Evaluation of the Advanced Specialist Practitioner care homes project

Macmillan Cancer Support

Final report

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Project details

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1. Executive summary

This report brings together evidence from a two-year evaluation of the Barnsley Advanced Specialist Practitioner (ASP) care homes pilot project, funded by Macmillan Cancer Support and run in partnership with South West Yorkshire Partnership NHS Foundation Trust (SWYPFT). The pilot has aimed to provide enhanced care planning to care home residents in the last year of life, working with care homes directly and wider health services.

M·E·L Research was commissioned to evaluate this ASP project in Barnsley, to increase understanding of:

- the impacts of the ASP on **high quality** clinical and personalised holistic **care and personalised choice** in the last year of life
- what an appropriately skilled and **integrated system** working looks like
- the **sustainability** of personalised holistic care planning within the system.

This executive summary pulls together evidence from across our two-year evaluation. This includes resident-level statistical data, an audit of 999 calls in care homes, a host of contributions from care homes directly and interviews with wider stakeholders. This summary answers the overriding evaluation questions and the sub-questions that underpin these (the fuller evaluation framework is summarised at Appendix A1).

The impact of Covid

This evaluation started in October 2019, almost two years ago. Back then, the ASP project had already started, with engagement in care homes, surgeries and community teams. Over that time the Covid pandemic has hit care homes hard, harder than many other settings, with impacts still being felt. In some homes, scores of residents have died quickly, rooms have been left unoccupied and staff placed on furlough or made redundant. This has had a financial and personal cost to those running and working in care homes.

But there is also a positive legacy from Covid, something unanticipated at the start of the project. Many care homes have realised the need for advance care planning, talking to residents about death, dying and end of life. As one of few health professionals physically going into care homes, the ASP has cemented herself even more firmly within them, supporting staff, residents and family members.

The ASP role has therefore had to evolve to suit the changing reality. Our evaluation has also had to adapt to this changing landscape. One part of this is how to disentangle the contribution made by the

ASP project to end of life (EOL) care for care home residents, rather than the wider context (eg Covid) or other changes (eg GP alignment).

High quality and personalised care

What constitutes high-quality and personalised care at end of life was a topic in some of the early stakeholder interviews. One stakeholder summarised this well, stating it was about wanting the best care, feeling valued and listened to, with care delivered in the right place for you. This meant identifying EOL residents earlier, making plans, discussing, identifying and meeting choices with residents and families and responding in a timely way. Avoiding discomfort for residents and avoiding distress for families is also part of this, including by reducing conveyancing to A&E and then unnecessary admissions to hospital. One community stakeholder said it's about "a beautiful death".

Recognising and identifying palliative care home residents

If identifying somebody earlier in their EOL journey is the first step, the number of care home residents with EPaCCS (electronic palliative care coordination systems) is one indicator that the ASP project is making a difference. This shows just over a third (35%) of residents were on the palliative care register with their GP. Stakeholders said this would have been lower without the ASP intervention.

Care homes are better trained on EOL and some, though not all, are using tools like the Gold Standards Framework (GSF) to look for and better classify deterioration they see in residents. Care home staff repeatedly spoke about the colour-coded prognosis indicator assessment, for example. This is giving some care home staff greater confidence to advocate on behalf of their residents, even if means challenging health professionals including GPs.

Care home residents accessing enhanced quality palliative care

There are good indicators that the ASP role has supported a real improvement in EOL care for residents in care homes in Barnsley. The high proportion of these residents having recorded a preferred place of death is positive. Three-quarters of residents (75%) had explicitly stated a preference, almost all to die in the care home. Most of these who died do so in this preferred place (where known), 95% of the 135 residents who had died by the end of May 2021.

What the ASP did was "the big thing", one GP said early in our evaluation. This included the training for care homes, the prognostic indicator guidance, My Care Plans and EPaCCS. Looking at preparations for end of life, EPaCCS data shows high proportions of residents having an advance care plan or best interest plan (87%), a treatment escalation plan (84%) and an emergency health care plan (77%). The EPaCCS has been providing a framework to have these conversations and log resident wishes.

Including family members in decisions

Several stakeholders referred to the ASP's emotional intelligence, describing her as "approachable", really "connecting" with them and nurturing existing relationships. Already being known among care homes has helped, allowing the postholder to draw on past experience and established relationships. The emotional intelligence is as important as the clinical skills.

The ASP has supported more inclusive decisions, including with residents, family and care home staff, ensuring all are "comfortable" with decisions. The postholder has remained approachable and empathetic, whether to dying residents, distraught family members or carers who themselves have been grieving. This has included particular input into best interest discussions, an area the ASP herself has changed during the project. EPaCCS data shows that over a third (38%) had dementia as a primary diagnosis, for example.

Unplanned and avoidable emergency admissions to hospital

There are signs of reductions in unplanned secondary care admission among care home residents, with a lower proportion of residents being admitted and fewer average admissions per month after the ASP intervention. Of the 228 residents supported by the ASP over our evaluation period, exactly half (50%) had an unplanned secondary care admission in the six-month period before the ASP intervention. The average number of admissions was 0.95 per resident over this pre-ASP period, averaging 1.6 days in hospital per month for those admitted.

99 residents were still alive at the point of discharge from the ASP intervention. Of these, just 34 had an unplanned secondary care admission up to six months after the ASP intervention, representing just 34% of these residents. In addition, the average number of admissions per living month went down from 0.95 per resident to 0.16, just a sixth the rate, a big difference. However, the length of time in hospital for those admitted went up, to an average of 2.1 days per month for those admitted in the six months after the ASP intervention. This may suggest that the care and treatment was for more serious conditions in the later period, though other factors may also have played a role, including Covid.

In contrast, the 999 audit was less conclusive. For example, the proportion of 999 calls that led to a conveyance to hospital is similar in both periods when averaged across the care homes that took part, albeit with fewer 999 calls altogether in the later audit, in March 2021. As stakeholders made clear, carers aren't medically trained and therefore aren't the right people to decide on medical conditions that *do* require a clinical judgement. They can, however, advocate on behalf of their residents and be supported in conversations with paramedics with tools like one-page profiles of residents.

Enablers and barriers to successful outcomes from the ASP work

One care home manager (before the ASP intervention) described high-quality and personalised care for residents as focusing on dignity and respect, where possible meeting every need a resident has, having family around, medication to hand and a nice environment at the end. Some of the care home staff we spoke to had worked in social care for years or decades, so their EOL work built on lots of previous experience.

There was a lot of praise for the postholder in the ASP role throughout the evaluation, about how "valuable" and helpful the ASP role was, particularly in contrast to a more varied picture with GPs (before GP alignment, this is). The ASP had helped to put plans in place and fast-tracking services, one care home manager said, unlike GPs, who just saw care home residents as elderly. Staff at homes found it reassuring that they can pick up the phone and get a willing response from the ASP or the EOL Facilitator for advice, such as when they're struggling with GPs.

There was still some unease and nervousness about broaching the subject of EOL with residents, however. One care home colleague felt "less uncomfortable" – though not *comfortable* – each time she spoke to residents about it. While Covid has had a dramatic impact on care homes, it has highlighted the need to talk about death and plan for end of life with residents in advance.

Also needed was a greater focus on advance care planning earlier into somebody's journey rather than EOL care in a crisis at the end. This also demands that care homes can "pipe up", confident of speaking on behalf of their residents' wishes. However, as care home staff generally don't have a medical background, it can be useful to have somebody like the ASP role to ask about medical issues.

Integrated system

Care homes can feel disconnected to the healthcare system. Part of the ASP's remit has been to pull together different agencies across health and social care.

Key players within the system

It's clear that care homes make use of a wide range of healthcare services. The 999 audits, for example, showed that care homes called GPs, the 111 service and, by March 2021, Rightcare, before making

999 calls. Later into the evaluation there was more mention – and praise – for MDTs, contributing to better EOL care, some said. This was partly helping to overcome the challenge of GPs lacking time for care home residents.

Enablers and barriers to effective integrated working for palliative care home residents

Care homes are better connected to wider services now than at the beginning of the evaluation. Covid has also played a role in this, though the ASP should take credit too. Not just for the work of the role within care homes but also championing care homes to the wider healthcare sector. This inside knowledge has been shared widely among other professionals and senior roles in Barnsley. There is an ongoing need for this, especially as discussions continue at national and local level about further integrating health and social care.

Arguably, Covid does seem to have prompted a 'big bang' approach to GP alignment – sitting within the PCN contract and ECHC framework – which really do seem to be making a positive difference to EOL care. Homes are finding it easier to contact practices, regular MDT meetings are taking place and residents are being discussed. Different professionals are being involved in EOL care in homes, including community matrons and frailty nurses, alongside dedicated resource from the enhanced care home team. All of this is helping both to shine a spotlight on care homes and their residents but also to upskill carers, seniors and managers there. The ASP has had a central role in this.

However, power dynamics are still at play within the social and healthcare system, highlighted by the ASP work. Seen as Macmillan nurses, not care assistants, the EOL Facilitator and ASP are able to influence GPs more than homes can themselves. The ASP's clinical background, use of medical terms and perhaps the seniority of the role are important elements here, we believe.

The ASP influence over integrated working

The role of the ASP has been to train, support and coach care homes as well as to advise and potentially case manage complex cases. Having a dedicated and protected resource has really added value, including providing time for EOL discussions with residents, families and carers. A challenge here, though, is to provide this strategically across Barnsley without continually being dragged back to earlier care homes with routine case management. The ASP acts as an intermediary, a mediator between care homes and GPs but also between care homes, residents and families. This is even more important where residents lack mental capacity or their capacity fluctuates. With proportions of dementia forecast to rise across the population, this will only become a greater need in future. There is also a need to find new ways to engage more reluctant care homes in EOL care.

Skills or culture needed within the system

Educating care home managers and staff on EOL care has been an important part of the ASP role. Yet, again, this builds on existing training. Several care home workers spoke highly of practical training delivered, including the ECHO training. Carers also spoke highly of the training provided by the EOL Facilitator, describing her as “brilliant”, having “a good way of getting things across” even death and dying and in a really soothing voice. Training included on the Gold Standard Framework, with the need to identify residents earlier in their EOL path, My Care Plan and practical elements like EOL oral care. In respect of the ASP role, one manager spoke about the ASP role teaching rather than lecturing, a nice contrast. However, training care home staff will need to be a rolling activity, especially given the high turnover of staff.

A GP spoke glowingly about the change seen at one care home after the ASP intervention. Communication was now better and support provided earlier to residents, such as when the prognosis colour changes. This home has two key EOL workers, with staff “more empowered,” “more confident” and having better technical knowledge, taken seriously if they raise concerns. One surgery worker described having EPaCCS now, including sharing them with out of hours doctors.

There is still work to be done to move from end of life meaning weeks and months to live, to advance care planning taking place with months or a year-plus to live. This goes for care homes and GPs, who may still be too reactive and focus on crises. MDT meetings do seem to be helping with this, which sit within GP alignment. This is important as we know that EOL and palliative care registers often miss care home residents who should be on those lists. Linked to this is ensuring that EOL is acknowledged and planned for all conditions, including residents with dementia, not just limited to those with cancer. The important role that the ASP has delivered around decision-specific best interest discussions should be applauded.

Wider infrastructure needs for integrated working

One last element of integrated working was about changes in the wider infrastructure to improve integrated working. This didn’t emerge much during the evaluation. Some stakeholders did voice problems around IT, however, in particular the difficulty of accessing full EPaCCS data at EMIS practices, those using this primary care clinical record keeping system instead of SystmOne, as the two systems don’t coordinate. While things are getting better on this front, such as showing the last three practice consultations, other data was having to be re-entered. One stakeholder put it bluntly, saying EPaCCS are a “waste of time” if they can’t be seen. Yet we also heard from one care home about one-page profiles used there which are shown to paramedics, helping to simply convey information on a particular resident.

Sustainability

As a pilot project, our evaluation has looked at the lasting legacy from the ASP role, the tools to support high quality palliative care and whether there is a longer-term need for a dedicated role.

Legacy after the ASP intervention

EPaCCS data gives an indication of what end of life care is provided after the initial intervention by the ASP. The ‘outcome’ recorded against residents shows that once discharged over three-fifths of residents (62%) were being returned to care home staff but with education for staff, a quarter (25%) were under the care of district nurses and small percentages going to a community matron (5%) or being kept by the ASP herself (4%). The majority are therefore remaining with EOL care overseen by care home staff. Supporting them is the legacy of more detailed EOL plans, more residents having electronic EOL plans and families involved in advance planning.

A GP described the legacy as being asked more proactively for involvement by care homes, a positive move. Other surgeries also described a much better relationship with care homes after the ASP had been involved. For some, it was the focus on advance decision instead of just the last months and weeks of life. For others it was the ASP modelling good performance for wider community colleagues or providing specialist palliative input when needed.

Tools to ensure longer-term sustainability of personalised holistic care

The Gold Standards Framework is a key tool, mentioned by several care homes and stakeholders too, helping homes to identify residents at different stages, including spotting deterioration. However, some homes admitted that they hadn’t embedded the GSF enough at the time of speaking. For one home, the ‘what is important to me’ document was a lasting tool. Several homes described the wider package of support on offer to them, training repeatedly mentioned, especially later into the evaluation period. One health stakeholder believed the project’s success relied on re-educating care homes about earlier identification of EOL residents and hospital admissions, especially given the high staff turnover. In fact, two GPs questioned whether the positive results through the ASP project would continue as new care staff and managers come in and need new training, in a tough sector with high staff turnover.

The need for a dedicated role

Many stakeholders did believe a designated role like the ASP was required, especially with the time needed for care home residents. Several homes also wanted a dedicated resource to continue, able to offer them reassurance, such as when challenging GPs. Other roles simply don’t have the time and aren’t looking at “the whole picture” for residents, including those with more complex needs and lacking mental capacity. The need for an advocate for care home residents at EOL was also raised, increasing awareness generally of end of life and palliative care and helping to improve the management of care, rather than intervention, at that point. Some likened the ASP role to a nurse consultant, providing clinical leadership as well as clinical decisions.

At different stages in the evaluation some stakeholders suggested other routes to achieving what the ASP was doing. Earlier in the evaluation, some believed GP alignment had the potential to instil a habit of weekly ward rounds and having a named GP for care home residents, as well as GPs and surgeries getting to know care home staff. Arguably, GP alignment does seem to be making a big difference in the relationships between care homes and GP surgeries, although this also came after the groundwork and advocacy for EOL from the ASP project.

Has the ASP role resolved all problems with end of life care for care home residents in Barnsley? No. But the ASP role has been instrumental in a shift in how care homes are viewed within healthcare and how residents are viewed by GPs and others. The ASP sits within a wider framework that supports EOL care in homes. It is almost impossible to single out the contribution of one role among lots of other changes. But without such a dedicated role, there would be a hole to fill.

2. Introduction

This report brings together evidence from a two-year evaluation of the Barnsley Advanced Specialist Practitioner (ASP) care homes project, funded by Macmillan Cancer Support and run in partnership with South West Yorkshire Partnership NHS Foundation Trust (SWYPFT).

Barnsley context

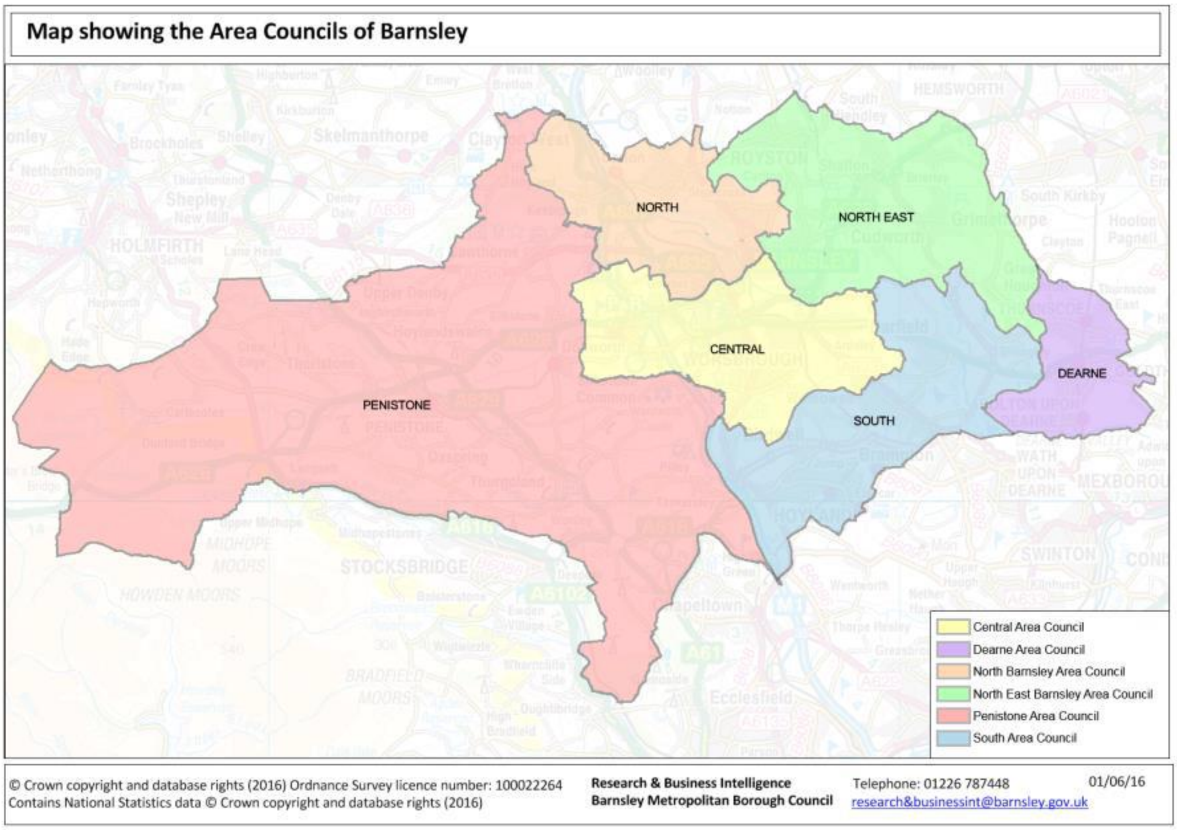
In the recent years before the ASP role started, Barnsley had experienced an increase in its elderly population and a subsequent increase in the number of elderly people living with cancer or palliative care needs. Alongside this, Barnsley had seen a decline in the number of nursing beds and homes and a loss of appropriately skilled staff. This has led to an increasing reliance on residential care homes where the required skills needed to support palliative care for residents was lacking.

