AT THE CROSSROADS

How can the NHS Long Term Plan improve end of life care in England?

Contents

Case studies used in this report all provided informed consent to Macmillan and are used with permission.

Executive summary: **Taking the right route**

There are few certainties in life, but there is one thing we can be sure of: we will all die. So we all need and deserve high-quality end of life care. And yet, despite policy ambitions now in place calling for improvements that will deliver personalised end of life care, this report finds that in too many cases people are not experiencing this.

There is no shortage of evidence or good practice to guide us on what constitutes high-quality end of life care for people with cancer and other health conditions but many of the underlying components needed to deliver this care are still not in place. The NHS Long Term Plan has set the national direction of travel for the NHS in England for the next 10 years and includes welcome commitments to improve end of life care. However, simply stating these commitments in not enough: for people not receiving personalised care this needs to translate into action now.

Despite the examples of excellent practice, professionals tell us that more needs to be done to ensure health and care services are universally strong at identifying people who are approaching the last year of their life. In addition, we need to see all health care professionals supported to recognise people's palliative care needs and their needs at end of life. At the most basic level, end of life care should be everyone in health and care's business, so they can confidently have conversations with people about death and dying. And to underpin this vision, all services need to have the right tools and ways of working to effectively deliver truly personalised end of life care.

This report is rooted in the reality of delivering end of life care, offering a message to both national policy-makers, and, with five-year plans being drawn up in Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs), to local health systems too. National and local systems now need to work together to seize the opportunities contained in the NHS Long Term Plan and push forward to achieve lasting improvements in end of life care.

Given we know that the demand for palliative care services is set to increase in the future, it is vital that we see dramatic improvement in end of life care. This will only become a reality, however, when end of life care is properly prioritised, with clear actions and responsibilities set for driving this improvement at a local level.

Seven priorities for the road ahead

Key findings and recommendations
This report is based on research and insight gathered from health care professionals working on the front line. It is their real experience of trying to deliver personalised care for people at the end of life in what remains a fragmented system. These professionals ranged in location and job title, but there were many similarities in what they had to tell us.

We framed our conversations with professionals around seven commitments in the new NHS Long Term Plan we have identified as being most relevant to end of life care. For each commitment, we address what needs to happen in health and care to ensure services can be successful in delivering improvements to end of life care. This report presents a clear call to action for every person involved in the next stage of delivering the Long Term Plan.

POLICY PRIORITY ONE:

The need to prioritise end of life care in all parts of the health and care system

Key finding

Many professionals are concerned that among competing priorities, end of life will lose out when local health systems implement the Long Term Plan. Many professionals drew upon their experience of the National Commitment for end of life care; a well-intentioned document with buy-in across the sector. However a lack of mandated deliverables from NHS England means that progress has been slow.

Key recommendations

* NHS England must provide clear guidance on what local health systems are expected to deliver and prioritise in relation to end of life now the Long Term Plan is getting implemented.

* Every Sustainability and Transformation Partnership (STP) and Integrated Care System (ICS) must state how they intend to fulfil the end of life commitments in the Long Term Plan when they draw up their five year delivery plans.

POLICY PRIORITY TWO:

Personalising care at the end of life through shared decision making and advance care planning

Key finding

Our research finds that communication about death and dying is not always happening between health and care professionals, the people they care for at the end of life and their loved ones. There are still hurdles to overcome to ensure that health and care professionals feel fully confident and able to open up and facilitate conversations about someone's advance care plan - the key to personalising care at the end of life.

Ultimately, if health and care professionals are not having these conversations with the patients they care for, it also has an impact on the conversation a person may be able to have with their family and loved ones about what is important to them at the end of life. When these conversations don't happen, it can mean that people's wishes are not taken into consideration or are not fully understood by others.

Key recommendations

- NHS England must ensure local health systems are delivering on the ambition for everyone who may be in their last 12 months of life to be offered an advance care planning conversation where appropriate.

- Any shared decision-making conversation or support tool must ensure carers and loved ones of a person at the end of life are key members of a patient's care team as per NICE guidance NG31 – 'Care of dying adults in the last days of life'.

POLICY PRIORITY THREE:

Sharing records via Electronic Palliative Care Co-ordination Systems (EPaCCS)

Key finding

It is widely known that the Electronic Palliative Care Coordination Systems (EPaCCS) roll-out varies across the country. We heard from professionals in some areas that had well-functioning systems, but many areas that did not. The main challenges were clinical buy-in, functionality and data sharing.

If care and support is to be provided to people at the end of life out of hospital and in the community, these issues need to be fixed. Good communication is more important than ever, in implementing the Long Term Plan. Plans such as community rapid response teams require multiple professionals to have quick access to a person's end of life decisions. These include groups that are often excluded from patient information sharing, such as 111 call operators and ambulance crews.

Key recommendations:

- Clinical Commissioning Groups (CCGs), and the STPs and ICSs they work with must have plans in place to develop an EPaCCS system or an equivalent tool for coordinating palliative care. They need to show how they are considering the needs of end of life patients in wider plans for digitalisation and on data interoperability.

- Any system being developed must work with all health and care providers, including private providers of care such as local 111 services or residential and care homes.

POLICY PRIORITY FOUR:

Integrating care in the community

Key finding:

Professionals largely welcomed the elements in the Long Term Plan that focused on community based care, and the opportunities this provided to facilitate choice at the end of life. However, many sounded warnings about what needs to happen to ensure these changes work for end of life care, advising that it is essential that the planned rapid response community teams had the right skill mix. These plans will also fail if the community workforce is not resourced enough; for example key role numbers such as district nurses are declining.

Key recommendations:

- NHS England must provide guidance to ensure rapid and urgent response teams have the right skills, competencies and experience to support people at the end of life.

- STPs/ICSs must ensure all health and care professionals are able to access shared patient records to support coordination of end of life care.

POLICY PRIORITY FIVE:

Training professionals to have the confidence to support people at the end of life

Key finding:

This report finds that end of life training for professionals in England is a mixed picture. It is a commitment in the Long Term Plan to train staff to identify and support patients at the end of life. However, we heard from professionals that workforce pressures mean accessing end of life training is difficult. It is also hard to get buy-in from some professionals, despite training being offered at different times of the day and in different settings. More needs to be done to ensure that end of life is everyone's business.

Key recommendations:

- The Care Quality Commission (CQC) should ensure inspectors consistently use criteria related to both the quality and amount of training on end of life that professionals receive. This should be highlighted as a priority for all relevant health and care providers providing end of life care.

- All relevant health and care professionals should be able to access funded training for improving their support skills for patients at the end of life.

POLICY PRIORITY SIX:

A whole system approach to enabling personalised care

Key finding:

A common theme in our conversations with professionals was the lack of confidence that the wider health and care system can truly enable choice at the end of life. Worryingly, some staff reported that they were actively avoiding starting discussions with people about their end of life wishes. This is because they did not want to 'open the floodgates', knowing that the patient may not be offered a Continuing Healthcare package that would enable them to die at home. Common issues included gaps in the social care workforce and a lack of access to out of hours pain medication.

Key recommendations:

- The upcoming Spending Review must provide urgently needed funding for social care.

- In the longer term there needs to be a sustainable funding settlement for social care.

- The NHS must also work with social care partners to ensure that recruitment to the NHS, especially for nursing positions, complements plans underway to recruit and retain professionals in social care.

