as enablers. Respondent nine suggested that funded training could also be mandatory. Respondent seven echoed this belief in a later comment shown in the text box.

ii. Staffing

Two providers proposed additional SPC staff with a responsibility for working with care homes would facilitate better support. Respondent three wrote: *'[...] ideally a dedicated post / funded sessions to provide care home education [...]'.* They also explained that strains on the SPC team could be alleviated with *'a fully staffed SPC team, [...] resources for adequate cover for long term absence from the SPC team and funded admin support.'*

Respondent five proposed that education and training could help retain nursing home staff: *'Commitment to private sector nursing homes to developing skills and qualifications for all levels of staff to tackle the challenge of staff retention.'*

iii. Accessible education/training

The provision of 'accessible education/training' (2 references) was thought to facilitate relationship building and help to overcome some of the identified challenges to engagement with education and training. Respondent seven described evening and early morning teaching which they said *'the more proactive care homes have welcomed'.* Respondent four reiterated the benefit of their blended learning approach to training for the

> *'The palliative care modules that are being offered in our area should be made mandatory for Care Home staff. This would ensure better end of life care for all their residents not just those referred to the community palliative care team.'*
>
> (Respondent seven)

high turnover care home workforce. This approach was described as providing training that is little but often and formally informal. Focused on generic palliate care, patient focussed and reflective. (See section 7c for the full extract).

iv. Support approach

Two providers suggested the way in which SPC teams approach the support of care homes could be improved. Respondent nine proposed having *'more informal time for SPC teams'* and respondent two wrote *'we needed a project which will take us into homes in a non-threatening way, regularly.'* Offering practical support that care homes value such as free equipment loan was also suggested.

Table 4: Enablers to providing SPC support to care homes frequency coding by type

Enabler	Coding frequency
Increased funding	4
Commitment to education/training	1
Mandatory education/training	1
Accessible education/training	2
Changed approach to support	2
Dedicated SPC staff to work in care homes	2
Free equipment loan	1

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. Six of the nine total survey population took this opportunity.

i. Education/training

Accessible education/training was again raised as good practice by two providers. The importance of the correct timing and approach to teaching as discussed in the previous section were reiterated. One provider highlighted the north Wales Six Steps to Success training programme as an example of an initiative that had successfully engaged care homes. Run with circa 40 care homes it was said to have had *'[…] good attendance and commitment of care homes and been well evaluated.'*

ii. Advance Care Planning Support

Two examples of best practice in Advance Care Planning (ACP) were shared. A cluster ACP project that ran ACP awareness events in care homes with follow up that facilitated ACP (or best interest documents) for individuals was highlighted as a project of interest. Attention was also drawn to the 'invaluable' support of ACP Clinical Nurse Specialists.

iii. Multi-disciplinary meetings and end of life audit

Multi-disciplinary meetings between community SPC staff, nursing home staff and GPs in order to identify residents approaching the end of life phase of care was identified as good practice by one provider. An end of life audit for care homes was cited as good practice by another who suggested this should be done on a home-by-home basis and the results, such as information about achievement of preferred place of death, should be shared with care homes.

9. Conclusion

Whilst the sample of Welsh survey respondents was small, providers' great commitment to the delivery of high quality SPC support to care home residents and staff was evident. The information and views shared through this report offer a glimpse of the SPC support provided in the care home setting in Wales.

There were limitations to the quantitative data supplied; however free text accounts helped to identify weaknesses in data capture relating to the support of care home residents and staff, which could influence improvements in the future. Providers written accounts have enhanced our understanding of the challenges and potential enablers to the delivery of high quality support from an SPC provider perspective.

Some of the identified challenges are not new and others, such as care home staff retention are endemic of a much wider problem in the health and social care sector. However, issues with Welsh SPC staffing levels and the impact this has on service delivery may warrant closer inspection.

Going forward, a more in-depth qualitative approach such as face-to-face or telephone interviews may help to engage a wider group of SPC providers and elicit an even greater level of rich contextual information.

Whilst recommendations cannot be inferred from the data given by the small sample of Welsh providers alone. The themes identified in the Welsh data echo and add weight to the results of a much larger sample of SPC providers in England, that were gathered concurrently through the same survey.[8] The following recommendations should therefore be considered in the Welsh policy, commissioning and service context.

10. 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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