Due to competition for care home places, many people were not able to access suitable and affordable end of life care near to their previous place of residence and were forced to move. This often resulted in residents changing their GP, making it difficult for primary care professionals to provide future planning for individuals in their preferred place of care.

All of these factors can lead to a lack of clinical leadership, resulting in unavoidable hospital conveyance and admission, leading to poorer quality and less personalised care for those at end of life. It can also lead to people being cared for and dying away from their preferred place of care or death.

Advanced Specialist Practitioner project

Macmillan Cancer Support has therefore funded a three-year pilot with the local Palliative Care and End of Life Service in Barnsley, part of SWYPFT. It started in January 2019, had a four-month gap when the ASP role was seconded into the Trust's community team during Covid and will end in March 2022. The pilot has aimed to provide enhanced care planning to care home residents in the last year of life through improved collaborative, enhanced care planning. This work has been facilitated by an Advanced Specialist Practitioner who has worked across Barnsley, one neighbourhood at a time, alongside the existing Clinical Nurse Specialists, with a strong focus on delivering personalised care to residents.



Working alongside both primary and secondary care colleagues, the ASP role has aimed to use her advance clinical assessment skills and palliative care knowledge to ensure a robust individualised care plan is in place for each resident where appropriate, and where this is the resident's or family's choice. Sometimes this is done directly with care home residents, but a lot of the ASP role is also about engaging and educating care homes and their staff, as well as wider service involvement, particularly with GP practices in Barnsley, multi-disciplinary team (MDT) meetings and community teams. Alongside the ASP role is support from other elements, particularly later into the evaluation period, such as the End of Life (EOL) Facilitator.

The Covid-19 pandemic also presented different challenges for EOL care for residents in care homes. The ASP was temporarily seconded back into a community role to work with homes, often physically there, for a four-month period at the height of the first wave of Covid infections. Returning to the Macmillan-funded role in August 2020, care homes continued to have restrictions due to Covid. This has been the context for the later wave of work as part of this evaluation.

Alongside the ASP role, wider work on EOL and palliative needs for care homes have come into being over the course of the evaluation, stemming from the Enhanced Care to Care Homes framework. This includes GP alignment, where a single practice has been aligned to each care home, and an increase in MDTs between care homes and surgeries. Other changes include a move from long-term condition practitioners to frailty nurses working with care homes. In the community, the national move to Primary Care Networks (PCNs) has also strengthened community nursing teams, including the role of community matrons.

Ultimately, the aim of the ASP project has been to ensure a proactive and meaningful care plan is developed and is led by the individual’s needs and ensures liaison with all involved, aiming to avoid unnecessary hospital admissions and safeguarding quality of care. It is also about ensuring an individual’s choice right through to death, including dying in their preferred place.

Evaluation approach

M·E·L Research was commissioned to evaluate this ASP project in Barnsley. The aims of this evaluation are to increase understanding of:

- the impacts of the ASP on **high quality** clinical and personalised holistic **care and personalised choice** in the last year of life
- what an appropriately skilled and **integrated system** working looks like
- the **sustainability** of personalised holistic care planning within the system.

This evaluation started in October 2019 and has run to June 2021, guided throughout by a steering group made up of representatives from Macmillan, SWYPFT and the ASP postholder. The evaluation was intended to end sooner, in June 2020, but was extended by a year because of the impact of Covid. The evaluation framework used is summarised at Appendix A1.

Wherever possible, we have tried to capture a range of evidence, including from neighbourhoods and care homes at different stages of involvement with the ASP. This has included those where the ASP had already worked (described as ‘after’ homes in this report), where the ASP was currently working (‘during’) and an attempt to engage homes and professionals in neighbourhoods the ASP was still to go (‘before’). This offers one way to compare working practices with and without the intervention. We have also aimed to triangulate data, comparing evidence from different sources. This also helps to build a fuller picture of how the ASP project has worked.

Over these near-two years, we have gathered evidence in a variety of ways, summarised below:

- EPaCCS (electronic palliative care coordination systems) data at an anonymised patient level from January 2019 to May 2021.
- Hospital admission data for care home residents who had been seen by the ASP role, covering a six-month period before the intervention and six months after, to compare before and after the involvement. A first analysis of this data covered hospital admissions spanning November 2018 to June 2021.

- Two audits of 999 calls for care homes in Penistone, first before the ASP role had been to that neighbourhood (in February 2020) and then after her involvement there (in March 2021).
- Interviews with nine care home managers and staff at various stages in the evaluation.
- A focus group with two ‘after’ care homes representatives, in May 2021.
- Received feedback forms from six care homes (1 before, 3 during, 2 after) alongside additional written feedback from four care homes.
- Postcards with qualitative feedback from 10 employed carers, all from the same care home, although shared with a wider group of care homes where the ASP had been working.
- 19 interviews with healthcare stakeholders. This includes GPs, palliative or end of life specialist roles, community teams, SWYPFT staff, health commissioners and more. Another such stakeholder provided written feedback instead.
- The regular evaluation steering group meetings also provided valuable evidence throughout the course of the project.

The table below shows these data collection methods matched to the overriding evaluation questions and shows when they took place.

2.1: Data collection methods matched to evaluation questions

Evaluation question	Data collection method	When collected
High quality personalised holistic care and choice	EPaCCS data	Feb 2020 Oct 2020 Jun 2021
	Hospital admission data	Nov 2020 Jun 2021
	999 audit	Feb 2020 Mar 2021
	Interviews with care home staff	Nov 2019 Feb/Mar 2020 Nov 2020 May/Jun 2021
	Care home postcards	Apr 2021
	Written feedback from care homes	May/Jun 2021
	Care home focus group	May 2021
	Stakeholder interviews	Nov 2019 Mar 2020 Sept 2020 May/Jun 2021
Integrated system	Interviews with care home staff	Nov 2019 Feb/Mar 2020 Nov 2020 May/Jun 2021

Evaluation question	Data collection method	When collected
	Care home feedback form	Nov 2020 Apr 2021
	Care home focus group	May 2021
	Stakeholder interviews	Nov 2019 Mar 2020 Sept 2020 May/Jun 2021
Sustainability	999 audit	Feb 2020 Mar 2021
	Interviews with care home staff	May/Jun 2021
	Care home postcards	Apr 2021
	Written feedback from care homes	May/Jun 2021
	Care home focus group	May 2021
	Stakeholder interviews	Nov 2019 Mar 2020 Sept 2020 May/Jun 2021

The contact with care homes is outlined in Appendix A2. We heard from 16 different care homes throughout the evaluation, several of these in more than one way, such as an interview and written feedback or the 999 audits. This has been one way to capture change over time. The care homes have come from five of the neighbourhoods and at all three stages (after the ASP intervention, during and before).

The table below also shows the range of wider stakeholders we've engaged with during the evaluation, including the timing of fieldwork.

2.2: Engagement with wider stakeholders during the evaluation

Nov 2019	4: community, health, GP
Mar 2020	4: GP surgeries
Sept 2020	ASP steering group
May/Jun 2021	10: community, health, GPs

Limitations

In order to be transparent, it's right to set out limitations of this evaluation:

- As with so much of our lives since March 2020, the Covid pandemic has had an impact on the evaluation. We understandably had to curtail some of our planned evaluation activities. For example, due to pressures at care homes, we did not send out online feedback forms to complete, nor have we been able to contact any care home residents or their families. All fieldwork has had to take place remotely, including speaking to care homes and wider stakeholders. This has also limited our ability to engage directly with care home residents and their families. Even without Covid, this can be a challenge, for example if residents lack mental capacity or if families are grieving, when it wouldn't be morally or ethically right to engage them in research. This means our findings on high quality care are not direct from residents themselves and have to come via secondary sources such as carers, wider stakeholders and other data.

- We anticipated using CQC data on care homes, including to tease out differences between care homes (eg large or small, independent or a chain). However, through several conversations, the data CQC could provide us would not capture the key differences by care homes, such as staff turnover. Also, Covid has affected CQC and their inspection programme too.
- Instead of using Yorkshire Ambulance Service (YAS) data on conveyancing to hospital, we have been able to analyse anonymised hospital admission data for care home residents. This has been an even richer source of evidence.
- Another source of data we hoped to see was from GP palliative registers. The evaluation itself has found that these registers aren't as full as originally expected for care home residents. We would have encountered information governance barriers too.
- As an independent evaluator, we bring out skills and experience to the research and evaluation. However, we're in the hands of those working on the ground locally to direct our attention to the right stakeholders to speak to. This can introduce potential bias in who is selected. Thankfully, we have engaged a range of care homes and wider stakeholders, with mixed views.

Report structure

The rest of this report outlines the evidence. It starts with resident level data, first from EPaCCS and then hospital admission data. Then comes the analysis of the two 999 audits carried out in care homes in Penistone. After that are the views of care home staff, followed by views from wider stakeholders. Each of these sections has a summary. We end with our conclusions and recommendations. Appendices provided greater detail in certain areas, including a glossary of key (medical) terms.

3. Resident-level statistical data

This section presents data collected at a resident level, first from EPaCCS, the electronic palliative care coordination systems, then from hospital admissions records.

EPaCCS

A key source of data comes from EPaCCS, the electronic palliative care coordination systems, which are used to record and share an individual's care preferences and key details about their care at the end of life. For this evaluation, this data is particularly important when looking at the impact of the ASP role on clinical and personalised choices and care at end of life, such as whether advance care plans have been discussed, preferred place of death, resuscitation preferences and much more. This rich EPaCCS data has been made richer by extra information provided directly by the ASP, data not currently captured within the SystmOne electronic full patient records.

We have data at the anonymised EPaCCS patient level for 210 residents of care homes in the neighbourhoods where the ASP has actively worked from January 2019 to May 2021. As the data is anonymised, this data is useful to show the difference made by the ASP project at large, presenting the results from homes after ASP interventions. Even being able to present and analyse this data is testament to the work in the ASP project, as many – perhaps all – of these 210 residents have an EPaCCS in place because of the project.

Following an earlier analysis of the data within the evaluation (covering March 2019 to February 2020), the final EPaCCS data also includes additional rows for residents seen more than once. While the overwhelming majority of residents have just one set of data, 15 residents (or 7% of the total) are shown two or three times. In total, there are 228 rows of data analysed. Depending on the analysis below, we show data either for the 210 individual residents or all 228 rows.

The data records the primary diagnosis of residents, which we've classified into groups, as shown below. It shows the high level of residents with EPaCCS that have dementia, over a third (38%), but a relatively low number that have cancer as a primary diagnosis (just 8%). Given the age of these residents, many will have co-morbidities, so secondary diagnoses may include dementia or cancer.

3.1: Primary diagnosis group

	Count of residents	% of total
Dementia	79	38%
Other non-cancer	76	36%
Cancer	16	8%
Unknown	39	19%
Total residents	**210**	**100%**

Just over a third (74 or 35%) of these residents were on the palliative care register. It's hard to find comparative data for this, though wider feedback we received during the evaluation suggests it's likely that fewer were on GPs' palliative care registers beforehand. If so, this is a testament to the ASP project. Being on the register ensures that these residents are discussed more regularly by practices, including at MDT meetings and (virtual) ward rounds.

Looking at preparations for end of life, the EPaCCS data shows a range of plans. They show that high proportions of these records with either an advance care plan (when they have capacity) or best interest plan (when capacity is lacking), some 87%, as well as 84% who had a treatment escalation plan and 77% with an emergency health care plan. (Many of these terms are explained in the glossary at the end of this document.) Just 6% have a preferred priorities for care document. In a similar way, most residents (84%) had a stated CPR (cardiopulmonary resuscitation) preference, with 77% of all with a recorded CPR decision not for resuscitation and just 7% with a decision to attempt resuscitation (the remaining 16% were blank for this question). This is often a medical decision as opposed to a personal choice, though.

3.2: Plans in place for records

	Count	% of total
Advance care plan or best interest plan	198	87%
Treatment escalation plan	191	84%
Emergency health care plan	176	77%
Preferred priorities for care document	14	6%
Total records	**228**	

A sub-set of the EPaCCS data provide details about whether there were previous EPaCCS or plans in place before the ASP intervention. This represents 79 residents, over a third (35%) of them. Of these, 49 had a full or partial core assessment, 60 had documents regarding resuscitation decision, while others had certain elements but not others, such as an emergency health care plan, Karnofsky or Rockwood scores or preferred wishes recorded. Some of these records also show that other people have been involved in these plans, including care home staff and managers or GPs talking to family. This suggests that forward planning and recording of wishes around end of life are taking place in care homes.

ACPs can be seen as one indicator of setting up wishes and plans sometime in advance of dying. They are only possible where somebody has mental capacity, so there are limits to their use with residents who lack capacity. Less than half of residents did have an ACP in place, although this is slightly higher where the main diagnosis is cancer or other non-cancer and, unsurprisingly, lower for those with dementia as a primary diagnosis.

3.3: Proportion of records by primary diagnosis group with an ACP

	Count	ACP	No ACP	ACP status blank
Dementia	85	39%	59%	2%
Other non-cancer	81	51%	47%	2%
Cancer	17	53%	35%	12%
Unknown	45	40%	49%	11%
Total records	**228**	**44%**	**51%**	**5%**

Connected to this is whether a mental capacity assessment has been carried out. The table below shows this by primary diagnosis. This data suggests that two-fifths of records (41%) did have a mental capacity assessment, highest for those with an ‘other non-cancer’ but not dementia as the primary diagnosis.

3.4: Proportion of records by primary diagnosis group with a mental capacity assessment

	Count	Yes	No	Not recorded
Dementia	85	25%	71%	5%
Other non-cancer	81	54%	44%	1%
Cancer	17	41%	59%	0%
Unknown	45	49%	49%	2%
Total records	**228**	**41%**	**56%**	**3%**

Looking in more detail at ACPs, it’s useful to compare the proportion with and without these plans by their Gold Standard Framework (GSF) prognostic indicator, as shown below. This GSF indicator aims to support earlier identification of people nearing the end of their life and is colour-coded according to people's expected length of remaining life. The proportion with an ACP is highest for those with a blue indicator stage (year+ prognosis), with more than six in ten having an ACP. The level is substantially lower for all other groups, nowhere more than 40% with an ACP. This may again indicate residents' mental capacity, with reducing levels of capacity closer to death.

3.5: GSF prognostic indicator and ACP

GSF prognostic indicator stage	Count	ACP	No ACP	ACP status blank
Blue: year+ prognosis	63	62%	35%	3%
Green: months prognosis	74	36%	59%	4%
Yellow: weeks prognosis	40	40%	55%	5%
Red: days prognosis	23	39%	61%	0%
Prognosis not recorded	28	36%	50%	14%
Total records	**228**	**44%**	**51%**	**5%**

We're also able to see the changes made to the 15 residents who have been recorded more than once on EPaCCS, ie after the ASP or somebody else has updated them. In the notes, it shows that some of these are reviews on behalf of colleagues or to update the EPaCCS. In five cases, the GSF prognosis indicator had changed, from year+ (blue) or months (green) to live to weeks (yellow) or weeks to days (red) to live for one, with a gap in time between the entries, matched by a reduction in Karnofsky score for two of these.