POLICY PRIORITY SEVEN:

Quality improvement in primary care

Key finding:

We identified the new Quality Improvement (QI) cycle in primary care, and its focus in the first year of implementing the NHS Long-Term Plan, as a key lever to drive improvements in end of life. Professionals told us that they see this as an opportunity to encourage primary care to innovate in end of life care provision. It's encouraging to see end of life care as a QI focus for 2019/20, but the focus now needs to shift to ensuing that improvements in this area are sustained past the QI cycle.

Key recommendations:

- NHS England must report on progress made against the Quality Improvement module for end of life care, set for 2019/20, and communicate its success to encourage more quality improvement activities.

- After QI 2019/20 activity in end of life care, a new indicator to replace the removal of regular MDT meetings for palliative patients should be included in the Quality Outcomes Framework.

Section one: Introduction

Macmillan has a long history of advocating improvements in end of life care. We work with partners across health and social care to bring about real change. We fund healthcare professionals and provide learning and development materials and educational grants to help health care professionals such as GPs and nurses deliver joined-up, high-quality end of life care. We also work with the NHS and local health systems to plan and innovate services – across health and care settings – to ensure that at the end of life, the care that a person receives is personalised and dignified.

Quality care provided at the end of life should not depend on what you die from, especially as our ageing population means people are increasingly dying with two or more long term conditions. That is why we advocate for better end of life care for everyone, not just people with cancer, and why we are a committed member of the End of Life Care Coalition; six charities working together to ensure end of life is a priority for policy makers. The Coalition partners are Macmillan Cancer Support, Marie Curie, Sue Ryder, Cicely Saunders Institute, Motor Neurone Disease Association and Hospice UK.

Macmillan's vision for end of life care

For Macmillan, truly personalised care at the end of life means being able to have a timely conversation with health and care professionals about your preferences.

That means:

- being able to make clear decisions for your advance care planning.
- being able to make it clear where you want to die and having honest conversations with professionals about your wishes.
- being supported so you can make informed decisions on continuing or stopping treatment.

Ultimately, it's about being sure that your wishes and preferences will always be understood and respected, no matter which healthcare team is looking after you.

It's knowing that the NHS will be able to provide the services you need to support you and that choice at end of life is both possible and attainable. And it's the comfort of being certain that the healthcare professionals who look after you are trained and empowered to provide the best care when you need it the most.

Macmillan's strategy places high-quality end of life care at the heart of its plans: influencing policy-makers so that good end of life care can be a reality for all and working in partnership to demonstrate how this can be done. We are especially guided by six principles for good end of life care in the community, which we have tested, evaluated and we are now working hard to see spread. Essentially, these are principles designed to enhance end of life care in the community that is personalised to meet individual needs.

Six principles for end of life care

- Dedicated support from a consultant in palliative medicine.
- Early referral into specialist palliative care.
- Rapid response to unscheduled care needs.
- Integrated and co-ordinated care across teams and boundaries.
- Multi-skilled and multi-professional teams.
- Learning and development for both specialist and generalist staff.

What needs to happen?

We believe that change only happens when there is direction from above and a groundswell in support and change in behaviours from below. In end of life care, like all other areas of policy, there needs to be national leadership to mandate and drive improvements. But there also needs to be local leadership and a workforce in place to meet local population need and translate national policy commitments into sustained action.

This report attempts to examine how national policy and local action – combined – now need to work in tandem to seize the opportunities of the NHS Long Term Plan[1] and push forward to achieve lasting improvements in end of life care. The NHS Long Term Plan has set the national direction of travel for NHS commissioners and providers in England for the next 10 years. It builds on previous government commitments[2]. Having the right policy commitments set at a national level must always be the foundation stone for good care. But the insight in this report, gathered from health professionals, highlights sensible policy recommendations are not in and of themselves, enough. There has been no shortage of national policy documents calling for change in end of life care. But for those who work in this field striving to make

improvements, some fundamental problems remain unaddressed. We have also highlighted that receiving end of life care at home depends on the availability of properly funded social care services, with an adequate workforce and a stable provider market.

Our report aims to be rooted in the reality of delivering end of life care. We offer a message to both national policy-makers and local health systems to fit with the five-year plans being drawn up in Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs).

To state end of life is a policy priority is not enough: for people not receiving personalised care, this needs to translate into action now.

Action at a local level, rooted in delivery of care

Speaking to professionals, we know that ambitions set out in national policy documents are often difficult to translate into tangible, local delivery plans that result in real change on the ground.

Therefore, a key target audience of this report is England's local health systems, whether they are STPs or ICSs, who are now tasked with improving health and care outcomes in their local populations. The Long Term Plan for the NHS in England has set out a high-level vision, supported by an implementation framework, which means local systems must now draw up specific delivery plans in their area. These plans must now contain concrete, specific actions on improving end of life care.

In 2017, the End of Life Care Coalition analysed the plans for STPs in England and found that 41% of them had no mention or little detail of how end of life care would be improved in their populations[3]. In addition, recent analysis of 152 regional Health and Wellbeing Boards showed that only half of

the Health and Wellbeing strategies mentioned end of life care, few prioritised it and no strategies provided evidence for effective interventions at end of life[4].

As STPs and ICSs undergo their planning phase for the NHS Long Term Plan we expect that all will give specific consideration to and plan for how their local health and care system will deliver good quality end of life care services. After all, there is an urgent need for this to happen to deliver the ambitions of the NHS Long Term Plan.

This report is rooted in health managers' and professionals' experiences, from commissioners to nurses. Their insight on how to seize the opportunities presented in the Long Term Plan is the basis for our recommendations.

Policy context

In July 2014, recognising that end of life care was too poor in quality for too many people who needed it, the government commissioned an independent expert review to provide advice on improving care for adults at the end of life. In February 2015 – after extensive consultation – the findings were published in the Review of Choice in End of Life Care[5]. The final report set out a comprehensive vision for how end of life care services needed to be reformed to give people greater choice and higher quality care at end of life.

In July 2016, the government responded to the Choice Review with six commitments to end the variation in end of life care across the health system by 2020[6]. This included helping people nearing the end of life to have honest discussions with care professionals about their needs and preferences and make informed choices about their care. It also covered discussing and documenting personalised care plans with care professionals, involving family and carers and knowing who to contact for help and advice at any time.

Those commitments remain, from Macmillan's perspective, the right blueprint to deliver improvements in end of life care. They stand alongside the Ambitions for Palliative Care framework[7] - a framework developed in 2015 by a national partnership of statutory and voluntary organisations that sets out a vision to improve end of life care through partnership and collaborative action at local level throughout England.

While these commitments were positive, and work has been delivered through the NHS England National Programme Board for end of life care, the government commitment came with no extra funding. More than three years later we are disappointed with the lack of progress to bring about real change to people's experiences of care at the end of life.

We know there continues to be unacceptable geographic variation and inequality in the end of life care people with cancer receive in their dying months. While some people have choices around where they die, and the chance to spend time with the people who matter to them, others spend their final year in and out of A&E and have little opportunity to access the care of their choosing[8].

Opportunities in the Long Term Plan

In January 2019, NHS England published its 'Long Term Plan' which sets out to redesign patient care in the NHS in England for the next decade. It seeks to ensure the health system and health care professionals are best placed to deliver an integrated, coordinated and personalised care experience, at all stages in life.

Overall, Macmillan believes the Long Term Plan represents an opportunity for the NHS in England to deliver more sustainable, high quality and personalised care for people at end of life. The much-needed focus on community care and the need for quality improvement (through quality improvement modules in the GP contract) has the potential

to increase capacity where it's most needed to help people to die in their preferred place of care – which is often their home.

And it's encouraging to see that there are explicit commitments to end of life care, such as the roll out of training to help staff identify and support people at the end of life. The recognition of the importance of proactive personalised care planning for everyone in their last year of life is also welcome.

Other commitments in the Long Term Plan that have the potential to improve end of life care include:

• the establishment of rapid response teams of GPs, nurses and physiotherapists to provide urgent care in the community and keep patients out of hospital.
• the implementation of the Universal Model of Personalised Care, with a focus on the principle of shared decision making and a drive to further widen access to personal health budgets.
• the establishment of Primary Care Networks to create integrated teams of GPs, community health and social care staff. This will enable GP practices to work together to deal with pressures in primary care and extend the range of local services.

About this research

The research in this report was carried out with professionals across England and involved:

• desk based research and a review of the latest evidence on end of life care.
• in-depth interviews with a mix of health care managers and professionals such as GPs, palliative care nurses, commissioners, district and community nurses, paramedics and practice development nurses.
• three focus groups comprised of health care managers and professionals including: GPs, palliative care nurses, practice nurses, commissioners, end of life care education leads, district and community nurses, paramedics and practice development nurses.

In NHS England's Long Term Plan there are commitments on end of life care which mirror or build on the UK Government's pre-existing 'national commitment' to improve end of life care. The focus of our research has been to explore the reality of delivering end of life care in England – and to understand, from the perspective of healthcare professionals, where they see the opportunities and challenges to implementing the Plan's commitments. This report contains a series of recommendations based on these findings.

Section two:
The current state of end of life care in England

The UK has a long history of pioneering palliative care. It was the birthplace of the hospice movement and has previously been ranked top in an international comparative study for end of life care[9]. However, there is a danger that England is falling behind, and that current end of life services are not sufficiently equipped for the changing volume and increasing complexity of deaths in future years.

This chapter reviews the most recent evidence and data on end of life care provision. The focus of this report – on delivery of NHS England's Long Term Plan – means the data presented in this report covers England only where available.

It should be noted that routine data collections on end of life provision are relatively sparse. We recognise that provision is fragmented; end of life care involves professionals across different health and care settings, from community services to hospitals to hospices, which can make data collection difficult.

But this is in itself a strong argument for the government and the NHS to collect robust data on the end of life provision, starting with the end of life workforce and progress on specific commitments such as the roll-out of staff training and advance care plans.

Indeed, a practical first step would be for the UK Government to continue to publish the National Survey of Bereaved People (VOICES), which was published annually but has not had a new release since 2016. This is a valuable document that tracks reported quality of end of life care in the last three months of life from the perspective of relatives and carers.

Setting the scene

Just under half a million people died in England in 2017, with cancer (as a broad disease group) being the leading cause of death[10]. In fact, cancer deaths are increasing slightly and have risen by 7% from 2001-2016[11]. This is likely to be due to the demographic trend of our ageing population.

The need for end of life care is increasing. By 2040, annual deaths in England and Wales are projected to rise by 25%[12]. Trends also indicate that the care people receive at the end of their life will be over a longer time period and more complex as the number of people with long-term health conditions is expected to rise to 18 million by 2025[13]. For three quarters of these people, death did not occur suddenly, indicating that planned, dignified end of life care is possible for most.
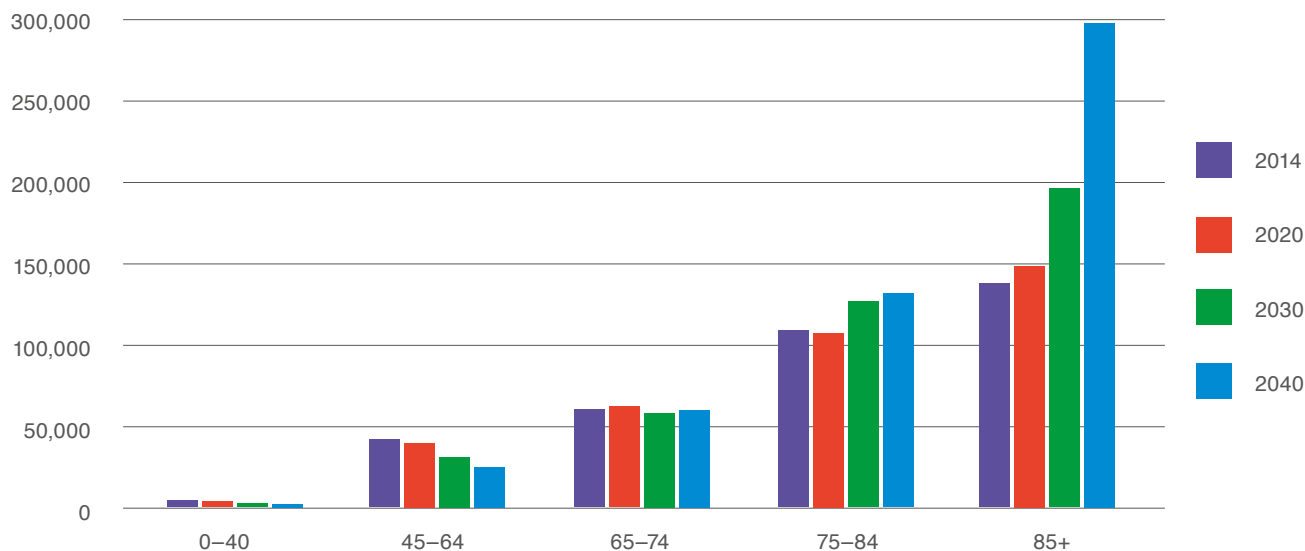
Figure 1
**Demand for end of life care in England and Wales will increase in the next decades –
number of people estimated to require palliative care by age, 2014–2040.**

Source: Etkind et al. BMC Medicine (2017) (Reproduced under Creative Commons Attribution 4.0 International
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Where do people die?

Home	Care home	Hospices	Hospital	Other communal establishment	Other
30.7%	13.8%	17.1%	36.7%	0.2%	1.3%

Figure 2
Place of death due to cancer in England and Wales in 2017. [14]

Home	Care home	Hospice	Hospital	Somewhere else	Don't know	Prefer not to say
64%	1%	18%	1%	2%	14%	0%

Figure 3
**If the right care and support where available, where people living with cancer in
England would prefer to spend their final days (2017).** [15]

As figures two and three demonstrate, for people living with cancer there is currently a large gap between the wish to die in a preferred place and the actual place of death. Despite only 1% of the cancer population stating a preference to die in a hospital, it is the most common place of death, with 37% of people dying there[16]. Too many people experience poor care as they approach the end of their life and many dying people spend their last months, weeks and days in hospital – even though most of them do not want or need to be there.

This is despite the policy direction of recent years to promote choice at the end of life. The personalisation agenda, which has been continued in the new Long Term Plan, needs to make significant progress in closing this gap. The purpose of this report is to provide practical recommendations to ensure the rhetoric of the plan is carried through to real change.

There does, however, need to be an acknowledgement that the reality of receiving end of life care at home can be at odds with the policy aspiration that choice is available for all. Some evidence suggests that the quality of end of life care in people's homes can be compromised if adequate support services are not available. Indeed, a national survey reported that pain relief was less effective in the home compared with hospitals, care homes and hospices[17].