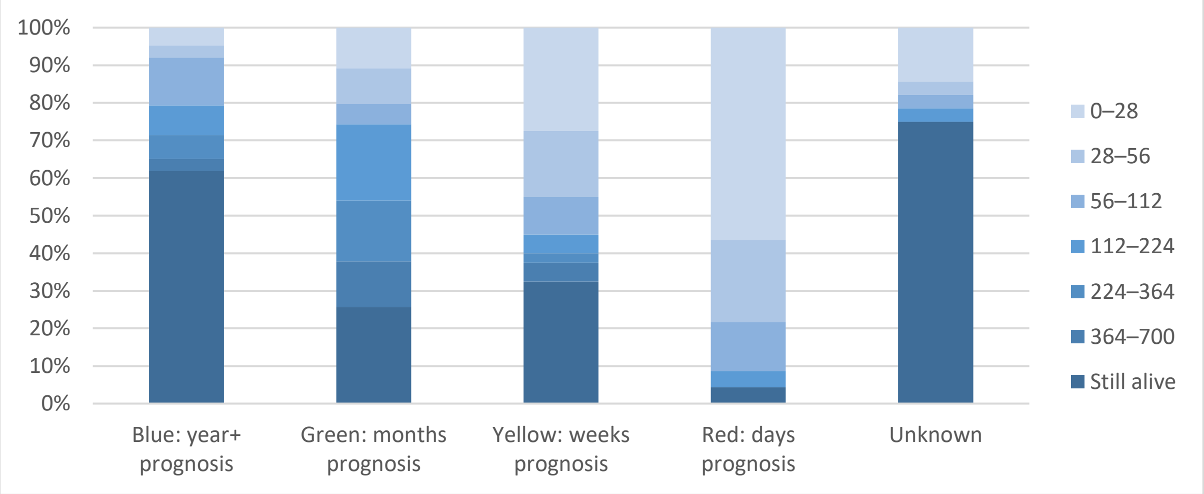
Returning to the GSF prognosis indicator, from the data it's possible to compare the prognosis given with the actual date of death, showing how long residents actually lived after that prognosis. This gives an idea about how accurate the prognosis has been.

3.6: Time from ASP intervention (EPaCCS date) to death by GSF prognostic indicator

Days from referral to death	Blue: year+ prognosis	Green: months prognosis	Yellow: weeks prognosis	Red: days prognosis	Unknown	Total
0–28	5%	11%	28%	57%	14%	13%
28–56	3%	9%	18%	22%	4%	10%
56–112	13%	5%	10%	13%	4%	9%
112–224	8%	20%	5%	4%	4%	11%
224–364	6%	16%	3%	0%	0%	7%
364–700	3%	12%	5%	0%	0%	6%
Still alive	62%	26%	33%	4%	75%	41%
Total	**63**	**74**	**40**	**23**	**28**	**228**

The prognosis given is broadly right, as you can see from the table above and chart below. It shows that the majority of those with a blue prognosis (year+ to live) were still alive at the end of May 2021; among these still alive, there were 262 days on average from the date of referral to the end of May, when the data was run. The mid-point (median) for those with a green prognosis (months) was dying 224–364 days after referral, or about 7–12 months after. For those with weeks to live (yellow indicator), the mid-point is 56–112 days after referral, or 8–16 weeks. For those with days to live (red indicator), the mid-point is 0–28 days after referral, or up to four weeks.

3.7: Time from referral to death by GSF prognostic indicator



Who oversees residents' EOL care needs is also important. The 'outcome' recorded against residents shows that over three-fifths of residents (62%) were being returned to care home staff but with education (for staff), a higher figure than in our earlier analysis, when it was just 52%. A quarter (25%) were under the care of district nurses (compared to 30% earlier), 5% with a community matron (compared to 3%) and just 4% being kept under the ASP herself (against 9%).

3.8: EOL residents' support

	% of total
Back to care home staff with education	62%
Under care of district nurse	25%
Under care of community matron	5%
Keep with ASP	4%
Unknown	3%

As well as medical needs and support, end of life care planning can also support arrangements with family or others, including setting up formal lasting powers of attorney. In England, the law allows these to be set up to cover personal welfare issues, property and affairs, or both. The EPaCCS data suggests 46 residents (20%) had any form of power of attorney. 18 of these had both welfare and property, 11 for welfare alone and 17 for just property. It was much more common for these legal powers to be set up for residents with dementia, particularly for powers over welfare.

3.9: Powers of attorney

	Residents
Over welfare alone	11
Over property alone	17
Over both welfare + property	18

A key indicator for this evaluation is whether residents die in their preferred place of death. Knowing the preferred place of death is therefore important before the event. As shown below, the overwhelming majority of residents (172 or 75%) *had* explicitly stated a preference, almost all to die in the care home (99% of all residents with a stated preference). For 40 residents, 18% of all these, the discussion on a preferred place of death was not appropriate or declined, the resident was unable to express a preference or was undecided on where to die in a fair proportion of cases. It's possible that the place of death was known for some of these, though it was not recorded on EPaCCS.

3.10: Preferred and actual place of death

	Actual place of death			Still alive	Total
Preferred place of death	Care home	Hospital	Unknown		
Care home	91	5	13	61	170
Unable to express preference	9	4	5	11	29
Not recorded	1		3	12	16
Discussion not appropriate	1		1	3	5
Discussion declined			1	3	4
Patient undecided			1	1	2
Home				1	1
Hospital				1	1
Total	**102**	**9**	**24**	**93**	**228**

The final element to draw out from this data relates to death itself, also shown above. Of the 228 residents, 135 of them had died by the end of May 2021, representing 59% of them. Of these, 91 had died in their preferred place of death, all in a care home. This represents 95% of residents where both the preferred and actual place of death is known. In contrast, just 18 residents stated a preference to die in a care home and either died in hospital (5 residents) or the actual place of death isn't known. Among other residents who had died, the picture is somewhat more mixed. None of these residents had an explicitly stated a preferred place to die. Taking these 26 residents together, 11 died in a care home, 4 in hospital (all four marked as for clinical reasons) and the place of death is unknown for 11 of them. Although smaller numbers in this undecided or unrecorded group, it suggests that care home residents who expressly state a preferred place to die are much more likely to die there, almost all in a care home. Comparative data is not readily available. However, Public Health England data[1] shows that in the Barnsley CCG area in 2017 just 47% of residents died in their usual place of residence. This is highest in the oldest age group shown, those aged 85 or older, yet it is still just 55%.

Hospital admissions

As part of our evaluation of the ASP care home project, we have analysed anonymised data showing unplanned secondary admissions to hospital six months before the ASP intervention and up to six months after (or shorter if the patient had died beforehand). This covers a period of ASP involvement from January 2019 to early June 2021.

Over this period the data covers 127 of the residents supported by the ASP, representing 56% of the 228 residents she supported over this period.

Six months before ASP intervention (pre data)

114 residents did have an unplanned secondary care admission in the six-month period before the ASP intervention, representing 50% of all residents and accounting for 216 such admissions. The average number of admissions over all of these residents was 0.95 over this pre-ASP period (though 1.89 among those who had any admissions).

These admissions accounted for 1,097 days in hospital, average 4.8 per resident (or 9.6 among those admitted). The longest stay was 104 days.

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[1] Palliative and End of Life Care Profiles: Death in usual place of residence

3.11: Number of unplanned secondary care admissions in six months before intervention

Number of admissions	Number of residents	% of all residents
0	114	50%
1	60	26%
2	32	14%
3	8	4%
4	8	4%
5	3	1%
6	1	0.4%
7	1	0.4%
8	1	0.4%

When translated to a monthly average, this means 0.2 unplanned secondary care admissions and 0.8 days in hospital per month for each care home resident. For those who were admitted, this translates as 0.32 admissions and 1.6 days per month.

It can also be useful to see whether hospital admissions are more likely outside of normal working (or surgery) hours. To begin with, we are able to see whether admissions were mid-week or during the weekend or on public holidays. This is shown below. As you can see, three in ten admissions were over the weekend or on public holidays, which is almost exactly the same proportion of such days over that period (31%).

3.12: Unplanned secondary care admissions in six months before intervention and whether mid-week or during weekends and public holidays

	Number of admissions	% of admissions
Mid-week	115	70%
Weekends / public holidays	65	30%

When looking at the time of day of admission, below, we see that 71% were during daytime hours (8am–5pm), while 29% were out of hours. These normal working hours account for nine out of 24 hours in the day, though a greater share of time when people tend to be awake. As such the proportions below seem reasonable.

3.13: Unplanned secondary care admissions in six months before intervention and whether daytime (8am–5pm) or out of hours

	Number of admissions	% of admissions
Daytime	153	71%
Out of hours	63	29%

The hospital admission data also shows the reason (primary diagnosis) for admission, as presented below. This table shows the 20 top reasons, which accounted for just over half (55%) of all admissions among these residents. 'Unspecified acute lower respiratory infection' and 'urinary tract infection, site not specified' were the top two, with 16 admissions each (or 7.4% of all pre-ASP admissions).

3.14: Top 20 reasons for unplanned secondary care admissions in six months before intervention

Reason	Number of admission	% of admissions
Unspecified acute lower respiratory infection	16	7.4%
Urinary tract infection, site not specified	16	7.4%
Lobar pneumonia, unspecified	10	4.6%
Chronic obstructive pulmonary disease with acute lower respiratory infection	9	4.2%
Pneumonia, unspecified	7	3.2%
Pneumonitis due to food and vomit	7	3.2%
Unspecified dementia	6	2.8%
Transient cerebral ischaemic attack, unspecified	5	2.3%
Emergency use of U07.1	5	2.3%
Cerebral infarction, unspecified	4	1.9%
Type 2 diabetes mellitus	4	1.9%
Senility	4	1.9%
Sepsis, unspecified	4	1.9%
Acute renal failure, unspecified	3	1.4%
Syncope and collapse	3	1.4%
Gastrointestinal haemorrhage, unspecified	3	1.4%
Tendency to fall, not elsewhere classified	3	1.4%
Unspecified injury of head	3	1.4%
Superficial injury of head, part unspecified	3	1.4%
Volume depletion	3	1.4%

29 of the 128 residents died within the ASP intervention period, usually within a few days of that date.

Six months after ASP intervention (post data)

99 residents were still alive at the point of discharge from the ASP intervention.

Of these, 65 residents did not have an unplanned secondary care admission up to six months after the ASP intervention, leaving 34 who did have such an admission, or just 34% of these residents. This alone could be a strong indicator of the success of the ASP intervention, significantly reducing the proportion of residents having unplanned secondary admissions to hospital. Of course, a large caveat here is that the data includes the time of the Covid-19 pandemic for some care home residents. It's therefore possible that this wider context also has a bearing on the differences in hospital admissions.

There were 53 admissions over this period, so an average of 1.6 admissions for those residents admitted.

Because a number of the residents died in the six months following the ASP intervention, we have calculated figures based on living months. This allows for a fairer comparison between the pre and post data. This is based on the number of days between the date the ASP intervention ended (labelled 'DateDischarge' in the data) to the date of death, then turned into the number of months.

For example, one patient was discharged from the ASP service on 24-1-19 and died on 22-4-19, 88 days later, which equates to 2.89 months. This patient had one unplanned admission after the ASP intervention, which averages at 0.35 admissions per living month.

We've also taken account of the length of time from residents being discharged from the ASP and the end of the data collection period.

The average number of admissions per living month was 0.16 across all of these 99 residents (or 0.48 for the 34 who were admitted). This is about a sixth (17%) of the value for the six months before the ASP intervention (0.95 to 0.16), a significant difference. For those residents who had been admitted in the six months before, there was also a reduction after the ASP, to just 25% the level of admissions beforehand (1.89 to 0.48). This can suggest that the ASP intervention is contributing to a reduction in unplanned secondary care admissions. Changes because of Covid-19 may well have accounted for some of these, however.

Looking at the length of time in hospital, it's fairest to compare residents who were in hospital in the pre-ASP period with those in the post period. This shows an average of 1.6 days before the ASP intervention and 2.13 days in the period up to six months after the ASP intervention. This is an increase, so may suggest that the care and treatment was for more serious conditions. Other factors may well have played a role.

Leaving aside Covid, we can again look at which day of the week these admissions fell in the period up to six months after ASP intervention. This is shown below, with three-quarters (74%) mid-week and just a quarter (26%) at weekends; no admission took place on a bank holiday. This is a slightly smaller proportion being admitted at weekends, which is a good sign. However, it's based on relatively low numbers, so hard to conclusively point to the impact of the ASP project.

3.15: Unplanned secondary care admissions in six months <u>after</u> intervention and whether mid-week or during weekends and public holidays

	Number of admissions	% of admissions
Mid-week	39	74%
Weekends	14	26%

When looking at the time of day of admission, slightly over three-quarters (77%) were during daytime hours (8am–5pm), while 23% were out of hours. Positively, this is a lower proportion out of hours, down from 29% in the pre-ASP period. This may suggest that care homes are feeling more confident in caring for residents in the care home and less likely to call 999 out of hours and at weekends.

3.16: Unplanned secondary care admissions in six months <u>after</u> intervention and whether daytime (8am–5pm) or out of hours

	Number of admissions	% of admissions
Daytime	41	77%
Out of hours	12	23%

For this data, we've shown the top eight reasons for unplanned secondary care admissions in period up to six months after intervention; all other reasons accounted for just one admission each. As we're not clinicians, we can't comment on the differences between the pre and post ASP periods, nor any issues to do with Covid or seasonality of conditions. Again, these are relatively low numbers, so caution should be taken with wider conclusions on the reason for admission.

3.17: Top eight reasons for unplanned secondary care admissions in six months after intervention

Reason	Number of admission	% of admissions
Urinary tract infection, site not specified	6	11.3%
Emergency use of U07.1	5	9.4%
Lobar pneumonia, unspecified	4	7.5%
Chest pain, unspecified	2	3.8%
Unspecified acute lower respiratory infection	2	3.8%
Chronic obstructive pulmonary disease with acute lower respiratory infection	2	3.8%
Congestive heart failure	2	3.8%
Open wound of head, part unspecified	2	3.8%

Summary

This section presents data collected at a resident level, from EPaCCS on 210 care home residents from January 2019 to May 2021 and hospital admissions records from November 2018 to June 2021. From the **EPaCCS** data we know that over a third (38%) had dementia as a primary diagnosis. Also, just over a third (35%) of these residents were on the palliative care register with their GP.

Looking at preparations for end of life, the EPaCCS data shows a range of plans, with high proportions having an advance care plan or best interest plan (87%), a treatment escalation plan (84%) and an emergency health care plan (77%).

The ‘outcome’ recorded against residents shows that once discharged by the ASP over three-fifths of residents (62%) were being returned to care home staff but with (staff) education, while a quarter (25%) were under the care of district nurses and small percentages going to a community matron (5%) or being kept under the ASP herself (4%).

EPaCCS can also record the preferred place of death. The overwhelming majority of residents (75%) had explicitly stated a preference, almost all to die in the care home (99% of all residents with a stated preference). 135 residents (or 59% of the 228) had died by the end of May 2021. Of these, 91 had died in their preferred place of death, all in a care home. This represents 95% of residents dying in their preferred place of death where known.

Of the 228 residents supported by the ASP over our evaluation period, 114 had an **unplanned secondary care admission** in the six-month period before the ASP intervention, representing exactly

50%. The average number of admissions over all of these residents 0.95 over this pre-ASP period (though 1.89 among those who had any admissions), average 4.8 days in hospital per resident (or 9.6 among those admitted).

99 residents were still alive at the point of discharge from the ASP intervention. Of these, just 34 had an unplanned secondary care admission up to six months after the ASP intervention, representing just 34% of these residents. On the face of it, this looks like a strong improvement from the 50% admitted in the six months beforehand. Of course, Covid had a bigger bearing on the post period than the pre period.

A fairer comparison between these two periods is to look at the average number of admissions per *living* month, taking account of those who died within the following six months of the ASP intervention. We've also taken account of the length of time from residents being discharged from the ASP and the end of the data collection period.

On this comparison, results look positive. The average number of admissions per living month went down from 0.95 per resident to 0.16, just a sixth the rate, a big difference. Looking at the length of time in hospital for those admitted, there is an increase between the two periods. It averaged at 1.6 days per month before the ASP intervention and 2.13 days after the ASP intervention. This may suggest that the care and treatment was for more serious conditions in the later period, though other factors may also have played a role.

We've also compared when admissions to hospital took place, whether mid-week or weekends and at what time of day. Three in ten (30%) admissions were over the weekend or on public holidays in the pre-ASP period, a similar proportion to such days over that whole period. This fell slightly to just a quarter (26%) at weekends in the post-ASP period; no admission took place on a bank holiday. By time of day, 29% were outside daytime hours (5pm–8am) in the six months beforehand and this drops to 23% in the six months after the ASP intervention. Both of these are good signs and may suggest care homes are more confident in keeping residents in their homes rather than calling 999 and then residents being taken and admitted to hospital. However, other factors, particularly Covid, may also have made a difference here.

4. Audit of 999 calls in care homes

Moving on from patient-level data, we've also carried out two audits of 999 calls in care homes in one neighbourhood, Penistone, before the ASP intervention (in February 2020) and after the intervention (in March 2021). This is another way to monitor change because of the ASP intervention. Of course, Covid may well have also altered care home behaviour. Also, it accounts for all residents in these care homes, not just ones approaching end of life and known to the ASP. For these and others, a 999 call is sometimes the most appropriate action to take. Mindful of sensitive data, we've anonymised the care homes here, although the same letter used represents the same home in each audit (before, after).