So, for some people, hospital is an appropriate place to die. Our report reflects this as we ensured that acute-based health professionals were consulted during the qualitative interviews and focus groups. In fact, almost three-quarters (74%) of respondents to the VOICES survey of bereaved relatives, friends and carers whose loved one died in hospital believed that their loved one died in the right place, despite only 3% of all respondents stating that patients wanted to die in hospitals[18]. Some professionals we consulted spoke of the

need in policy for improved recognition of the reality of the final days of life, and acknowledge that for some people, hospital might be a more appropriate place to die.

It's also important to recognise that place of death is not the only way personalised care at the end of life should be measured. We know that many people who are dying, and their families, place significant importance not on where they want to die, but on effective communication and shared decision making, expert care and respectful and compassionate care[19].

Quality of end of life care

Evidence suggests that the location of care at end of life can impact on the type of care a person receives. End of life care in hospitals can be worse, with people less likely to experience good quality of care. Indeed, in hospital, people at end of life are at higher risk of undergoing unnecessary medical treatment[20]. The VOICES survey found that the relatives of people who died in hospital rated overall quality of care significantly worse than any other place of death, with 31% rating the care 'fair' or 'poor'[21].

A key indicator of the quality of end of life care, emergency admissions in the last year of life, shows that too many people are being admitted to hospital at the end of life. The average number of admissions in England is nearly twice as many as in Scotland or Wales[22]. On average, 35% of those who die each year from one of eight common types of cancer have five or more emergency visits in the last year of life. This can be both distressing for patients and a potentially inefficient use of NHS resources[23].

However, the overall picture is relatively good for end of life care in England and the commitments in the Long Term Plan start from a solid base. 75% of families rated their loved one's end of life care as 'outstanding',

'excellent' or 'good' in the most recent VOICES survey'[24]. While the most recent Care Quality Commission ratings for acute hospitals show that end of life care is on average the best rated core service[25].

But we want to see universally excellent end of life care, which means we must continue to identify areas where this does not happen. Evidence suggests advance care planning is effective in promoting personalisation and choice, with studies indicating that people without an advance care plan are more likely to die in hospital compared to those without. A study in the south west of England of people using hospice services found that 11% of people who had completed an advance care plan died in hospital, compared with 26.5% who had not[26]. However, there is extremely limited data on uptake of advance care plans in England.

Of course, advance care plans can only be effective if they can be easily accessed and shared between different health professionals. So in England, national policy has promoted the use of Electronic Palliative Care Co-ordination Systems (EPaCCS), promising full roll out by 2020[27]. However, as with advance care plans, data on roll out is extremely limited and it is difficult to hold these commitments to account. There is much to do to ensure quality improvement occurs in end of life care. And not much time to do it.

Section three:
How can the implementation of the Long Term Plan deliver better end of life care in England?

This section sets out what professionals involved in end of life care provision have told us needs to happen now to improve care. To illustrate this, we have included examples of best practice Macmillan has been involved with or been told about by professionals.

It's divided into seven policy priorities, derived from the Long Term Plan commitments, that are most relevant for end of life care, as well as the insight generated from health professionals across different health settings. We believe these policy priorities are vital if the commitments on end of life in the Long Term Plan are to be effective. Each priority is based around a specific commitment in the plan, and for each one we offer policy recommendations based on our findings.

The policy priorities outlined in this section are:

1. The need to prioritise end of life care in all parts of the health and care system.

2. Personalising care at the end of life through shared decision making and advance care planning.

3. Sharing a person's record via Electronic Palliative Care Co-ordination Systems (EPaCCS).

4. Integrating care in the community.

5. Training professionals to have confidence to support palliative and end of life care patients.

6. A whole system approach to enabling personalised care.

7. Quality improvement in primary care.

We have framed our seven policy priorities around a specific ambition or commitment in the NHS Long Term Plan to show what needs to change, before providing recommendations on how this needs to happen. We also identify case studies of services that deliver on one or more of our seven appropriate policy priorities.

POLICY PRIORITY ONE:

The need to prioritise end of life care in all parts of the health and care system

There have been well-intentioned policy commitments at a national level for end of life care since the Choice Review in 2016. The 2019 NHS England Long Term plan has continued in this direction of prioritising personalisation at the end of life, with the ambitions of enabling more discussions about the preferences people have around the type of care and the setting for their care.

As stated in the Long Term Plan[28] paragraph 1.42: 'With patients, families, local authorities and our voluntary sector partners at both a national and local level, including specialist hospices, the NHS will personalise care, to improve end of life care.'

Since the Choice Review, there has been important work by NHS England, local health systems and individual NHS trusts to enable personalisation of care for people at end of life. But our research with professionals strongly signals that more needs to be done at all levels of the health and care system. Death is not an unexpected part of healthcare, it happens to us all. Local health systems must take opportunities to think about how they can play their part in delivering truly personalised care for everyone at the end of life.

National agenda to local implementation

Our research found a mixed picture in terms of health managers and professionals' level of knowledge and understanding about how the government's six-point National Commitment and the Long Term Plan are expected to be delivered or the extent to which they should drive local decision-making about end of life provision. It was a common theme for professionals to tell us that they felt the six-point National Commitment was a good framework, but was

not something that had dictated strategic prioritisation of palliative and end of life care services in their area.

Professionals also told us that there was a mismatch between the national agenda around personalised end of life care and the local drivers that exist to make this happen in the system. While it was good to hear about some geographic areas where end of life has had a level of priority placed on it at all levels of the system, it was disappointing that action had tended to come from a poor CQC rating, rather than specific direction from a national perspective or local planning to address population health need.

'Of course the national ambitions are good sense, and no one can disagree with them, but they just seem to be there and have no drive behind them somehow.'
Health care professional

We heard there was a need for more specific deliverables from NHS England around end of life care to support effective commissioning and enable people to place the needed priority on end of life care services across all health and care settings. The lack of national mandated deliverables in end of life care is apparent in end of life being absent from NHS England's 2019/20 planning guidance. This could have been used as an effective tool to drive change.

From our conversations with professionals, it's clear that future planning guidance needs to reference the Long Term Plan end of life care commitments if they are to be met.

The Long Term Plan Implementation Framework, published in July 2019, also presents a missed opportunity, with end of life care only referenced once (specifically, children's palliative care services). This appears to reinforce what professionals told us; for all the high-level commitments, improvements in end of life care stall through a lack of subsequent implementation planning.

It is clear that corrective action needs to take place so local systems prioritise end of life provision; additional guidance from NHS England and Improvement regional teams would help ICSs and STPs to develop their five year plans to reflect the importance of high-quality end of life care at a local level.

The demand for palliative and end of life care services is set to grow in the future. So, there must be more direction at a national level to translate the national agenda into local implementation and support STPs, ICSs and other local health systems to plan and forecast for their population need. Especially given death is the one inevitability in life.

Importance of strong leadership

Areas with a strong strategic priority on end of life care at a local level tended to be where good clinical leadership existed to push forward the agenda within an STP or CCG setting. Professionals told us that end of life care networks or clinical expert reference groups had often been developed by passionate end of life advocates. These people had brought together interested parties to influence the STP to think about death and dying as a population need and how to strategically commission palliative and end of life care services - as well as considering how these integrate with the wider system such as ambulance teams, social care and voluntary sector services.

So it is vital to ensure health care professionals and managers who are passionate about end of life care are recognised as important drivers in delivering local personalised end of life care.

Importance of routinely collected data

Most data collected on the quality of end of life care services are proxy measures, such as the place of death or the number of emergency admissions in the last 90 days of life. With data for the VOICES bereavement survey no longer collected at a national level, there is very little data that CCGs and STPs can use to understand their services. This is particularly true for data on patient experience, which is concerning given the national policy direction towards personalisation and choice over recent years. While a survey such as VOICES remains a proxy to understand experiences of people at the end of life through bereaved relatives and friends' view of a person's care, without it, we have little indication whether policy changes have been successful.

In our research, we heard from those with commissioning and strategic responsibilities that the lack of routinely collected data on end of life care services made it a real challenge to think about how to improve, let alone innovate.

It's clear that commissioners and strategic planners are working in a challenging environment with growing demand and need[29]. To commission new services or encourage innovation, significant gaps in the pathway need to be highlighted with data or evidence presented that a new service will be cost efficient.

Either way more needs to be done at a national and a local level to inform services how they are performing, whether they are effective and what the experience is of people receiving end of life and palliative care services.

What can be done?

We heard clearly from professionals that for improvements in end of life care to be achieved, strategic priority must be placed on considering death and dying as a local population need.

As one professional told us: 'There's nothing more sure in life, that each and every one of us at some point is going to be at end of life. Yet we do not prioritise it as a health and social care system…we prioritise birth and maternity…But we don't do that at end of life. There's two things that's sure isn't it, you're born, you die. That's it.'

Macmillan believes practical steps must be taken:

- NHS England must provide clear guidance on what local health systems are expected to deliver and prioritise in relation to end of life now the NHS Long Term Plan is getting implemented.

- Every Sustainability and Transformation Partnership (STP) and Integrated Care System (ICS) must state how they intend to fulfil the end of life commitments in the Long Term Plan when they draw up their five year delivery plans.

- STPs and ICSs must place an emphasis on strong end of life leadership within health systems. This could be achieved by ensuring that each STP/ICS has a clinical network on end of life care.

- NHS England must address the lack of routinely collected data on patient experience of end of life care services to support more strategic commissioning.

POLICY PRIORITY TWO:

Personalising care at the end of life through shared decision making and advance care planning

Macmillan has always advocated the importance of advance care and we were pleased to see that previous national government commitments to **'develop and document a personalised care plan, based on what matters to you and your needs and preferences, including any advance decisions and your views about where you want to be cared for and where you want to die, and to review and revise this plan throughout the duration of your illness'**[30] was a feature of the NHS England Long Term plan in paragraph 1.42[31]: **'we will introduce proactive and personalised care planning for everyone identified as being in their last year of life.'**

We believe advance care planning conversations are vital in ensuring end of life needs are identified and met. They are crucial in enabling personalised care for people who are approaching the end of their life – in fact when staff have a record of where someone would like to die, that person is almost twice as likely to die in their place of choice[32]. **As part of the delivery of the Long Term Plan, we expect to see how national and local health systems plan to ensure every person who is in their last year of life is able to have an advance care planning conversation.**

We spoke to health care professionals in primary, community and acute settings, some with a palliative care background, and some without. All of them told us that there are two key steps that the system must get right in a person's journey. Firstly, identifying that someone is in the last year of their life. Secondly, having open communication and a conversation with a patient and their carer/family.

Early identification

Identifying a patient who is nearing end of life is the key enabler to starting any conversation about personalising someone's care. It is the opportunity for a professional to start thinking about how best to provide the holistic care a patient may need as they enter this part of their life.

When patients are not identified early, challenges in the system mean it can be harder to take into account a person's personal preferences. This is the case even if a healthcare processional spoke to them about advance care planning and what was important to them. When patients aren't promptly identified, this will be at odds with a Long Term Plan which seeks to deliver greater personalisation for patients.

We also heard from professionals that they needed more time to be able to manage the expectations of patients (and often families too), about the practical realities of the system supporting them to die in their preferred place. There were situations where patients had expressed their wish to die at home, but changed their minds after talking to health care professionals about dying at home without 24/7 care packages.

Some professionals said that by the time they see some patients who are approaching the end of their life, the patients were themselves surprised to hear they were dying because they had not been told. This may be because both patients and professionals mainly focus on treatment and so there isn't an easy opportunity to talk about dying.

Conversations

From health care professionals to people who are dying and their families, everyone needs to be better equipped and resilient to talk about the one thing we know will eventually happen to all of us.

'How can I care for somebody the way they want to be cared for, unless I know what they want?'
Health care professional

While there is a time and a place for advanced communication skills, professionals commonly said that starting a conversation about death didn't require an unattainable or high-level of skill; just time and thought. But this needs health care professionals to recognise a patient is at end of life, and to feel confident and encouraged to initiate conversations about death and dying.

We are concerned that many generalist health care professionals are not exposed to, and certainly don't continually care for or interact with, palliative and end of life care patients. This is having a detrimental impact on their confidence to open up the conversation or acknowledge the cues from a patient to talk about death and dying. We know this is having an impact on health care

professionals and on people who are approaching the end of their life. For example, while more than three quarters (76%) of people living with cancer have thought about the fact they may die from their cancer[33], worryingly only 8% of these people spoke to their healthcare team about the subject[34].

As we already know from previous Macmillan research[35], many health and social care professionals who don't work in palliative care are unclear about who is responsible for having an advance care planning conversation with someone who is in the last year of their life. It was common in our research to hear professionals tell us, that they feel uncomfortable about a conversation 'opening up the flood gates' to providing further care that they did not feel they had the capacity to deliver or sort out.

The impact of this uncertainty means professionals often feel they do not have the expertise or capacity to talk about end of life planning with patients. Alongside a misunderstanding about who is responsible for initiating advance care planning conversations, many professionals are concerned about documenting a preferred place of care, as dying at home may not be possible and they do not wish to raise unrealistic expectations for their patients. A recent national clinical audit of case notes reviews highlighted that, while approximately three-quarters of deaths are expected, advance care planning discussions were recorded in fewer than half of the deaths registered[36].

Talking about death and dying in society

In recent years there have been major efforts to raise the profile and the importance of talking about death and dying as a society. But it remains a challenge to get people talking about their own or their loved one's death. We heard from professionals that this still has a real impact on them being able to deliver personalised care for people at the end of life.

We also heard from a range of health care professionals that wider family dynamics beyond the patient can make it hard to facilitate a patient's preferences following advance care planning conversations. This often happened because the patient hadn't wanted to talk about their preferences with their family, or their family had different views. Health care professionals told us that

this was very much a part of the challenge we have as a society about talking about death and dying. For personalised care to be delivered for the dying person, we need to find a way to better engage carers and loved ones in the advance decisions a patient may be making. Only then can we ensure professionals are indeed able to facilitate personalised end of life care to the best of their ability.

For people with cancer who are at the end of their lives, shared decision making can be about a number of things: being enabled to have supportive conversations about their care preferences at the end of life; deciding whether to remain on active treatment or start palliative treatment. Whatever the ultimate outcome, we believe that shared decision making is key to delivering personalised end of life care. Health professionals must be supported and equipped to do this.

'….I have a patient that I saw last week and had never met before and clearly….she is dying but she does not want to have that conversation, she very clearly said, "I don't want to talk" and yet, if we don't at some point touch on things, it's going to be really difficult to plan her care…'
Healthcare professional

What can be done?