Before the ASP intervention

We did this in February 2020, right at the start of the ASP's involvement in the neighbourhood, thus close to capturing their actions before her intervention. This is also before the Covid-19 outbreak in the UK, so not influenced by that, we believe. For the evaluation, this is important to see what is happening before focused work with the ASP project, and is a useful indicator of what care homes are already doing.

Like any exercise of this type, it relies on care home staff to (remember to) complete the form and to log data accurately. As we've captured data over just a single month and from five care homes, some of the sample sizes are small. Nonetheless, it gives a good snapshot of care home activity mostly before the ASP intervention. It's also worth bearing in mind that because the data was anonymised (to us), it means we can't be certain of whether any of the 999 calls in particular care homes were for the same resident; it's possible that the perceived needs of certain residents led to multiple 999 calls.

We have findings from five care homes in this neighbourhood, which recorded 26 calls to 999 between them. There is a lot of variation between care homes, as can be seen below. Across the care homes, an average of just over five 999 calls were made over the month, which represents 13% of residents (although some may be for the same resident, repeatedly). The numbers range from zero at care home B to a third of residents at care home C. Do bear in mind that this is a small sample and just a snapshot over one month. The picture may well look different from one month to another, even within the same care home. In future, comparing this data with that from YAS will be telling.

4.1: Number of 999 calls by care home (before)

Care home	Max number of residents	How many 999 calls	Calls as % max residents	Note
A	40	4	10%	
B	27	0	0%	CQC: requires improvement 2019
C	36	12	33%	Nursing home too
D	33	7	21%	CQC: requires improvement 2019
E	62	3	5%	Nursing home too
Average	**39.6**	**5.2**	**13%**	

One element of the 999 audit has been to see who was called first, before calling 999. Again, there is considerable variation between the four care homes that did make a 999 call. For care home C, two-thirds started with a call to the GP; none of the other care homes stated that they'd called the GP first. Instead, other care homes were much more likely to call 999 directly. For example, six of the seven calls made by care home D were direct to 999.

4.2: Origin of 999 calls (before)

		Who homes called originally			
Care home	How many 999 calls	GP %	111 %	999 %	Unknown %
A	4	0%	0%	75%	25%
B	0	–	–	–	–
C	12	67%	25%	8%	0%
D	7	0%	14%	86%	0%
E	3	0%	33%	67%	0%
Average		**31%**	**19%**	**46%**	**4%**

A key element in the ASP project is to minimise unnecessary hospital trips for end of life care home residents, especially those who would prefer to be cared for in the care home rather than be hospitalised and undergo interventions and treatment that may not improve their *quality* of life, even though it may try to *extend* their life. On this aspect alone, half of recorded 999 calls led to a trip to hospital, while half didn't. Again, there is a very big difference between care homes. All of the four 999 calls from care home A led to a hospital trip, whereas just 8% of the care home C ones did. Because of the higher number of 999 calls altogether from care home C, it disguises that most calls from the other three care homes did result in a hospital trip.

4.3: 999 calls leading to hospital visit (before)

Care home	How many 999 calls	Led to hospital visit	
		Yes %	No %
A	4	100%	0%
B	0	–	–
C	12	8%	92%
D	7	86%	14%
E	3	67%	33%
Average		**50%**	**50%**

It's possible that the time of day makes a difference to 999 calls and their outcome, especially if calls are out of hours. Although we asked care homes to note the time of the 999 calls, the responses are too varied to fully code (eg full time, just the hour, 'AM' or 'PM', blank). Instead of showing this data at a care home level, we've grouped them all together, as shown below. This shows that, where time *is* known, more overnight calls led to a hospital visit (where time is known), while fewer daytime ones did. This theory seems to hold true.

4.4: Overnight 999 calls leading to hospital visit (before)

Hospital visit	How many 999 calls	Overnight (11pm–7am)	Daytime (7am–11pm)	Unknown %
Yes	13	31%	8%	62%
No	13	0%	38%	62%
Average		**15%**	**23%**	**62%**

When looking at the reasons for the calls, a fall, often "unwitnessed", accounted for 11 of them, some 42% of all recorded calls to 999 (as shown below). The next most common recorded reason, "generally unwell", came almost all from just one of the five care homes. Being unresponsive – due to having stopped breathing or having seizures – was the reason given for two calls to 999 (or 8%), both from one care home. There were other, more varied, reasons given for the 999 call, such as possible pneumonia, low BP and "SCRS", agitation, pain and swollen legs, "confused, cold clammy".

4.5: Reason for 999 calls (before)

Reason	How many 999 calls	% of total
Fall	11	42%
Generally unwell	9	35%
Unresponsive	2	8%
Other	4	15%

The audit form also records the advice given. However, it's not entirely clear if this is the advice from the initial service called (eg GP, 111) or by 999 or any paramedics called out. For care home C, the most common advice was to prescribe antibiotics, for UTI four times and for a chest infection once. This care home, which had by far the fewest number of visits to hospital following the 999 calls, also records advice to administer other medication: codeine and "increased promethazine". In two of the care homes, care homes A and D, all actions that were recorded (not all were) were to call 999; these were mostly for falls. Other notable advice given was to have a best interest meeting (a resident at care home C) and the need for a long-term plan (one at care home E). This last one suggests the need for end of life support.

After the ASP intervention

We repeated this same exercise in March 2021, after the ASP intervention in Penistone. We aimed to repeat it in the same month, to minimise seasonality issues, eg more illnesses during winter months. However, we agreed to push this rerun back a month in order to reduce the impact Covid was having on care homes and their approach to calling 999. To avoid confusion, we also excluded from this audit one home that had been converted into an intermediate care unit and Covid unit. Nonetheless, this still offers a useful before and after comparison, especially as it involved the same neighbourhood and mostly the same care homes.

For this period, we have findings from four care homes in Penistone, this time excluding care home E as they had drastically limited the number of professionals coming in because of Covid. Across these four homes, they recorded 14 calls to 999 between them. Care home B called 999 no times over the month, instead using the out of hours district nursing service for one incident, a fall. Because Covid had limited new residents moving into the homes and because some residents had died, we have not shown the figures here as a percentage of the (maximum) total, as we did in the 'before' data, with resident occupancy typically much lower.

4.6: Number of 999 calls by care home (after)

Care home	How many 999 calls	Note
A	7	
B	0	During month, had one fall and contacted Crisis Response (out of hours district nursing service) instead
C	4	Nursing home too
D	3	

Again, we looked at who homes called first, before calling 999. Again, there is quite some variation between the three care homes that did make a 999 call. Two of the three calls to 999 for care home D started with a call to the GP, whereas close to three-quarters of 999 calls from both care homes A and C were made direct to 999. One of care home A 999 calls started with another to 111, while one call from care home D stemmed from a call to Rightcare.

4.7: Origin of 999 calls (after)

		Who homes called originally			
Care home	How many 999 calls	GP %	111 %	Rightcare	999 %
A	7	0%	29%	0%	71%
B	0	–	–	–	–
C	4	25%	0%	0%	75%
D	3	67%	0%	33%	0%

Like the first audit, we again wanted to see whether 999 calls made by care homes were leading to conveyance to hospital. Almost three in five of recorded 999 calls did lead to a trip to hospital, while about two in five didn't. Again, there are differences between care homes, though care homes A and C are much more similar, both no more than half of 999 calls leading to a conveyance. In contrast, all three of the 999 calls from care home D led to a hospital visit.

4.8: 999 calls leading to hospital visit (after)

Care home	How many 999 calls	Led to hospital visit	
		Yes %	No %
A	7	43%	57%
B	0	–	–
C	4	50%	50%
D	3	100%	0%
Average		**57%**	**43%**

Just like the ‘before’ 999 audit, we again looked at the time of day of calls to see if they were out of hours. Thankfully, in this audit the time was recorded for all 999 calls. We can see that the majority of conveyances to hospital took place during daytime hours (7am–11pm). In contrast, where a hospital visit didn’t happen, all took place during daytime hours. This may suggest that conveyancing to hospital is more likely overnight, though the small numbers mean this isn’t conclusive.

4.9: Overnight 999 calls leading to hospital visit (after)

Hospital visit	How many 999 calls	Overnight (11pm–7am)	Daytime (7am–11pm)
Yes	8	38%	63%
No	6	0%	100%
Average		**21%**	**79%**

When looking at the reasons for the calls, a fall was the single most common reason, accounting for 5 of the 999 calls. Two of these went into more detail, one resident with a “laceration to eyebrow”, the other with a bang to the head. Low blood pressure and being generally unwell each accounted for two 999 calls. Beyond that, all other reasons were mentioned just once. This ranged from chest pains, a potential TIA, difficulty breathing and more.

4.10: Reason for 999 calls (after)

Reason	How many 999 calls	% of total
Fall	5	36%
Low blood pressure	2	14%
Generally unwell	2	14%
Other	7	50%

Summary

The aim of this 999 audits was to see if care homes behaved differently after the ASP intervention. However, due to Covid and the relatively low numbers of 999 calls, these results should be seen as indicative rather than conclusive.

Nonetheless, the data does show a reduction in the number of 999 calls from two of the four care homes over this period, though an increase for another. Because of the different occupancy levels in March 2021, it's not possible to fairly compare the number of 999 calls as a proportion of maximum residents.

4.11: Number of 999 calls by care home before and after the ASP intervention

Care home	How many 999 calls (before)	How many 999 calls (after)
A	4	7
B	0	0
C	12	4
D	7	3
E	3	(not included)

Who was called first, before the 999 call, was mixed in both audits, as shown below. Calling 999 direct was most common overall both times. One notable change, though, was for care home C. In February 2020, two-thirds of calls stemmed from another to a GP. This went down to just a quarter in March 2021. In contrast, more 999 calls followed contact with the GP for care home D in this year's audit. Without knowing the full circumstances of individual residents, it's hard to judge what has prompted this different behaviour and whether different staff on duty or the Covid context has made a difference. What's clear is that care homes make use of a range of services and advice before calling 999, including GPs, the 111 service and, at least in March 2021, Rightcare; however, more calls go straight to 999.

4.12: Origin of 999 calls before and after the ASP intervention

Who homes called originally	Before	After
999	46%	57%
GP	31%	21%
111	19%	14%
Rightcare	0%	7%
Unknown	4%	0%

The proportion of 999 calls that led to a conveyance to hospital is similar in both periods when averaged across all the care homes included. In February 2020 it was exactly half of callouts. In March 2021 this was slightly higher, at 57%, albeit with fewer 999 calls altogether. As above, it would be unfair from this data alone to indicate changed behaviour at a care home level based on this, as paramedics must judge the patient in front of them at that time.

4.13: 999 calls leading to hospital visit before and after the ASP intervention

Care home	Before	After
A	100%	43%
B	–	–
C	8%	50%
D	86%	100%
E	67%	(not included)

There's a view that 999 calls are more likely out of hours, such as when GP surgeries or other agencies are less readily available and when there may be fewer staff around to discuss residents. Because of a lack of data from the first audit, it's hard to compare this between the two time periods; the time is unclear in 62% of records in the first audit.

When looking at the reason for 999 calls, a fall was the top reason in both audits, accounting for similar proportions, around two-fifths of calls. There was more variety in reasons to call 999 in the March 2021 audit.

Altogether, the two 999 audits suggest that about one in two 999 calls will lead to a hospital conveyance. Care homes rely on a range of agencies to support their decision to call 999, though simply calling the number direct remains common. Care home staff are not typically medically trained, so seeking professional, in-person medical input is very likely to continue.

5. The view from care homes

As shown in the introduction, we engaged with a number of care homes across Barnsley throughout this evaluation. This section pulls together that evidence from interviews, a focus group, written feedback forms, thoughts from employed carers on postcards and extra written evidence sent to us. Where relevant, we have identified whether comments were made before, during or after the ASP intervention. We've presented it by the main evaluation questions, starting with high-quality and personalised care, then elements to do with an integrated system and finally, sustainability.

High-quality, personalised care

One (before) care home manager described high-quality and personalised care for residents as focusing on dignity and respect, meeting every need a resident has where possible, having family around, medication to hand and a nice environment at the end, even including music and a priest if appropriate. This all has to be about high standards, she said. Others spoke about residents being pain-free and comfortable.

"I am passionate about giving my residents calm, pain-free passing whilst being in the place they choose" (deputy, 'during' care home)

Existing experience within care homes

Some of the care home staff we spoke to had worked in social care for years or decades. One had worked in social care for 30 years for example, while another had 16 years of experience in care. One manager said she'd looked after some residents for 10 years; they clearly know these residents well, can see when they are deteriorating and have deep empathy for them. They have lots of experience to build on, even before the ASP project. One said they already did a lot around end of life, listing My Care Plan, understanding wishes and best interest decisions, including with family members when residents lack mental capacity, as well as (advance) medication.

What does your care home do well already on EOL? "Providing dedicated , person centred care and closely involving families and all external professionals" (manager, 'after' care home)

What does your care home do well already on EOL? "Cares for our residents; it is their home and if that is their preferred choice for EOL we do whatever we can to respect and uphold their wishes" (manager, 'during' care home)

On a feedback form, one (during) care home rated their staff's confidence in working with residents at end of life as 10 out of 10, very high. They already respect peoples' capacity and choices and consult the palliative care team early, they said. For another it was also about treating residents with dignity, trying to get things right for them and meeting their wishes and preferences. They were passionate about high standards of care for residents. One said: "I work in *their* home." Involving and communicating with families came through from several care homes, including those where the ASP hadn't been. Some care homes are clearly not starting afresh from a blank canvas when the ASP comes in.

"We have a lot of experienced care staff that have looked after those reaching the end of their life. They are confident and willing to share their experience and knowledge with newer, less experienced staff, but are also feel comfortable to ask for advice when needed. Staff are encouraged to talk about past experiences, how it affected them and what they think went well and what didn't. We value reflective practice" (deputy manager, 'during' care home)

Expectations from and praise for the ASP role

We asked (before) care home staff what they were expecting from the ASP project and her involvement. They wanted up-to-date information, support around medication and broader support for residents and families. Another such colleague wanted more training from the EOL Facilitator, as this helps staff to grow more confident, so they know there's "nothing to be scared of", frightened or upset with a resident dying. Much of this was in fact provided, as can be seen above. One (before) colleague said she would "welcome [the ASP] with open arms", clearly looking forward to the "Macmillan" ASP's involvement. Here is a clear promoter of Macmillan services. The brand is welcome.

"Nowt is too much for her" (manager, 'after' care home)

"Katie's very approachable and very supportive" (manager, 'after' care home)

There was a lot of praise for postholder in the ASP role throughout the evaluation. One of the first interviews we carried out with a care home manager compared how "valuable" and helpful the ASP role was, in contrast to a more varied picture with GPs (before GP alignment, this is). The ASP was helping to put plans in place and fast-tracking services, unlike GPs, this manager believed, who just saw care home residents as elderly. This manager spoke about the ASP role going "above and beyond" her role. Others also spoke highly of the ASP, even more so because of Covid.

"Massive support, emotionally as well" ('after' care home)

“Her positive and enthusiastic approach is truly inspiring … There are no words to express how truly grateful we are for what Katie has been able to bring to our home to make the service that we offer better” (manager, ‘after’ care home)

Impact of Covid

Understandably, Covid has had a significant impact on care homes. One carer said it’s “been hard; not been easy”. It has been tiring and exhausting for staff. Care homes have been affected differently, with or without outbreaks and at varying points in the pandemic. Comparison data from CQC and PHE[2] shows that care homes in Barnsley had up to 20 residents die with suspected Covid in their homes between April 2020 and March 2021. One home said some residents had died with Covid but that the outbreak there wasn’t as bad as elsewhere, while another described a “big outbreak” and really valued the ASP’s support. We heard of one home that had experienced 26 deaths from Covid by March 2021. One manager also described the support provided by the ASP for the grief she experienced personally, while others described support for the whole staff team, such as when lots of residents had died close together. Staff were going through the grieving process themselves.

“We could not have managed without her support” (carer, ‘after’ care home)

“Katie and her team were the only support that our staff and residents at [care home] had during the time of Covid-19, and the support that they provided for us and our residents was outstanding, many staff members have reported how much the support from Katie and her team helped them during a time that was so difficult” (‘after’ care home)

Another home expanded on the support during Covid, talking about help with DNACPRs, controlled drugs and advanced care plans during Covid. For one (during) care home, Covid had highlighted the need to produce detailed plans regarding EOL sooner than they previously did so they can respect peoples’ wishes and be ready to act. Care homes had been trying to keep residents out of hospital during the height of Covid infections, at least up to September 2020. During the second wave of Covid infections, some care homes were printing out EPaCCS information to pass to ambulance crews on arrival. This had helped crews to follow resident wishes. This shows how Covid was influencing the behaviour of some care homes, perhaps for the better in terms of EOL care.