Macmillan believes that truly personalised end of life care can only come when people are identified as early as possible. This is backed by professionals who have told us that this is the key element to enabling them to properly care for a patient. More action must be taken in all parts of the health system to take responsibility for acknowledging and identifying when a patient might be in the last 12 months of life and what their health and care needs look like in relation to this.

This then provides the opportunity for health care professionals to encourage their patient to have open and honest conversations about death and dying.

It is a real concern for Macmillan that professionals are not having some of the most important conversations a patient ever needs about their health and care: about the last year of their life. More must be done to enable professionals to open these conversations with patients and their families.

- NHS England must ensure local health systems are delivering on the ambitions that everyone who may be in their last 12 months of life is offered an advance care planning conversation where appropriate.

- Any shared decision-making conversation or support tool must ensure carers and loved ones of a person at the end of life are key member of a patient's care team as per NICE guidance NG31 – Care of dying adults in the last days of life.

- NHS England and ICS/STPs must collect robust data on patient experience of end of life care.

- Every CCG, STP or ICS should be communicating to all health care professionals in their local systems the importance of end of life care and their role in delivering good quality care.

- Every GP practice in England should be properly accounting for their end of life population and ensuring an up to date palliative register is kept in line with QOF indicator PC001[37].

POLICY PRIORITY THREE:

Sharing a patient record via EPaCCS

It remains the ambition that '**NHS England will ensure that shared digital palliative and end of life care records, such as Electronic Palliative Care Coordination Systems (EPaCCS), have been rolled out to the majority of local areas by 2018 and all areas by 2020, to support the sharing of information and to promote personalised care.**'[38]

Yet from our conversations with professionals it's obvious how far there is to go for some areas to deploy EPaCCS or similar palliative care coordination systems. In the areas that did have an EPaCCS system, they were reported to be 'clunky', difficult to use and in most cases still not fully implemented for all key healthcare professionals to use. Either way, the inability to share records across the health and care settings was impacting on what care professionals were able to support patients with.

Professionals told us about the despondency many feel about the challenges to finding a fix to ongoing interoperability issues. People we spoke to talked about having worked on rolling out an EPaCCS system for ten or more years.

One independent evaluation has found the benefits of EPaCCS depend on the state of the wider system, including staff capacity, technological capabilities and collaborative working across teams[39]. These principles were also brought up in some interviews for this report; EPaCCS can help make a good system more efficient but are not a 'silver bullet'.

We heard cases of three systems being set up in one area for GPs with no end user, so information was not going anywhere and was not accessible to others. We heard about situations where EPaCCS were in place, but a district nurse, who was often the link in the community to palliative patients, was not able to access the system.

We heard from professionals in some areas that are putting the roll out of EPaCCS on hold to focus on wider issues with interoperability across CCGs and Trusts.

'I think I will retire and it will still be ongoing work to get a coordinated system that makes a difference.'
Health professional

While the importance of sharing end of life care records was recognised, it felt that this issue highlighted a wider problem with sharing any patient records.

Professionals need the information about a patient to make an informed decision about care, particularly when that patient is at the end of their life. And enabling choice for all at end of life relies on professionals being able to share and access records that clearly state an individual advance care plan, which may include a decision to refuse treatment.

A person who is dying should not have to repeat their preferences more than once. When a paramedic attends the house of an individual who is dying, they should be able to quickly see whether that person has a preference about their care. When a person gets to A&E the health care professionals there should be able to make decisions about their care based on any preferences that person may have.

We heard of instances where patients who have had an advance care plan conversation still needed to keep these preferences written down in a booklet, and even on a piece of paper on the fridge. While this may work for some people, it starkly illustrates how challenging it really is for professionals to deliver personalised care without easy access to someone's preferences, especially at the very end of life. We also know that this is a real worry for patients. A recent survey of the general public found that 61% of respondents were 'worried' that their GP records were not available to A&E departments[40].

What can be done?

We believe there is a need to prioritise health and care professionals' ability to access people's care records, right across acute, primary and community settings. We recognise that many STPs and CCGs are making an effort to try and overcome the challenges that exist within the IT infrastructure of the NHS. However, we believe solving this challenge is fundamental to delivering truly personalised care for people at the end of life.

- CCGs, and the STPs and ICSs they work with must have plans in place to develop an EPaCCS system or an equivalent tool for coordinating palliative care. They need to show how they are considering the needs of end of life patients in wider plans for digitalisation and on data interoperability.

- Any system being developed must work with all health and care providers, including private providers of care such as local 111 services or residential and care homes.

Best practice

Coordinate My Care (CMC) is a London-wide clinical service which facilitates the creation of urgent care plans, including advance care plans, for patients with a life threatening or life limiting illness. Underpinned by a digital information care exchange, CMC allows patients to record and share their medical details, advance care plans and wishes with healthcare providers in real time.

The advance care plan a patient creates with their healthcare professional through CMC aims to guide staff on a person's wishes, and/or the limitations to the treatment they would like. For patients, the benefits include an increased likelihood of dying in their preferred place and a better chance of dying outside of a hospital setting. Given this broader planning and decision-making process, patients are also more likely to receive appropriate treatment and less likely to have interventions that are inappropriate, distressing or against their wishes.

CMC acts as the Electronic Palliative Care Co-ordination system (EPaCCS) for London.

Since 2010, 68,590 care plans have been created for people at end of life, 58% of which were created in general practice.

Since 2010, 63% of patients with a CMC record have died in their own home or a care home and only 18% of people have died in an acute trust – compared to the national average of 36.7%. While 75% of people achieved their preferred place of death[41].

POLICY PRIORITY FOUR:

Integrating care in the community

Paragraph 1.8 of the NHS Long Term Plan[42] states that: 'Over the next five years all parts of the country will be asked to increase the capacity and responsiveness of community and intermediate care services to those who are clinically judged to benefit most. Extra investment and productivity reforms in community health services will mean that within five years all parts of the country will be expected to have improved the responsiveness of community health crisis response services to deliver the services within two hours of referral in line with NICE guidelines, where clinically judged to be appropriate.'

The NHS England Long Term Plan[43] set out its vision for better integrating care in the community, ensuring that by increasing investment in urgent community response and recovery support teams, people would be cared for in their homes so preventing avoidable emergency hospital admissions. This is something that is extremely important for people who are in the last year of their life, and for their carers and family.

We know that currently an estimated 48,000 people in England experience poor care in the final three months of their lives[44]. And more than 12,500 cancer patients spend the last two days of their lives without adequate pain relief[45], Building on this, 22,000 (35%) of those who die each year from one of eight common types of cancer have five or more emergency visits in the last year of their life[46], and more than 3,000 (5%) of these patients have more than 10 emergency visits in their final 12 months[47].

As part of our research, we spoke to professionals about their experience of working with multi-disciplinary rapid response teams and found that many areas had some form of this service in place.

We heard that, in some areas, there were fully established multi-disciplinary teams providing urgent care in the community, some where there were features of a rapid response service (such as a triage number for people to call) and some areas had nothing at all. It did not seem from our

research as if there was one established definition as to what represented a rapid or urgent response team.

In areas that did have a service, professionals – and in particular GPs – told us of the benefits to patients and professionals in receiving more effective and efficient coordinated urgent care.

It was also clear from the insight we gathered that integrated working made professionals more confident that they could support patients in their homes and that patients would receive better care, more quickly. However the professionals we spoke to did concede this collaborative working relied heavily on the relationships between professionals.

'Corridor conversations are really the only joined-up-ness for those conversations [about patient care]'
Health professional

This is particularly pertinent given that we heard that, in some cases, rapid response teams were not upskilled in using palliative care approach for patients at the end of life. These teams sometimes sought to support the patient based on a medical model of care, rather than having an honest conversation and assessment of where the person was in relation to the end of their life. One of the outcomes of this was that the patient could still end up with an avoidable

hospital admission even though a rapid response team had been able to reach them.

While professionals talked about the positive aspects of rapid response teams in the community, they also stated that these services were under resourced and experiencing increasing demand. Though many of the urgent response teams are co-located with significantly improved communication and relationships, much patient care is still coordinated through individuals because the digital infrastructure needed to share records is not in place.

It was also clear from our conversations with professionals that areas in England had both a different set up and different interpretations of what constitutes a rapid response or urgent response service. In some areas this was a full multi-disciplinary team, in others a telephone service.

Developing rapid response teams must take into consideration how local health systems can meet the need of patients to access rapid response in out-of-hours primary care. In some parts of the country out-of-hours primary care services are a key element of community care at the end of life. And, in some cases, out of hours services see around one third of all patients who die in a local population[48].

Macmillan is concerned that we continue to see a gap in the resources needed for community-based health and social care services. These pressures in community-based health are visible in the workforce, with district nurse numbers declining sharply[49]. For social care, these pressures are most acutely apparent in terms of funding, with spending by local councils on social care by adult resident falling by 11% in real terms between 2009/10 and 2015/16[50]. But optimal levels of provision would dramatically increase the opportunity to provide the care needed to stop people dying in pain, outside of their preferred place and unnecessarily visiting hospital in an emergency.

What can be done?

The following needs to happen if we are to realise the ambition to achieve more personalised care via community-based urgent response teams:

- NHS England must provide guidance to ensure rapid and urgent response teams have the right skills competencies and experience to support people at the end of life.

- STPs/ICSs must ensure all health care professionals are able to access shared patient records to support coordination of end of life care.

- NHS England must provide guidance on what their minimum standard is for the commissioning of community health crisis response teams.

- STPs and ICSs must rapidly address access to out of hours services for patients at the end of life.

Best practice

The North Manchester Macmillan Palliative Care Support Service (NMPCSS)

Before this service launched in north Manchester, the number of deaths in hospital for patients with life-limiting conditions was higher than the national average. There is was no hospice in the local area and research found that 70% of people would prefer to die at home.

This service, which is delivered by The Pennine Acute Hospitals NHS Trust, was launched in April 2015 to ensure patients with life-limiting illnesses can access the care and support they need at home.

The team comprises professionals and trained volunteers who work together to deliver a full package of support to patients in the heart of the community. They take a multidisciplinary approach, led by a Macmillan consultant in palliative care who supports the dedicated professionals working with patients and carers.

Data showed that 82% of patients on the caseload died in their recorded preferred place of care in 2015/16, compared with 59% in 2014/15. For patients on the caseload, average deaths in hospital reduced from 21% in 2014/15 to 13% in 2015/16.

Evaluation of the service showed that a key factor of success is the multidisciplinary nature of the team and the way the team has integrated care. The team ensured better integration and coordinated care by holding daily triage meetings with healthcare professionals. They were also responsible for a single telephone point of access to support wider health and care professionals[51].

Source: Macmillan Cancer Support. Missed Opportunities. 2018.

The North Manchester Macmillan Palliative Care Support Service

POLICY PRIORITY FIVE:

Training professionals to have the confidence to support palliative and end of life care patients

Our research suggests there is still too much variation in the types of staff receiving training to support palliative and end of life care patients. A 2014 audit of hospitals in England reported that 96% of trusts had a formal in-house continuing education programme on end of life care. The offer of formal in-house training for communication skills was available for 71% of registered nurses, 63% of medical staff and 49% of allied health professionals.[52]

However, in 2016 training on caring for the dying was only mandatory in 22% of trusts for doctors and 29% for nurses.[53] Furthermore, just over one in ten nurses in a 2014 survey stated that they felt equipped to deliver appropriate end of life care.[54] In another survey, 39% of clinical professionals stated that a lack of relevant experience amongst staff was a barrier to meeting the needs of terminally ill people.[55]

As stated in the Long Term Plan[56] paragraph 1.42: "… 'training to help staff identify and support relevant patients… we will introduce proactive and personalised care planning for everyone as being identified as being in their last year of life'. [57]

Training of health and care professionals to deliver high-quality end of life care has been a commitment for many years and runs through the National Commitment and the NHS Long Term Plan. There have been many attempts to increase the numbers of professionals receiving training in end of life and palliative care, yet we continue to hear that professionals are not accessing this vital resource.

Many professionals told us that while there is training on offer for staff in the community, often from local hospices, they were not able to attend. This was most often because staff could not be released from front line care. The NHS workforce is widely reported to be under strain and Macmillan's research shows that many staff are concerned about the impact of current pressures on people with cancer. For example, in a recent poll, over 50% of GPs and nurses surveyed in the UK said that, given current pressures on the NHS workforce, they are not confident it is able to provide adequate care to cancer patients.[58]

'There is a district nurse in my team…. that covers a patch of 12,000 patients and it is unrealistic to think that person will be able to leave front line care to train.'
Health professional

So, we must not underestimate the impact of shortages in general practice and community services, as it will often be professionals in these settings that encounter people at their key times of need. The GP workforce is not rising to keep pace with patient demand.[59] And, in the community, nearly two-thirds of trusts that provide community services are worried or very worried about community services being able to maintain adequate staffing in 12 months' time.[60]

We know that community end of life care is one of the few interventions shown to be effective in reducing reliance on emergency and acute care, largely through preventing avoidable emergency admissions and providing personalised care[61]. For this to be

achieved, there needs to be continued investment in both palliative care specialists and generalist health and social care professionals with the knowledge, understanding and time to deliver choice and provide high quality care for people at the end of their lives. We also know that vacancy rates for the palliative care nurse workforce working in cancer remain higher than the average UK rate. Plus, it is common for these posts to be filled on a part time basis, with only 41% of specialist palliative care nurses in full time posts who responded to the cancer workforce census. Worryingly, we also know that 40% of these nurses are aged 50 and above[62]. NHS England and Health Education England are currently reviewing the wider NHS workforce and how it can meet the commitments of the Long Term Plan. It is essential that the forthcoming NHS People Plan addresses the wider staff issues that we refer to in this report.

Good end of life care requires the input from a wide range of the NHS workforce, from GPs, nurses and consultants who can identify those who are approaching the end of life and coordinate and deliver care in a community setting. We believe that the wider NHS workforce requires substantial investment to secure both the creation of new posts and the ongoing education and training of the workforce to ensure all staff can meet the needs of people at the end of their life. As one professional told us:

"Everybody's resources are stretched. We're just getting through the day, and very often a lot of it is done on goodwill… virtually every day staff are working over their hours, or not taking full breaks."

As well as work pressures stopping people both receiving training or providing informal training (such as peer to peer support), we also heard there is no mandatory or standardised approach to end of life care training for professionals – particularly generalists. For example, some professionals told us that the scope of CQC enquiries during inspections included availability and uptake of end of life care

training, but others told us this was not an area reviewed in their CQC inspection. Professionals felt that if this was something that CQC inspected, then they would be forced to ensure staff had necessary training. We were commonly told that training to enable important conversations about death and dying should form part of the core curriculum for all health and care professionals and that there should be a focus on training people in the earliest part of their career. Encouraging professionals to gain experience and confidence talking about palliative and end of life care with their patients is crucial.