“We live in a world of many changes, Covid-19 has been extremely difficult as we all know. Our commitment, dedication and passion to end of life care will continue no

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[2] ‘Information on CQC death notifications involving COVID-19 & comparative PHE death certifications’ v1.0, 21-7-2021

matter what life changes we experience. advance planning is the key" (manager, 'after' care home)

Changes because of Covid: "EOL care can approach quickly and unexpectedly" (deputy, 'during' care home)

Covid has also affected how homes interact with families, usually remotely but still keeping them informed about residents. This could be harder when time to speak to families was more pressurised. One carer said: "Katie has been a fantastic help with everything throughout the Covid pandemic." Covid was having other effects on care homes. One manager in November 2020 said their home had "taken a battering" on occupancy, with fewer than three-fifths of beds occupied at the time. This is a huge impact on the care home as a business.

"Katie was a massive help with a resident that was dying, and there was family dynamics. She helped dissolve the situation, showing professionalism, warmth and understanding" (carer, 'after' care home)

Best interests of residents

The work the ASP role has done with families was also applauded by one carer, not just during Covid. The ASP has supported more inclusive decisions, including with residents, family and care home staff, ensuring all are "comfortable" with decisions. One manager said families can sometimes be a barrier to delivering high quality EOL care to residents. The ASP can help in these situations. Another (after) home described how "best interest meetings with staff and resident's families to enable their wishes to be acknowledged around their future medical care". Even during Covid restrictions, best interest meetings continued but carried out virtually.

There was still some unease and nervousness about broaching the subject of EOL with residents, however. When do you talk about death with new residents, one carer asked. Another felt that you got more used to it the more you carried out such conversations with residents, feeling "less uncomfortable" each time. One (during) manager said: "It's a subject that people don't talk about, even now." Her approach was to be honest with residents, "they're not children … they're not delusional". Start with what's important to them, then span into care plans, was her advice.

Ongoing support from the ASP

The postholder's knowledge if "off the scale" (carer, 'after' care home)

"If we need some advice or guidance Katie is always willing to care through and help us" (carer, 'after' care home)

Staff at homes found it reassuring that they can pick up the phone and get a willing response from the ASP or the EOL Facilitator for advice, such as when they're struggling with GPs. Even if they're busy, they'll get back to you. A (after) care home manager agreed that having the ASP on call was a real bonus. The (during) care home described a resident who they knew was at end of life. Staff could see the change in him, knew "something's not right". They wanted to stop his medication in fear that he wouldn't swallow it and would therefore choke on it or he'd tuck the medication inside his cheek and then overdose when given the next dose later. This resident's GP didn't agree. The home spoke to the EOL Facilitator, who supported them to get the opinion of a more senior GP at the practice, who ended up agreeing with the home staff. Being called back for advice does pose a challenge about the future of the role, however, particularly if the ASP is constantly called to manage cases in previous neighbourhoods.

"Katie is an amazing MacMillan nurse, who is a fountain of knowledge, and who is always willing to help and support us in any way she can" (carer, 'after' care home)

"Katie is always professional within her job role; she has approached families for us with difficult questions. Katie will always answer any questions that is asked from making us feel at ease" (manager, 'after' care home)

"Katie needs more recognition 😊" (manager, 'after' care home)

"Brilliant. Priceless. Cannot praise or thank the staff enough. As management we feel far more supported and in general much more enthusiastic" (deputy, 'during' care home)

One care home colleague said that being short of staff can be a challenge in delivering end of life care. While not a particular issue for her home, when it does happen they wisely allocate experienced staff to end of life residents, so are able to judge the situation better and base their actions on what they know the resident and family prefer.

Skilled and integrated system

This sections looks at training and skills of care home staff, the integration of homes with wider healthcare services and challenges faced by care homes.

Care home staff training, and coaching

Educating care home managers and staff on EOL care has been an important part of the ASP role. It also builds on existing training. All staff had done end of life training at one care home, for example. Some more senior roles told us about doing a foundation course in end of life care with the ASP and the EOL Facilitator. Some care homes had also worked with the ASP in her previous role, having received update training from her in the past. The ASP had delivered training previously for some care homes, before the ASP project. One (before) home manager particularly remembered elements around talking to families and on pain relief in this previous training. This shows how people know of the ASP and have worked with her beforehand.

"Lovely wonderful person. Lots of support when needed. Helped me loads over last few years. Brilliant at her job" (carer, 'after' care home)

On a feedback form, one (after) care home manager described the training that staff already receive on palliative needs and end of life care. This included e-learning, attending the EOL training at the hospice and attending MS Teams meetings. Others spoke about the more recent ECHO training too, eg on oral health and nutrition. Again, practical aspects of EOL care were singled out by care homes. Another (before) home also included ongoing clinical training for use of syringe drivers by a Macmillan nurse. One (after) home manager said the training provided by the ASP had made "our end-of-life care better and a 'smoother' process". Who in care homes had attended EOL training varied. The managers and senior carers often had, though this hadn't trickled down to all carers in all homes. There was variation in this.

Staff have benefited from training from both the ASP and End of Life Facilitator. Carers spoke highly of the training provided by the EOL Facilitator. One described her as "brilliant", another (during) one said she had "a good way of getting things across" even death and dying and in a really soothing voice. The training included on the Gold Standard Framework, with the need to identify residents earlier in their EOL path, My Care Plan and practical elements like EOL oral care. One home manager said that the EOL Facilitator explains things like My Care Plan in a "good way" and with enough time, not rushed. In contrast, if the manager or another carer would introduce new staff to the Plan, it would be done quickly between shifts. One carer said she didn't realise before the training that EOL could be seen as any time, not just imminently close to death. Beforehand she thought EOL was about days and weeks left. Now she knows it's about preparing in advance. However, for one (during) care home it was still early days, not yet put into practice, though feeling "more knowledgeable".

"She has visited at short notice and also assisted with communication between the home, GP, hospital and emergency services" ('after' care home)

In respect of the ASP role, one manager spoke about the ASP role teaching rather than lecturing, a nice contrast. Another (after) described the coaching and mentoring provided by the ASP, including to EOL champions in the home, with no question too silly to ask her. This last point was repeated by several care home staff we heard from. A carer in another (after) home said the postholder spent time with staff, explained things well but also very polite and caring with residents. Another spoke about the ASP's compassion and empathy, important traits for the role.

"Lovely, polite, professional, informative. Very caring woman, amazing at her job"
(carer, 'after' care home)

"She is very helpful, polite and caring" (carer, 'after' care home)

One home said that the EOL Facilitator is always willing to help us out if they need any more training. There was a preference for any more training to be done face-to-face instead of virtually, where there is more chance of distraction from the day job. Topic-wise, carers from one home asked for more about mental capacity and EOL, when you can't get information directly from residents. Here is an honest view about what would happen if the training was left to the care home team themselves.

Care home integration with wider health services

Moving on from training, this evaluation theme is also about how well integrated care homes are or have become following work with the ASP. There does seem to be a difference in care home views early into the evaluation and later.

Earlier on, care homes described variation among the work of GPs. In March 2020, one manager described both an "absolutely lovely" GP and an unresponsive one. She wanted stability, for the GP to know residents, not one who shirks their responsibilities and instead sends for paramedics to carry out observations. One care home manager felt bad going above the heads of the other GPs to seek second opinions. She didn't feel comfortable doing this. Perhaps other, less experienced staff wouldn't have challenged the original GP decision. But it shows the strength in character and determination of this care home colleague – "like a dog with a bone", she said – and how her instinct, long-term relationship and empathy with the resident supported her decision. Getting the EOL Facilitator's support helped to back her up. In contrast, other colleagues described situations when GPs weren't challenged, allowing a resident in a previous home to be admitted to hospital against the resident's wishes, even though she was dying.

There are power dynamics at play within the social and healthcare system, which are highlighted by the ASP work. Seen as a Macmillan nurse, not a care assistant, the EOL Facilitator and ASP are able to influence GPs more than homes can themselves. The ASP's clinical background, use of medical terms and perhaps the seniority of the role are important elements here, we believe.

"Katie has helped us get GP visits when needed and has helped us reduce unnecessary hospital admissions" (manager, 'after' care home)

Extending the length of our evaluation has let us witness the evolution of wider changes around EOL care in care homes in Barnsley. These include the enhanced care home offer from SWYPFT and GP alignment (where individual GPs were assigned to particular care homes, therefore supporting all residents there). One care home praised the latter, saying it was twice as good and offered better continuity of care. You're "not faffing from one number to another number", between GP practices, able to access to access surgeries. It's helped to building relationships with the aligned GP practice and its staff, which did seem to be delivering more consistency and more regular communication with homes. Carers here also valued the weekly doctor's round. Home staff are able to prepare a list with any concerns and discuss these residents weekly or fortnightly in MDTs. They help to accommodate prescriptions, for advice and with referrals if needed.

We also picked up the wider changes over the course of the evaluation. In November 2019, a (after) manager of a dual registered home spoke about difficulties in accessing district nurses, at least, perhaps because they view that the home already has nursing resource in-house. A year later, in November 2020, a different (after) home manager praised the community matron alongside the postholder, particularly for access to people in person during the pandemic, in contrast to the GP. This might be to review medication, for example, and increase the maximum dose of morphine. Interactions with community teams, including community matrons, got more airing later during our fieldwork. This includes liaison with other community or specialist services, including district nurses or Macmillan nurses as well as GPs. Some of this was about updating care plans. One (during) home also spoke about having improved support with other professionals, for advice, support and input. One (before) manager talked about best interest discussions taking place that involved the GP and a Macmillan nurse. The focus group with homes in spring 2021 said they'd call out the community matron if there were lots of admissions, for example, to develop an escalation plan. The ASP role, on the other hand, was when residents were moving towards EOL, to get advice, such as when dealing with families, or when looking at inclusive best interest decisions.

Challenges for care homes

At least one care home described the high turnover of staff in care homes generally. In fact, our feedback forms captured examples of this from six different care homes. We asked how many care workers had left over the past 12 months and also their current headcount, with valid responses received from five homes. For these, the average turnover is 17%, ranging from 3% to 32%, a wide variation. The labour market with Covid may have also changed what this looks like compared to normal, potentially dampening down turnover compared to more normal times.

We also heard one criticism of the way things worked from one (during) home, critical of needing six-monthly reviews on DNACPR decisions, which leads to lots of reviews. She gave an example of a lady in their 90s and with such a DNACPR decision, “nothing’s going to change miraculously,” she said.

Sustainability

We have evaluated three elements to sustainability: the lasting legacy, the tools to support this and the longer-term need (or not) for a dedicated role.

Lasting legacy

The first element is the lasting impact of the ASP role, particularly within care homes. One (during) care home described the changes made because of the ASP. These included more detailed EOL plans and all residents having electronic EOL plans with the GP, both positive outcomes from the work. Helping this has been the “visiting palliative care nurse”, one nurse allocated to the home who knows the residents. This also shows that the ASP role is part of a wider package of support to care homes, particularly in Covid-hit November 2020. Another (during) manager spoke about one-page profiles being produced on residents, which can be particularly useful for paramedics.

Back in late 2019, one (after) care home manager said she would advise other care homes to work with the ASP role, not an “outsider”. Other (after) advice given by homes included to involve families and see advance planning as key. Another (during) manager agreed with this, saying to improve EOL care at that home, advanced care planning needs to be in place early on, with earlier discussions with residents and family. One (during) manager advised to stand up for what you believe in and not to be afraid to challenge others, even doctors. Home staff also gave us wider lessons. For one, these include accepting people and being person-centred, for another it was the benefit of holding EOL debriefs. On the flip side, one (after) home was worried that palliative care wouldn’t be provided as quickly if the ASP service stopped.

“We now have plans for all our residents and are able put advance plans in place for all our new residents, they cover what the individual wants and how we can best support them and their family, any choices that the individual makes, we have covered diet and fluids, medication, and the process of dying” (manager, ‘after’ care home)

Support from tools and systems

The second element in sustainability is what tools and systems support this. The Gold Standards Framework is central to this. One (during) home described identifying residents at different stages, including spotting deterioration, echoed by another (during) home. Another (during) care home manager spoke about how the GSF was helping, for exampling gaining pre-emptive medication for residents. One more (during) home also felt they hadn't embedded the GSF enough as yet, repeated by another (during) home. One home, though, said they "treat [residents] as if they're here forever", irrespective of the prognosis, potentially a mild criticism of the GSF prognosis indicators.

Gold Standards Framework: traffic-light system "nice and clear", "not too overwhelming", in "layman's terms"; always involve care staff (manager, 'during' care home)

One (after) care home manager said in November 2020 that the lasting tools from the ASP project included the 'what is important to me' document. They also complete a Preferred Priorities for Care and ask the resident and family if a DNACPR is required. To improve things further, one (after) care home suggested being able to pass unused medication from one resident to another "if already prescribed and used correctly". This was raised in November 2020, so perhaps influenced by shortages and delays in getting supplies during the pandemic.

The need for a dedicated role

The third element in sustainability is whether there is a need for a dedicated role like the ASP to continue high quality palliative care in care homes. Care homes had less to say about this other than to praise the work of the ASP, the support and advice given and the ongoing need for such a role. One wanted continued reassurance, such as when challenging GPs. Another wanted training for GPs too, so they take more notice and give residents more attention, particularly for their end of life needs. Another gave a different view altogether, though not instead of the ASP role. For her, a (during) manager, she said there used to be a chaplain where she had worked previously, something lacking in her current home, so fewer people to speak to, whatever your religion.

Summary

We engaged with a number of care homes across Barnsley throughout this evaluation in a variety of ways, adapted because of the impact of Covid.

One (before) care home manager described **high-quality and personalised care** for residents as focusing on dignity and respect, meeting every need a resident has where possible, having family around, medication to hand and a nice environment at the end. Some of the care home staff we spoke to had worked in social care for years or decades, so their EOL work built on lots of previous experience.

There was a lot of praise for the postholder in the ASP role throughout the evaluation, about how "valuable" and helpful the ASP role was, particularly in contrast to a more varied picture with GPs (before GP alignment, this is). The ASP had helped to put plans in place and fast-tracking services, unlike GPs, this manager believed, who just saw care home residents as elderly. The work the ASP role has done with families was also applauded by one carer, supporting more inclusive decisions and ensuring all parties were "comfortable" with decisions. Staff at homes found it reassuring that they can pick up the phone and get a willing response from the ASP or the EOL Facilitator for advice, such as when they're struggling with GPs.

There was still some unease and nervousness about broaching the subject of EOL with residents, however. Yet one member of staff felt "less uncomfortable" – though not *comfortable* – each time she spoke to residents about it.

Understandably, Covid has had a huge impact on care homes. Several homes had lost residents to Covid, leaving staff to grieve too. Homes had to adapt to the changing situation, though often with lower occupancy and therefore less income; some had to furlough staff, for example. Several care home staff spoke highly of the support provided by ASP during the pandemic. However, for one (during) care home, Covid had highlighted the need to produce detailed plans regarding EOL sooner than they previously did so they can respect peoples' wishes and be ready to act.

Educating care home managers and staff on EOL care has been an important part of the ASP role. Yet, again, this builds on existing training. Several care home workers spoke highly of practical training delivered, including the ECHO training. Carers also spoke highly of the training provided by the EOL Facilitator, describing her as "brilliant", having "a good way of getting things across" even death and dying and in a really soothing voice. Training included on the Gold Standard Framework, with the need to identify residents earlier in their EOL path, My Care Plan and practical elements like EOL oral care. In respect of the ASP role, one manager spoke about the ASP role teaching rather than lecturing, a nice contrast.

Moving on from training, this evaluation theme is also about how well **integrated care homes** are or have become following work with the ASP. There does seem to be a difference in care home views early into the evaluation and later. For example, in March 2020 one manager described both an "absolutely lovely" GP and an unresponsive one. Wider improvements later into the evaluation period shone through, including the enhanced care home offer from SWYPFT and GP alignment. Home staff were able to prepare a list with any concerns and discuss these residents weekly or fortnightly in MDTs. They help to accommodate prescriptions, for advice and with referrals if needed. It seems engagement with the community nursing team had also improved, especially with the community matron roles.

However, there are still power dynamics at play within the social and healthcare system, which are highlighted by the ASP work. Seen as a Macmillan nurse, not a care assistant, the EOL Facilitator and ASP are able to influence GPs more than homes can themselves. The ASP’s clinical background, use of medical terms and perhaps the seniority of the role are important elements here, we believe.

We have evaluated three elements to **sustainability**: the lasting legacy, the tools to support this and the longer-term need (or not) for a dedicated role. The legacy of the ASP work includes more detailed EOL plans, more residents having electronic EOL plans with the GP and involve families in advance planning. The Gold Standards Framework is a key tool, helping homes to identify residents at different stages, including spotting deterioration. However, some homes admitted that they hadn’t embedded the GSF enough at the time of speaking. For another home, the ‘what is important to me’ document was a lasting tool. Several homes described the wider package of support on offer to them, especially later into the evaluation. However, for longer-term sustainability some homes wanted a dedicated resource for continued reassurance, such as when challenging GPs. Others continued to want training for GPs too, to take more notice of end of life needs.

6. Stakeholder views

As well as engaging care homes, we have spoken to a range of stakeholders across the whole time period of this evaluation. This helps to gain a wider view of how the ASP project has (or hasn't) worked and to compare views across different interests. Do GPs say the same as care home managers, for example, do commissioners feel the same as community staff?

Like the section above, we have again split this into the three main evaluation themes, starting with high-quality personalised care.

High-quality, personalised care

What constitutes high-quality and personalised care at end of life was a topic in some of the early stakeholder interviews. One community stakeholder described it as having good quality of care to provide the best quality of life, achieving the resident's own, and their family's, plans and then dying in your preferred place of death. This also means identifying EOL residents earlier, making plans, discussing, identifying and meeting choices and responding in a timely way. Avoiding discomfort for residents and avoiding distress for families is also part of this. This also comes from reducing conveyancing to A&E and then unnecessary admissions to hospital, including numerous readmissions in somebody's last three months of life, which should also result in monetary savings, one GP believed. One stakeholder summarised this well, stating it was about just wanting the best care, feeling valued and listened to, delivered in the right place for you.

"A beautiful death" (community stakeholder)

"Quality of life right up to the end" (health stakeholder)

"Let's try and keep people away from hospital if they don't need to [go]" (GP)

"Going into hospital is a really big deal. Some people just don't come out" (health stakeholder)

The difference made by the ASP

What the ASP did was "the big thing", one GP said early in our evaluation. They went on to talk about the training with care homes, the prognostic indicator guidance and EPaCCS, including reminding GPs to do the paperwork. This is supporting care home residents to have My Care Plans in place. This GP also said that the ASP was able to see resident much more often.

"Katie's fab" (GP)

“More than one Katie would be amazing” (GP)

“Can’t underestimate Katie’s [the ASP’s] work” (GP)

“Need the right person to do the right job” (health stakeholder)

One GP succinctly described the input from the ASP role:

“The patients I have encountered that have received input from Katie all have comprehensive documented discussions and plans of care in place for subsequent deterioration or current and future palliation where appropriate. The data is entered clearly in the EPaCCS template on SystmOne so is accessible to primary and community colleagues alike.” (GP)

A worker from one surgery spoke highly of the ASP, describing her as “approachable”, having known her for a number of years, even before this ASP role. This longer-term relationship is one part of the success of the role, really “connecting” with them, the emotional intelligence, a lesson to consider if replicating this model elsewhere. Building on good existing relationship also came through from care homes. Early into the evaluation, one GP said that care home staff love the ASP herself and are thankful for her support. A health stakeholder said that the personality was as important as the skills. This was also about valuing what care homes deliver. One health stakeholder believed that a success of the ASP project had been these relationships made, allowing care homes to trust somebody from health. The ASP gained a lot of credibility by doing the doing, one health stakeholder said, demonstrating in practice. This was even more so during Covid, as the ASP was one of few roles physically going into homes.

“Relationships [between the ASP and care homes] have been key” (health stakeholder)

“Great example of care homes and health working together” (health stakeholder)

“Second class citizens” in care homes nationally (community stakeholder)

A clear change for one GP was “more acceptance of managing uncertainty and ill health in the care homes”. This GP compared the evolving approach over time. Furthest back, care homes took the approach that it was ‘OK for residents to die’, they were “allowed to die”. More recently, this GP felt that care homes weren’t allowed to let residents die, that they had to justify why they weren’t doing something to prolong life. This inevitably leads to actions like calling the GP or 999. But this GP said that the ethos is now changing, with more talk of *care* in place of intervention, a “shift” whereby care homes have been given “permission to let somebody die”. Earlier stakeholder interviews echoed this, aiming for the ASP role to allow a “good” or “beautiful death”. If mirrored elsewhere, it is a major cultural change in the approach to end of life care in care homes.

“The additional support for patients offered by Katie was most timely and welcome” during Covid (GP)

Care homes have “never had so much support” since Covid (community stakeholder)

“Covid identified that there was a gap” (community stakeholder)

Advance care planning, not crisis management

One GP earlier in the evaluation wanted much more focus on advance care planning earlier into somebody’s journey rather than EOL care in a crisis at the end. When probed about what counts as good quality end of life care, the care home staff we spoke to described the final days of residents’ lives, not longer-term planning. For example, they spoke about providing anything that was needed, supporting family, the right (palliative) medication, dignity and respect, even a priest, music and the right environment. At the core, though, was striving for “high standards” at end of life.

“We leave it too late in this country” (community stakeholder)

For this same GP at the time (November 2019), it also meant care homes “piping up”. GPs don’t know all their patients in detail, they have to work reactively, not proactively. This means GPs don’t always see deterioration in patients. This can be even worse when surgeries use locums. Stakeholders spoke about carers not always feeling strong or confident enough to challenge the decisions of professionals, as if a clinician always knows best and can’t be challenged. In reality, carers are paid the minimum wage but are taking big decisions over somebody’s life or death. However, as one paramedic said, whether an admission is appropriate or not is a “really difficult decision”. Care homes may well be “covering themselves”, this person said, especially under scrutiny from CQC. In a similar way, a carer in the middle of the night can’t carry out the battery of tests that can be run in a hospital, one health stakeholder told us.

“Care homes had bad press until covid” (community stakeholder)

“Carers get undervalued” (health stakeholder)

Homes “are great places with fantastic people” (community stakeholder)

A community stakeholder in June 2021 also felt that GPs got involved at crisis points with care home residents, not pre-empting advance care planning. A health stakeholder felt this meant the intervention in a crisis was less likely to be person-centred. A community stakeholder also felt that care homes need lots of support, especially with symptom management and guidance on ACP, such as escalating treatment or knowing who to ring for advice.

The postholder “raised the bar of expectations” (GP)

However, one GP surgery worker spoke about the number of patients on their end of life register going up after opening it up beyond just cancer patients. While this is good from a system and personal care perspective, it also means that practices are busier with these longer lists. There is therefore a dilemma inherent in this. It also reinforces the view that EOL care home residents haven’t routinely been added to registers, “disappointing”, one stakeholder said. Others said that the frail elderly are not on palliative registers.

Variations between care homes

A GP spoke about the differences between care homes, for example having a trained nurse in a dual-registered care and nursing home or the severity of dementia at another care home. This may also explain some of the differences in the 999 audit (eg dual-registered care home C). A second GP described differences in approach between care homes in their neighbourhood, with some better than others. A third GP contrasted one dual-registered care home that had embraced the ASP project, was proactive with EPaCCS, for example, and wanted “every I dotted and T crossed”. In contrast, another care home seemed less engaged, with a high proportion of dementia residents and therefore without having Macmillan at the forefront. Another community stakeholder also spoke about the type of residents and how this changes a home’s outcome. If the home takes quite a few palliative residents, such as from hospices, they are more palliative-minded in general.

One health stakeholder, though, felt that care home residents can get better care from district nurses than in-house in nursing homes, especially because of the large ratios there, the turnover of staff and wider expertise from the district nurses. A community stakeholder said it can be lonely for a sole nurse in a home, unlike community nursing teams, and traditionally seen as a second class nurse.

Working with care homes “takes up a massive amount of time” for GPs (community stakeholder)

One GP recognised that care home staff are *carers* and don’t have a medical background. It can therefore be useful to have somebody like the ASP role, an approachable person, to bounce off about medical issues. One care home colleague echoed this, saying it wasn’t for her to make medical decisions, such as in best interest meetings. This GP wanted this to remain as a “legacy” of the project, advocating that the role continues. This can help residents to receive care rather than calling a GP or out of hours doctor who then decides to transfer a resident to hospital for clinical intervention.

Inclusive decisions

The ASP has also supported more inclusive decisions, including with residents, family and care home staff, ensuring all are “comfortable” with decisions. Earlier stakeholder interviews echoed this, with the ASP’s ability to put people at ease. As we’ve seen with care home staff, other stakeholders also spoke about the important work the ASP did with families, talking to them and giving opinions. It’s a difficult time for families. One example, early into the ASP project, was an “open and honest” discussion with a resident’s daughter and care home staff to “collectively” come to a decision. This led to the resident dying peacefully in the care homes with the one she loved.

“Still a lot of taboos” about talking about EOL (health stakeholder)

One community stakeholder described the ASP’s input into a best interest discussion. This is an area the ASP herself has changed over the project. The community stakeholder provided an example. A lady in care home was becoming frailer and in the last 12 months of life. Her grandsons were next of kin but were hard to get hold of and didn’t want to get involved; she had no lasting power of attorney. The ASP liaised with the social worker and care home staff to make a plan about what the resident would have wanted before she lost capacity. For this example, it ensured the resident got the care deemed that she would have wanted. Another (health) stakeholder echoed this, saying that the ASP had set up good structures, such as documenting decisions and maximising capacity.

Flexibility in the ASP delivery

It has been good to see changes in how the ASP role has worked and flexibility in how it’s been delivered. We noted this back in November 2019, comparing the difference between the first two neighbourhoods. The ASP started work with GP surgeries in the first neighbourhood, South. Discovering that EOL or palliative care registers didn’t include many care home residents, the ASP changed tack in the next neighbourhood, Central, and started work directly with care homes, then engaging with GPs, the opposite way to the first neighbourhood. While there can be frustration for the ASP when things don’t go to plan, it has led to reflection and positive learning about what could have been done differently.

In March 2021 there was also concern for high-quality care for people as a fallout from Covid. With people reluctant to go to GPs and with long waiting lists in hospital, people were receiving cancer diagnoses later, which will result in worse outcomes. Some patients will end up filling up hospices and palliatives beds, absorbing capacity. For those with dementia, many will have struggled at home during lockdowns, which are likely eventually to lead to an influx into care homes, some stakeholders believed. How does EOL care in care homes (and beyond) adapt to this emerging reality?

Skilled and integrated system

This section looks at how the ASP and care homes fit into the wider healthcare system, improvements stakeholders have seen in care homes, different approaches to EOL among GPs, information sharing and challenges for care homes.

The wider healthcare system

The ASP role isn't working in isolation. Other aspects to end of life care in care homes are also contributing. For one health stakeholder, one success measure from the ASP project they wanted to see was better links between care homes, GPs and neighbourhood teams. Another said similar, wanting integrated working with care homes. A GP highlighted the "intermediary" role that the ASP has delivered, helping GPs to get to know care home staff. One GP said that the ASP had also worked well with practices, not just with care homes. This GP felt this was the difference from the project, this dual role.

In Barnsley pride ourselves on "good work with care homes" already (community stakeholder)

"Katie's role combined with the additional community nursing, pharmacy and GP support, as well as the close working required for delivery of the vaccination programme to residents and staff during the pandemic (and pilot period) means that care homes are currently better connected with healthcare services than I have ever known in the past 20+ years." (GP)

We heard an example of one care home resident who was supported by another Macmillan nurse, not the ASP. A woman with dementia but at end of life was displaying behaviour that was hard to manage. The Macmillan nurse steered towards a multi-disciplinary, best interest meeting, which led to being able to treat end of life symptoms. A GP spoke about a few homes seeking advice from a Macmillan nurse, though this may well be right at the end of life symptom management and not for advance care planning. One Macmillan nurse said she usually saw residents in the last weeks and months of life, more reactive, "fighting fire", in contrast to residents with up to a year ahead as the ASP does. Here is another theme around working with residents who have dementia. Given the high level of EPaCCS residents with dementia, this is an important dimension. A care home colleague also spoke about Macmillan nurses coming in, dealing with things like pain relief and talking to families. The Macmillan nurse badge holds some sway, including with relatives, often more than care home workers.

"Can't take away the word cancer from Macmillan" (GP)

One GP also spoke about trusting the clinical judgements made by Macmillan nurses. This is different to the background and knowledge that care home staff have, they said. With these nurses, it's a different conversation, a different level of reporting than from a care home. You "do have respect for their clinical decision", this GP said. It makes a "a world of difference" of someone going in and seeing them, again reiterating the value of in-person contact with residents.

"More working together with care home staff" (GP)

One surgery colleague said they have an assigned Macmillan nurse to their practice who is involved in the MDT discussions. They discuss all end of life and palliative patients, not just those with cancer. The ASP has attended some of these MDTs too. Simply having MDTs, especially with different medical professionals present, is contributing to better EOL care, another practice worker suggested. For this practice, it included community matrons and social prescribers. Even earlier in the project, in November 2019, we were told that one GP had started palliative meetings, seemingly as a result of the ASP project. Not all GPs were running MDTs, though, we were told in March 2021. One GP did speak positively about their weekly MDTs in May 2021. Their one included the care home manager or a senior, sometimes a nurse for nursing homes, as well as the GP, community matron, clinical (community) pharmacist (eg for medicine reviews), now a care coordinator and health and wellbeing coach. One health stakeholder believed MDTs had spurred more proactive working from GP practices.

A GP said that the EOL Facilitator's work reinforces and complements what the ASP is doing. Another example was the useful training provided by SWYPFT's Education and Training Co-ordinator, including practical procedures. This shows the importance of training within the wider scope, or "upskilling", as one stakeholder put it. However, SWYPFT's Education and Training Co-ordinator isn't involved directly with GPs as the ASP is. One GP said that it's "selling" the idea, promoting planned work at end of life, that helps to make the difference, for care home staff and residents. One GP therefore spoke about the need to keep support in future but not necessarily the exact same ASP role.

The postholder has "been a great networking person to have on our side" (health stakeholder)

Improvements seen in care homes

One GP spoke glowingly about the change seen at one care home. Communication was now better and support provided earlier to residents, such as when the prognosis colour changes. This home has two key workers, with staff "more empowered," "more confident" and having better technical knowledge, taken seriously if they raise concerns. Staff have benefited from training from both the ASP and EOL Facilitator. A GP said the ASP's work had had a "big impact" in care homes, with staff still talking about her work. The ASP had "educated the staff a lot", this GP said. They went on to say that the timing was right for this kind of work. This highlights a condition for the success of the ASP project: the right timing. Others also spoke about increased communication and better liaison between surgeries and care homes. This wasn't the case for all care homes, however.

Different approaches to end of life care from GPs

From earlier scoping interviews, differences between GP practices also emerged, with varying approaches to end of life care. Even in June 2021, one stakeholder spoke about some GPs still not getting the GSF, fearful of talking about EOL and sometimes not culturally used to talking about things like DNACPR. Like care homes, GPs are also coming from different starting points and work-cultural backgrounds.

"A long way to go" with long-term conditions (community stakeholder)

We sensed some frustration, particularly in late 2019, about the role of primary care. One health stakeholder believed the gap in EOL provision for care home residents should have been filled by primary care, particularly as part of the 'making time for care' agenda. This should have been about making time for residents and avoiding inappropriate hospital admissions. This work by primary care wasn't happening, not universally at least, hence the need for the ASP project.

Information sharing

One surgery worker described having EPaCCS now, including sharing them with out of hours doctors. They were also trying to integrate them with YAS, though seemingly this hadn't yet been (fully) happened. EPaCCS do give ambulance crews more confidence. If there are no plans, it's really hard for the ambulance service. However, there is still more work to be done on this, including the script used by call handlers. This doesn't currently ask if a DNACPR is in place, even if for a care home resident who isn't breathing and not conscious, YAS said. The service would also like an emergency care sheet, telling the crew what a resident wanted in an emergency, with supporting documentation to back it up. Having more baseline data in records would also help, such as the resident's heart rate and blood pressure, to know what was normal for them. YAS would also like to see more CPD for crews, such as on EPaCCS.

The ASP "frees up doctors' time" (GP surgery)

One practice worker felt there had been no change at MDTs since the ASP role had started, yet they did say it possibly "frees up doctors' time". GPs lacking time was a clear barrier to better EOL care for care home residents, even GPs agreed. A practice colleague felt the practice was already good at helping people die at home. This was down to having district nurses, a Macmillan nurse, open communications and quick turn-around, such as GP reviews and drug cards. They work as a team, this person said, and *get on* as a team, with open communication. We also heard contrasting, negative views about some GPs and surgeries. One community stakeholder believed that care home residents were "invisible" to GPs. In the past, if a care home would ring a GP for a home visit, they would be directed to the iHeart visiting service instead.

Challenges for care homes

Two GPs questioned whether the positive results through the ASP project would continue as new care staff and managers come in and need new training. Low job satisfaction, unsociable hours, the hard physical work, previously unrecognised by society and demanding clients (eg with dementia) all contribute to higher turnover of staff. This makes it harder to embed end of life and palliative care for residents. This may stimulate an opportunity for an ongoing service, whether or not delivered by the ASP. Others also spoke about high turnover of staff, which leads to lack of continuity and uncertainty within care homes. Acceptance of change in care homes was a barrier to success for one community stakeholder. But also a lack of change in community settings too, such as not using the right care plans, eg if dying and needing a daily visit from a district nurse. Elsewhere, some stakeholders voiced IT problems: the difficulty of accessing full EPaCCS data at EMIS practices (those using this primary care clinical record keeping system instead of SystmOne, as the two systems don't coordinate). While things are getting better on this front, such as showing the last three practice consultations, other data was having to be re-entered. One stakeholder said EPaCCS are a "waste of time" if they can't be seen.

Sustainability

As in the care home section, sustainability spans three elements: the lasting legacy, the tools to support this and whether there is a longer-term need for a dedicated role.

Lasting legacy

One GP spoke about being asked more proactively by care homes to be involved. A worker at another surgery also described a much better relationship with care homes after the ASP had been involved, with residents now being discussed at practice meetings. This worker went on to say that this was the same with sheltered housing residents, which suggests a wider impact than simply with care home residents from the ASP project, with GPs more aware of hidden and quieter elderly patients who also need end of life care. Giving confidence to care homes will be the lasting legacy, one stakeholder believed.

Furthermore, this isn't just directly at end of life but also approaching end of life. For example, one surgery colleague said the ASP role was supporting *advance* decisions. This is a key theme coming from several stakeholder interviews. Instead of just the last months and weeks of life, care is being planned in the last year of life. Another stakeholder felt that the legacy was being able to pick up referrals from anywhere, given how well connected and known the ASP had become across care homes.

The ASP's support for wider community services, including matrons, is another legacy from the project, some said. This might be advice about particular residents, modelling good performance or providing specialist palliative input when needed. As one community matron put it: "we're not palliative care specialists". A district nurse said similar, that ACP goes to the ASP, while medical issues go to her.

Another GP couldn't see it having worked any other way, particularly as GPs and district nurses simply do not have the time. Another surgery worker echoed this about needing more time, as did other stakeholders. District nurses come and go repeatedly, for example, they metaphorically "put a plaster on it", as one GP said. Instead, having this defined, designated role has allowed a more holistic approach, looking at "the whole picture" and doing so with enough time, not rushed like some other clinicians. Another GP felt it useful to have someone to coordinate end of life work with care homes but from within the PCN, at least initially, while the network beds in. This could provide liaison with primary care, again in a joined-up way. Like care homes, one GP valued the advice given by the ASP, a "really good resource", especially if you get a bit stuck with a patient or process. The flexibility in approach was valued by another health stakeholder.

Support from tools and systems

Using the GSF to identify EOL residents early is one clear aim of the ASP project. One health stakeholder believed the project's success relied on re-educating care homes about earlier identification of EOL residents and hospital admissions. This is working where homes embrace the GSF but not in all homes. For one community stakeholder, good homes and leaders who were interested in change, more proactive and were more likely to embrace these ASP aims, always putting the best interests of their residents first. In contrast, the ASP was struggling to get into a few care homes in early 2020. Ideally, having the GSF embedded is part of the longer-term sustainability of the ASP project.

The need for a dedicated role

Stakeholders we spoke to also had a lot to say and varied views about the longer-term need (or not) for a dedicated role like the ASP. Other changes around EOL care in care homes were also taking place, even earlier into the evaluation in late 2019. These included daily virtual ward rounds by Skype, advanced EOL care homes and GPs working in care homes. One stakeholder spoke about the "accumulated impact" of all these changes alongside the ASP project, how each element can make a contribution, though not one in isolation.

"A change project within a change environment" (Macmillan stakeholder)

At the start of the evaluation, GPs could see the potential of GP alignment but recognised that it will take some time to be fully implemented, as they continue to work with existing patients in care homes outside their allocated homes. It will "not change overnight", said one GP early on. However, GP alignment took place in Barnsley with a "big bang" approach from October 2020. One GP, in May 2021, did call the alignment a "big disruption" over the last year.

A GP spoke about the PCN changing, describing an unclear situation. This approach offers a chance for GPs to be aligned to Macmillan nurses and to district nurses, alongside a stronger emphasis on the locality, a local geography. This GP wondered, hoped, that end of life may develop from this. One GP in May 2021 said that all practices across Barnsley met every other month, usually with a GP and practice manager attending, to discuss PCN work but also with breakout time for localities. Even pharmacists were being allocated to care homes, one stakeholder said.

Earlier into the evaluation, one GP suggested APNs visiting care homes as an alternative model. One GP practice described a new initiative that unfortunately hadn't started, because of workload at the surgery. This would involve planning a scheduled visit to care homes with the GP and the ASP, aiming to offer a better service by reviewing medication but from a palliative perspective and proactively addressing what patients and families want. Even in early March 2021, one GP wanted to see EOL support provided future but not necessarily via the ASP role. This GP saw mileage with walk rounds for GPs and the new GP contract. However, this GP also saw the need for an advocate for care home residents at EOL, something they didn't believe district nurses could do with their limited view of residents.

GP alignment is "a whole lot easier" (GP)

GP alignment "rocked some of care homes quite a bit" (community stakeholder)

Early on, GP alignment was seen as having the potential to instil a habit of weekly ward rounds and having a named GP for care home residents, as well as GPs and surgeries getting to know care home staff. Perhaps the ASP role was filling the gap in this interim period. In June 2021, one community stakeholder said that, in the past, care homes were seen as "a bit of a pain" for GPs, with a lot of needs and calling every day. This was contrasted to the current, improved situation. Separately, a GP and a practice colleague felt that the alignment may have the biggest impact for surgeries in the Central neighbourhood, offering a fairer allocation of care home residents to them. In fact, one such surgery did tell us in mid-March 2021 that the alignment was much better for then, with a fairer allocation of residents and therefore fewer for them. Yet at that time, not all care homes did have a single GP practice aligned, at least not in the North neighbourhood, we were told. For one community stakeholder it was also about providing a more equitable service to all care home residents, not just the homes where a GP would visit.

In fact, commissioners would have preferred the ASP to roll out on a needs basis instead of geographically by neighbourhood. This would have targeted the care homes repeatedly sending the highest number of residents to hospital, that are most burdensome, as one stakeholder put it. We sensed some unease around this between the ASP project and commissioners, each with a different focus.

"Due to the makeup of our ageing population there is an ever-growing role for quality palliative care in care homes and this requires adequate resourcing from all healthcare providers involved and I would welcome a more permanent appointment, working closely with the teams delivering EHCH element of the PCN DES." (GP)

No stakeholder believed there was no need for EOL support for care homes. Particularly because of the high turnover of care home staff, there would be an ongoing need to educate them about EOL care, including things like the GSF, back at the initial neighbourhoods. One stakeholder said it's like painting the Forth bridge, a task you never stop, describing this as the "biggest challenge". This, then, is a demand for ongoing training, though not necessary delivered by the ASP. In fact, the EOL Facilitator was repeatedly mentioned – and praised – for the training delivered to care homes, both from homes themselves and wider stakeholders. Also, some care homes simply weren't engaging with the ASP project, we were told. This is a tougher problem.

"Authentic and compassionate leadership" from the ASP (health stakeholder)

Many stakeholders did believe a designated role like the ASP was needed. For one GP, this was particularly around increasing awareness generally of end of life and palliative care and helping to improve the management of care, rather than intervention, at end of life. Another GP echoed this, describing this broader awareness as a “legacy” of the ASP project. The emphasis would be different if a district nurse delivered the same training but with their more limited end of life view. The ASP had also spent time working with these community nursing teams.

“Even experienced GPs don’t have the experience of a specialist Macmillan nurse” (GP)

A few stakeholders likened the ASP role to a nurse consultant. Although not on that band, the ASP role is a high-level practitioner. It is about clinical leadership, employed on an 8a band and able to provide clinical decisions. Sometimes the ASP is doing ACP and best interest meetings, other times it’s been enabling somebody else to do it, not deskilling them, knowing how to use your role flexibly. This was also role-modelling, a few stakeholders said, such as best interest meetings. It was also driving patient-centred care rather than crisis-led, bringing issues that haven’t been picked up and identifying resident’s wishes as an “excellent patient advocate”, one health stakeholder said. And also looking at the social side of EOL care, not just medical needs, which helps to prepare families for a vulnerable person dying. Filling in a DNACPR form isn’t advance care planning, as some care homes believed.

One health stakeholder provided one example. A gentleman had capacity while sober but fitted when not sober, leading to hospital admissions. The ASP supported this man with fluctuating capacity to enable him to be part of the EOL discussions. This also branched off into areas like detox and whether or not he had access to alcohol at the home. “Not your typical advanced care planning,” this stakeholder said. They went further and reiterated that mental capacity should be decision-specific, so every effort should be made to maximise inclusion. “Katie is excellent and showing that and delivering that.”

This also included taking part in meetings and forums like: the Enhanced Care Home Operational Group, which included PCN leads, the CCG and senior roles like the Deputy District Director and transformation lead at SWYPFT; multi-agency response meetings to Covid with public health and hospital colleagues; and End of Life Clinical Operational and Education meetings with community, hospice and hospital representation. All of these show the voice and wider influence of the ASP role. Interestingly, one health stakeholder believed that being funded by Macmillan, the ASP was able to function as a stand-alone project, without becoming absorbed into other NHS demands. It has also allowed the role and the project time.

“It requires an experienced clinician who is able to work autonomously and is time consuming work” (GP)

Who else could deliver this work? Community matrons may seem one possibility, yet they come from a general background, we were told, and don't specialise in EOL and palliative care. Equally, they have the wider community to work with, not just care homes. Instead, they also need a resource like the ASP "where they can take dilemmas to", one GP told us. Another GP agreed, saying the role offered an "invaluable resource" to GPs and matrons doing more complex work in care homes. There was also a role for frailty nurses, an evolving role at the time of writing (June 2021). But again, these would see people at home or when patients left hospital, not just focusing on care homes. This still demanded the need for support with more complex residents, especially with best interest discussions. One community stakeholder, for example, believed that GPs often weren't able to involve families in EOL decisions, something that was instrumental in the ASP's work. Somebody needs time to give to people to help make their choices, to deliver better outcomes, one health stakeholder said, to have those difficult conversations with people and support difficult decisions.

"Roles like Katie's are what we need" (health stakeholder)

The ASP has her "palliative care specs on", unlike community matron (community stakeholder)

The Palliative Care Consultant is another resource in Barnsley. This includes covering hospital and community palliative needs, including supportive care at home, including home visit alongside community matrons for non-cancer patients. The role also includes oversight of tricky or challenging cases, brought in for complex symptom management or for concerns or disagreement about ACP. The role provides advice by phone too. However, this isn't a replacement for the ASP role but part of the bigger EOL jigsaw.

"Katie is quite thinly spread" (community stakeholder)

There is also a challenge for the ASP role, around capacity and reach. If the ASP role is doing a lot of case management, this will limit the wider impact from the role, something a few stakeholders said, even back in late 2019. At the time, one believed that PCNs and neighbourhood teams should be picking up this EOL case management. This also means that a challenge will be how to prioritise people, especially if covering all care homes across Barnsley on top higher end strategic work. For example, what needs to be in place when a care home rings for an ambulance, how to embed EOL in primary care, offering a better understanding of care homes. Perhaps this needs somebody in every neighbourhood team who is specialist, as one stakeholder suggested.

Summary

As well as engaging care homes, we have spoken to a range of stakeholders across the whole time period of this evaluation.

What constitutes **high-quality and personalised care** at end of life was a topic in some of the early stakeholder interviews. One stakeholder summarised this well, stating it was about wanting the best care, feeling valued and listened to, delivered in the right place for you. This meant identifying EOL residents earlier, making plans, discussing, identifying and meeting choices with residents and families and responding in a timely way. Avoiding discomfort for residents and avoiding distress for families is also part of this, including by reducing conveyancing to A&E and then unnecessary admissions to hospital. As one community stakeholder said, it's also about "a beautiful death".

What the ASP did was "the big thing", one GP said early in our evaluation. This included the training for care homes, the prognostic indicator guidance, My Care Plans and EPaCCS. Needed was a greater focus on advance care planning earlier into somebody's journey rather than EOL care in a crisis at the end. This also demands that care homes can "pipe up", confident of speaking on behalf of their residents' wishes. One GP, however, recognised that care home staff are carers and don't have a medical background. It can therefore be useful to have somebody like the ASP role, an approachable person, to bounce off about medical issues.

Several stakeholders referred to the ASP's emotional intelligence, describing her as "approachable", really "connecting" with them and nurturing existing relationships. The ASP has also supported more inclusive decisions, including with residents, family and care home staff, ensuring all are "comfortable" with decisions. This included with particular input into best interest discussions, an area the ASP herself has changed over the project.

The ASP role **isn't working in isolation**. Other aspects to end of life care in care homes are also contributing. A GP highlighted the "intermediary" role that the ASP has delivered, helping GPs to get to know care home staff. And whereas other (traditional) Macmillan nurses often worked in care homes in the later stages of life, the ASP role saw residents up to a year ahead. With both Macmillan nurses and the ASP, GPs spoke about trusting their clinical judgements, including with residents with dementia.

Later into the evaluation there was more mention – and praise – for MDTs, contributing to better EOL care, some said. This was partly helping to overcome the challenge of GPs lacking time for care home residents.

One GP spoke glowingly about the change seen at one care home. Communication was now better and support provided earlier to residents, such as when the prognosis colour changes. This home has two key workers, with staff "more empowered," "more confident" and having better technical knowledge, taken seriously if they raise concerns. One surgery worker described having EPaCCS now, including sharing them with out of hours doctors.

Two GPs questioned whether the positive results through the ASP project would continue as new care staff and managers come in and need new training, in a tough sector with high staff turnover. This makes it harder to embed end of life and palliative care for residents.

As in the care home section, we covered **sustainability** with wider stakeholders. In terms of a lasting legacy, one GP described being asked more proactively by care homes for involvement. Other surgeries also described a much better relationship with care homes after the ASP had been involved. For others, it was the focus on advance decision instead of just the last months and weeks of life. For others it was the ASP modelling good performance for wider community colleagues or providing specialist palliative input when needed.

The GSF was mentioned by some stakeholders, using it as a tool to identify EOL residents earlier. One health stakeholder believed the project's success relied on re-educating care homes about earlier identification of EOL residents and hospital admissions, especially given the high staff turnover. This is working where homes embrace the GSF but not in all homes.

Many stakeholders did believe a designated role like the ASP was needed, especially with the time needed for care home residents. Other roles simply don't have the time and aren't looking at "the whole picture" for residents holistically, including those with more complex needs and lacking capacity. The need for an advocate for care home residents at EOL was also raised, increasing awareness generally of end of life and palliative care and helping to improve the management of care, rather than intervention, at end of life. Some likened the ASP role to a nurse consultant, providing clinical leadership as well as able to provide clinical decisions.

At different stages in the evaluation some stakeholders suggested other routes to achieving what the ASP was doing. This included the potential for GP alignment to instil a habit of weekly ward rounds and having a named GP for care home residents, as well as GPs and surgeries getting to know care home staff.

A challenge with the way the ASP has been working, however, is around capacity and reach, especially if continuing to case manage residents and being called back to earlier neighbourhoods. Here is a challenge over how to prioritise people, especially if covering all care homes across Barnsley on top higher end strategic work.

7. Conclusions and recommendations

This evaluation started in October 2019, almost two years ago. Back then, the ASP project had already started, with engagement in care homes, surgeries and community teams. Over that time the Covid pandemic has hit care homes hard, harder than many other settings, with impacts still being felt. The ASP role has therefore had to evolve to suit the changing reality. Our evaluation has also had to adapt to this changing landscape. One part of this is how to disentangle the contribution made by the ASP project to EOL care for care home residents, rather than the wider context (eg Covid) or other changes (eg GP alignment).

Covid has had dramatic effects on some homes, with scores of residents dying quickly, rooms left unoccupied and staff on furlough or being made redundant. This has had a financial and personal cost to those running and working in care homes. There is also a positive legacy from this, something that could not have been anticipated at the start of the project. Many care homes have realised the need for advance care planning, talking to residents about death, dying and end of life. As one of few health professionals physically going into care homes, the ASP has cemented herself even more firmly within them, supporting staff, residents and family members.

Arguably, Covid also seems to have prompted a ‘big bang’ approach to GP alignment – sitting within the PCN contract and ECHC framework – which this evaluation suggests is making a positive difference to care homes and GP surgeries. Homes are finding it easier to contact practices, regular MDT meetings are taking place and residents are being discussed, improvements which have been seen during the period of this evaluation. Different professionals are being involved in EOL care in homes, including community matrons and frailty nurses, alongside dedicated resource from the enhanced care home team. All of this is helping both to shine a spotlight on care homes and their residents but also to upskill carers, seniors and managers there. The ASP has had a central role in this.

If identifying somebody earlier in their EOL journey is the first step, the number of care home residents with EPaCCS is one proof that the ASP project is making a difference. Care homes are better trained on EOL and some, though not all, are using tools like the GSF to look for and better classify deterioration in residents. This is giving some care home staff greater confidence to advocate on behalf of their residents, even if means challenging health professionals including GPs and despite not wearing a Macmillan badge. Training care home staff will need to continue to be a rolling activity, especially given the high turnover of staff. This isn’t specifically the responsibility of the ASP role but it is needed in the wider EOL mix for care homes. Subjects should continue to include the GSF and practical aspects of EOL care, though there was also a call for wider training on topics like mental capacity.

There are good indicators that the ASP role has supported a real improvement in EOL care for residents in care homes in Barnsley. The high proportion of these residents having a preferred place of death is positive. Even better that most of these who die do so in this preferred place. There are also signs of reductions in unplanned secondary care admission, with a lower proportion of residents being admitted and fewer average admissions per month after the ASP intervention. In contrast, the 999 audit was less conclusive, continuing to show that carers aren't medically trained and therefore aren't the right people to decide on medical conditions that do require a clinical judgement. They can, however, advocate on behalf of their residents and be supported in conversations with paramedics with tools like one-page profiles of residents.

We believe there is still work to be done to move from end of life meaning weeks and months to live, to advance care planning taking place with months or a year or more to live. This goes for care homes as well as GPs, who may still be too reactive and focus on crises. MDT meetings do seem to be helping with this, which nestle within GP alignment. This is important as we know that EOL and palliative care registers often miss care home residents who should be on those lists. Linked to this is ensuring that EOL is acknowledged and planned for all conditions, not just cancer. Within this, there is definitely an ongoing need to provide better support for those with dementia at EOL. The important role that the ASP has delivered around time- and decision-specific best interest discussions should be applauded.

Care homes are better connected to wider services today than at the beginning of the evaluation. Covid has also played a role in this, though the ASP should take credit too. Not just for the work of the role within care homes but also championing care homes to the wider healthcare sector. This inside knowledge has been shared widely among other professionals and senior roles in Barnsley. There is an ongoing need for this, especially as ongoing discussions at national and local level continue about further integrating health and social care.

The role of the ASP is therefore to train, support and coach care homes as well as to advise and potentially case manage complex cases. Having a dedicated and protected resource has really added value. A challenge here, though, is to provide this strategically across Barnsley without continually being dragged back to earlier care homes with routine case management. The ASP acts as an intermediary, a mediator between care homes and GPs but also between care homes, residents and families. This is even more important where residents lack mental capacity or suffer fluctuating capacity. With proportions of dementia forecast to rise across the population, this will only become a greater need in future. There is also a need to find new ways to engage more reluctant care homes in EOL care.

Has the ASP role resolved all problems with end of life care for care home residents in Barnsley? No. But the ASP role has been instrumental in a shift in how care homes are viewed within healthcare and a shift in how care home residents are viewed by GPs and others. The ASP sits within a wider framework that supports EOL care in homes. It is almost impossible to single out the contribution of one role among lots of other changes. But without such a dedicated role, there would be a hole to fill.

Finally, we heard praise from every angle for the ASP postholder. In fact, there wasn't a single criticism spoken. Already being known among care homes has helped, drawing on past experience and established relationships. The emotional intelligence is as important as the clinical skills. The postholder has remained approachable and empathetic, whether to dying residents, distraught family members or carers who themselves have been grieving. Any efforts to replicate this role elsewhere must place attention on the whole person within the role, not just the technical dimension.

Recommendations

The evidence from our evaluation shows the value of dedicated resources supporting EOL in care homes. We support this ongoing support, especially around training – even though this may be permanent – as well as more specialist input to coach care home staff, interact with residents – including those lacking full capacity – and involve families in decisions.

GP alignment really does seem to be improving relationships between surgeries and care homes. However, power dynamics remain, with carers lacking medical knowledge and language and sometimes not feeling able to advocate strongly enough on behalf of their residents. This suggests a need for both training and development for GPs, especially to see the value of carers and their close contact with residents, but also for carers themselves, supporting them to speak up.

Some work has already taken place with YAS. This should continue, including pushing the use of one-page profiles of residents for times paramedics are called out to homes.

It has been harder for the ASP to engage some care homes. Managers, staff and residents are likely to be missing out of more specialist input. Continued effort and imagination should be used to try to engage with these homes. This goes likewise for any GPs who still don't put enough attention onto EOL for care homes.

For the ASP role itself, a challenge is ensuring a strategic and clinical lead at the same time as overseeing care homes across Barnsley. With ever-changing managers and staff in care homes, this can be testing. It also demands a continuing need to support community and Macmillan colleagues, sharing the advance skills in EOL care.

The GSF is a valuable tool to support earlier identification of people in the last year (or more) of life. There continues to be wider work needed on this, not just in care homes and GP surgeries, nor just in Barnsley.

For organisations like Macmillan or others interested in improving EOL care for care home residents, the ASP provides a clear model to replicate elsewhere. Key to this is getting the right person for the role, somebody with clinical knowledge but – arguably just as important – somebody with the right emotional intelligence, who can connect with people whoever they are. This role doesn't sit in a vacuum and must work with other parts of community healthcare, strategically and with care homes, residents and families. A real passion to ensure high quality, inclusive care right up to a "beautiful death" is paramount. At a system level, this also means wider support for care homes – particularly ongoing training around EOL and palliative care – but also connections between GP surgeries and community health teams. The ASP role has shown the need for advocacy for EOL care in care homes within this wider system.

Appendices

A1. Evaluation framework

A2. Engagement with care homes during the evaluation

A3. Glossary

A1. Evaluation framework

Key evaluation question and project outcomes	Sub-evaluation questions	Indicator
1. What impact does the ASP role have on **high quality** clinical and personalised holistic **care** and personalised **choice** in the last year of life? - Residents living with palliative care needs are pro-actively identified within care homes. - Care home residents have an opportunity to discuss and record their preferences and wishes for palliative care. - Residents' care and support at end of life is personalised and responsive to their individual, complex, changing needs. This includes dying in their preferred place. - There is a reduction in inappropriate / unplanned hospital admissions from care home residents.	1.1. What, if any, changes have there been to the way palliative care home residents are recognised and identified? 1.2. What difference has this made to the number of care home residents being able to access enhanced quality palliative care? 1.3. To what extent do family members feel included in decisions about their relatives living in care homes? 1.4. Has there been a decrease in the number of unplanned and avoidable emergency admissions to hospital? What has contributed to this? 1.5. What are the enablers and barriers to successful outcomes from the ASP work, whether at a system, care homes or individual resident level?	- Increase in proportion of residents with EPaCCS in place after ASP intervention - Increase in proportion of residents with advance care plans (or medical management plans for those lacking mental capacity) in place after ASP intervention - Increase in proportion of residents dying in their preferred place after ASP intervention - Good quality of care right up to death - High satisfaction from residents or family over the palliative care provided to residents - High satisfaction from residents and family over their involvement in advance care planning - Reduction in conveyancing at a care home level
2. What does an appropriately skilled and **integrated system** look like? - Care home residents' preferences and wishes	2.1. Who are the key players and what are their roles within the system? 2.2. What are the enablers and barriers to effective integrated working for palliative care home residents, including trust	- Increase in take-up of GSF at care homes - The number of palliative or EOL education or training sessions delivered to care homes

Key evaluation question and project outcomes	Sub-evaluation questions	Indicator
for palliative care are shared appropriately. - Residents receive the palliative care they choose because of effective working relationships and care pathways with primary care, secondary care, care home staff and existing community teams.	between sectors and roles, and care home staff skills and confidence? 2.3. To what extent has the ASP been able to influence this, including connections between care homes, GPs and community nursing teams? 2.4. What skills or culture are needed within the system, particularly care homes, to provide palliative care home residents with appropriate and timely care? 2.5. What wider infrastructure is needed in order for working to be truly integrated, eg IT, data sharing?	and, if available, positive feedback from this - Closer working between care homes and GPs or community health teams - Effective transfer of care, eg recognition of palliative needs, quicker access to right care, care preferences shared
3. How do we ensure the **sustainability** of personalised holistic care planning within the system? - Education for care home staff is embedded in new starters' induction. - Increased confidence (reduced anxiety of) care home staff and visiting health/social care services supports better care for residents at end of life, also reducing unavoidable hospital admissions. - GP (and other partners) make better decisions	3.1. Following the intervention of the ASP within a care home, how has the system continued to support palliative care residents in their preferred place of care? 3.2. How far does the Gold Standard Framework (or other tools, eg Macmillan six principles) ensure the longer-term sustainability of personalised holistic care planning in care homes? 3.3. Is there a need for a dedicated role to continue high quality palliative care in care homes? If so, what wider resources are needed for the success of the role? If not, what alternative options can ensure personalised holistic care planning within the system? How well equipped are	- Ensuring documentation put in place (ie EPaCCS / confirmation of GSF categorisation position) is amended and revisited in accordance with residents' level of need / deterioration - Other residents added onto palliative care registers after the ASP has finished in that neighbourhood - Other residents with advance care plans / preferred place of death etc in place after the ASP has finished in that neighbourhood

Key evaluation question and project outcomes	Sub-evaluation questions	Indicator
about palliative care for care home residents as they have more information.	these different elements to do so? 3.4. If starting again, what changes would be made to the design of this project and the ASP role? What are the wider lessons?	▪ More confidence from care home staff in caring for palliative residents ▪ Care home staff feel empowered to voice residents' wishes, eg to GPs and other medical professionals ▪ GPs and other medical professionals have more trust in palliative care information from care homes ▪ EOL and palliative care training / awareness provided to new care home staff ▪ More residents being case managed for palliative needs by community teams or GPs ▪ Continued lower level of conveyancing at a care home level ▪ Access to summary palliative care records to all who need them

A2. Engagement with care homes during the evaluation

Care home	Neighbourhood	Nov 2019	Feb/Mar 2020	Nov 2020	Mar 2021	Apr 2021	May/Jun 2021
		Method					
A	South	Interview (after)					Written feedback (after)
B	Central	Interview (during)		Feedback form (after)		Postcards (after)	Focus group (after)
C	Penistone		999 audit (before)				
D	Penistone		999 audit (before)	Feedback form (during)	999 audit (after)		Written feedback (after)
E	Penistone		999 audit (before)		999 audit (after)		
F	Penistone		999 audit (before)		999 audit (after)		
G	Penistone		999 audit (before)		999 audit (after)	Feedback form (after)	
H	North		Interview (before)				
I	North		Interview (before)				
J	Central			Interview (after)			
K	Dearne					Feedback form (before)	
L	North					Feedback form (during)	Interview (during)
M	North					Feedback form (during)	Interview (during) Interview (during)
N	South						Written feedback (after)
O	South						Focus group (after)
P	South						Written feedback (after)

A3. Glossary

Advance care planning

Advance Care Planning (ACP) is the voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline. If the individual wishes, their family and friends may be included. It is recommended that with the individual's agreement this discussion is documented, regularly reviewed and communicated to key persons involved in their care.

These formally documented conversations can then be used in the future by health and social care professionals if the person subsequently loses their capacity, to help make best interest decisions about their care. They should take into account their beliefs, goals and values. By taking into account the patient's wishes for their future care, this has the potential to improve the experience of patients and their carers in relation to the care they receive.

There are 3 levels of ACP as identified in the Mental Capacity Act: preferences and wishes which will inform best interest decisions but is not legally binding; advance decision to refuse treatments which when signed, witnessed and dated is legally binding when refusing specific treatments: Lasting power of attorney (LPA) for health and welfare, when registered with the Office of Public Guardian, gives legal rights to the appointed attorneys and will be involved in best interest decision making.

Best interest

If a person has been assessed as lacking capacity then any action taken, or any decision made for, or on behalf of that person, must be made in his or her best interests (principle 4). The person who has to make the decision is known as the 'decision-maker' and normally will be the carer responsible for the day-to-day care, or a professional such as a doctor, nurse or social worker where decisions about treatment, care arrangements or accommodation need to be made.

The MCA provides a non-exhaustive checklist of factors that decision-makers must work through in deciding what is in a person's best interests.

Some of the factors to take into consideration are:

- Do not discriminate. Do not make assumptions about someone's best interests merely on the basis of the person's age or appearance, condition or any aspect their behaviour.
- Take into account all relevant circumstances
- If faced with a particularly difficult or contentious decision, it is recommended that practitioners adopt a 'balance sheet' approach

- Will the person regain capacity? If so, can the decision wait?
- Involve the individual as fully as possible
- Take into account the individual’s past and present wishes and feelings, and any beliefs and values likely to have a bearing on the decision
- Consult as far and as widely as possible.

It is vital that a record of the best interest decision is made. Not only is this good professional practice, but given the evidence-based approach required by the MCA, an objective record of the decision should be rigorously recorded and be available to inform decision making but also to withstand scrutiny should the decision-making processes be challenged at any point.

DNACPR

DNACPR stands for ‘do not attempt cardiopulmonary resuscitation’ and this decision is communicated in a form. This form indicates that CPR should not be attempted in the event of the heart stopping beating; it does not refuse any other medical treatment.

Emergency health care plan

‘Emergency health care plans’ can support decision making in and out of hours for professionals who may be called for advice or when a visit is requested. Management plans for potential problems can therefore be very helpful in giving treatment guidance and suggestions to the health care professional e.g. ‘at risk of hypercalcaemia. Would be appropriate to treat with IV bisphosphonates’ or ‘has oral antibiotics and steroids at home for use in infective exacerbations of COPD’.

Emergency health care plans are medical management plans, but as with any advance care planning conversations or best interest outcomes, these should be reflected in the emergency health care plans.

EPaCCS

Electronic Palliative Care Coordination Systems (EPaCCS) are England's pre-eminent initiative in enabling advance care planning and improved communication and coordination at the end of life. They are electronic registers or tools and processes for pulling together and sharing data which aim to enable access to information about dying patients.

Gold Standard Framework

The Gold Standard Framework (GSF) is a tool to support end of life care. A key element is identifying people earlier in their EOL journey. The GSF Prognostic Indicator is a guide for clinicians enabling earlier recognition of decline for patients considered to be in their final year/s of life. It is a key tool to support earlier identification of patients, enabling better assessment of their needs and planning care in line with their needs and wishes.

The GSF indicators are defined as follows:

- GSF prognostic indicator stage A (blue) = year plus prognosis = stable
- GSF prognostic indicator stage B (green) = months prognosis = unstable
- GSF prognostic indicator stage C (yellow) = weeks prognosis = deteriorating
- GSF prognostic indicator stage D (red) = days prognosis = dying

Yet the GSF is also about appropriate conversations, finding out residents' wishes and meeting them, providing a personalised service that wraps around the person rather than the other way around and, much later, about things like pre-emptive medication.

Karnofsky Score

The Karnofsky Performance Scale Index allows patients to be classified as to their functional ability. The patient's overall performance status is assessed in 3 dimensions: activity, work and self-care and a continued and sustained decline in performance status can help to identify the deteriorating patient. The lower the Karnofsky score, the worse the survival for most serious illnesses.

For example:

Karnofsky Performance Status Scale Definitions Rating (%) Criteria

100 = Normal no complaints; no evidence of disease.
90 = Able to carry on normal activity; minor signs or symptoms of disease. Able to carry on normal activity and to work; no special care needed.
80 = Normal activity with effort; some signs or symptoms of disease.
70 = Cares for self; unable to carry on normal activity or to do active work.
60 = Able to care for most needs but requires occasional assistance
50 = Requires considerable assistance and frequent medical care.
40 = In bed more than 50% of the time.
30 = Almost completely bedfast.
20 = Totally bedfast and requiring extensive nursing care by professionals and/or family.

10 = Comatosed or barely arousable, unable to care for self, requires equivalent of institutional/hospital, disease may be rapidly progressing.

0 = Dead

Mental capacity

'Mental capacity' means being able to make your own decisions with sufficient understanding and memory to comprehend in a general way the situation in which one finds oneself and the nature, purpose, and consequence of any act or transaction into which one proposes to enter.

Someone lacking capacity - because of an illness or disability such as a mental health problem, dementia or a learning disability - cannot do one or more of the following four things:

- Understand information given to them about a particular decision
- Retain that information long enough to be able to make the decision
- Weigh up the information available to make the decision
- Communicate their decision.

The Mental Capacity Act aims to empower and protect people who may not be able to make some decisions for themselves. It also enables people to plan ahead in case they are unable to make important decisions for themselves in the future.

The Act can apply to all sorts of decision such as:

- major decisions such as decisions about personal finance, social care or medical treatment
- everyday decisions such as decisions about what to wear or eat

The law works on the principle that everyone is assumed to have capacity to make decisions for themselves if they are given enough information, support and time. It protects their right to make their own decisions and to be involved in any decisions that affect them. A person's capacity must be judged according to the specific decision that need to be made, and not solely because of their illness, disability, age, appearance or behaviour. There are legal safeguards that must be followed when making a decision on behalf of some who lacks the capacity to make the decision - it must be done in their 'best interest'.

Rockwood Frailty Score

The Rockwood Frailty Score is a clinical frailty scale that is used to define an individual's level of frailty and can be defined as follows:

1 Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 Well – People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, e.g. seasonally.

3 Managing Well – People whose medical problems are well controlled but are not regularly active beyond routine walking.

4 Vulnerable – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being "slowed up", and/or being tired during the day.

5 Mildly Frail – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 Moderately Frail – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.

7 Severely Frail – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9. Terminally Ill - Approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail.

Treatment escalation plan

The treatment escalation plan gives treatment parameters and indication of ceilings of treatments. The treatment escalation plan should reflect the patient's preferences and wishes, advance care planning conversations or best interest outcomes.

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