While communication skills are absolutely part of all health care professionals' core skill set, we found in our research that speaking to their patients about death and dying remains a challenge.

We heard that this meant local offers for training were being reduced, because they just couldn't get the numbers in the room to make it financially viable. This was particularly the case for local hospices who were seen by professionals as a key provider for this training.

As one professional highlighted when talking about providing training "we've done it in the evenings, we've done it on lunchtimes, we've done it for a whole day. We've put on free events. We've done every single format…. we've done it every single which way and people just don't come"

Where people were able to access training, it tended to be because they were making an effort to complete training in their own personal time – for example we heard that staff would come in on days off to fit training in, or that they had managed to acquire funding to backfill their post.

In some cases, we heard strong leadership was a key factor in accessing training, because emphasis on its importance came from the top. As demonstrated in our best practice example for palliative care support in north Manchester, it really is possible to support professionals to feel more confident in caring for people at the end of life.

What can be done?

It is clear from our research there remains a real need for professionals to access training and education to help increase their confidence opening conversations on end of life. Ultimately, the health and care workforce must be able to provide personalised care at the end of life.

- There must be a costed plan for a growing, appropriately skilled and sustainable workforce, which is vital if the NHS is to meet the needs of people at the end of life. Given the urgency of current and predicted shortages in nursing staff, it is essential the workforce plan is based on the projected increase in patient needs, both in overall volume of demand but also future complexity of new caseloads to meet new models of personalised care.

- Royal Colleges of Medicine must ensure education on end of life care is included in all pre-registration modules for health and care professionals.

- All health and care professionals should be able to access a funded training offer for improving their skills to best support patients at the end of life.

- The Care Quality Commission (CQC) should ensure inspectors consistently use criteria related to both the quality and amount of training on end of life that professionals receive. This should be highlighted as a priority for all relevant health and care providers providing end of life care.

Best practice

South West Ambulance Service NHS Foundation Trust and Macmillan Cancer Support

Macmillan Cancer Support and SWASFT are working together to enable the delivery of a supportive, responsive service to improve care for people affected by Cancer and at the end of life in the south west.

The SWASFT Learning and Development Team has come together with Macmillan Cancer Support to look at a ground-breaking and innovative partnership. This collaboration is the first of its kind to improve cancer and end of life care for patients in the south west.

The Macmillan Cancer Care Project aims to deliver a clear, equitable and evidence based service across the south west, accounting for differing regional demand and service provision. It focuses on developing the ambulance service workforce as well as enhancing and improving systems and services in order to improve the way SWASFT triages and responds to these patients, while ensuring their resources are used appropriately.

Preliminary data during the period 1 February 2017 – 31 May 2018 revealed that the SWASFT footprint saw just under 10,000 patients who clinicians deemed to be palliative or nearing the end of their life[63].

By the end of 2018 1,679 clinicians had received specialist face-to-face training delivered by the project, many more have accessed e-learning and distance learning and clinical supervision opportunities. Following the training, there has been increased staff confidence, wellbeing and satisfaction levels, demonstrated in pre/post confidence evaluations and user engagement.

Reporting has also shown improved care for patients and their loved ones, demonstrated by case studies, detailed audit, user and professional feedback – and, importantly – reduced inappropriate visits to the emergency department.

South West Ambulance Service NHS Foundation Trust

POLICY PRIORITY SIX:

A whole system approach to facilitating personalised care

Personalised care at the end of life has been the key policy direction for many years now. This has been illustrated by key strategies and commitments made by NHS England and successive governments. Sadly, some professionals said they felt that personalised care was a myth in the current climate of the NHS. Though the national agenda focused on offering patients' choice and control over their care, the feeling was that this is not realistic given the lack of resources across health and social care settings and the reality of day to day service provision.

We know that NHS England are focusing on Personal Health Budgets as an important part of supporting personalised care:

As stated in the NHS Long Term Plan , Paragraph 1.41[64]: 'We will accelerate the roll out of Personal Health Budgets to give people greater choice and control over how care is planned and delivered … to those receiving specialist end of life care.'

One way personalised care can be provided to people at the end of life is through Continuing Healthcare (Fast Track) and the option of a Personal Health Budget. Continuing Healthcare is a package of care, arranged and funded by the NHS which covers an individual's health care needs. This can often include social care needs related to their primary health condition.

However, professionals told us that the work of getting packages of care in place is often what cause the biggest delays to patients being in their preferred care setting and ultimately what impacts most on the patients and their loved ones. There were concerns from professionals about availability, quality and frequency of care through Continuing Healthcare (CHC) packages for end of life patients. As a recent Marie Curie report demonstrated, only 22% of the CCGs who responded to their Freedom of Information request were meeting the two-day timescale set out in guidance for delivering a fast track care package[65].

Professionals shared experiences that included:

- an acute lack of available care agency staff, particularly for night sitting
- packages of funding often not covering the cost of more than four one hour visits a day
- care agencies struggling to cope with the fluctuating demand of end of life care need in the community.

Ultimately, the impact of this is that patients cannot stay in their own home to be cared for until they die. Matters are made worse by the difficulties of setting up a care package for a patient in any care setting. Insight from professionals told us that in the acute setting there is such pressure to move patients out of beds and back into the community, that even if a patient says they want to die in hospital, it is just as hard to facilitate that it is to facilitate in the community. In the community, professionals told us there were challenges around safeguarding patients, particularly when the social care package offered is not enough to support the patient to stay in their home.

Given not everyone is accessing CHC funding[66], but many people at the end of life may have social care needs and be accessing a standard social care package through self-funding or local authority funding, there needs to be clear consideration on ensuring a well-funded, sustainable social care system. In fact, the Long Term Plan states that commitments in the plan rely on this:

The Long Term Plan[67] states: 'Both the wellbeing of older people and the pressures on the NHS are also linked to how well social care is functioning. When agreeing the NHS' funding settlement the government therefore committed to ensure that adult social care funding is such that it does not impose any additional pressure on the NHS over the coming five years. That is the basis on which the demand, activity and funding in this Long Term Plan have been assessed'[68].

However, social care is not functioning well and adult social care funding imposes additional pressure on the NHS. We know that it can be particularly difficult to secure social care for a patient. Local authorities are paying care providers at rates that do not cover the full cost of care and they report that some providers are handing back contracts that aren't viable[69]. Poor pay and conditions make it increasingly difficult to recruit and retain staff, with 58% of care workers in domiciliary care services on zero-hours contracts[70]. We heard that the social care workforce is not resourced to meet the needs of all the people in a local area at the end of life, because of fluctuating needs and unpredictable time scales of when enhanced care is needed and for how long.

Professionals told us that there was regularly a mismatch between the level of health and social care the patient, their carer or family was expecting to receive through the NHS and the reality of both what Continuing Healthcare funding would cover and what care was available. There were cases where patients were being left 20 hours of a day without formal care. While this may be the formal care offer for their level of need,

patients and carers/loved ones had much higher expectations of what care would be provided in the home and how long they would be left alone for. This all has the ultimate impact of seeing patients continuing to experience unnecessary emergency hospital admissions as their home is not set up as a viable place for the level of care they need.

Improvements need to be made for all people at end of life; promoting 'choice' as an abstract value is not enough. A better death at home can be improved by:

- Appropriate medication including pain relief being easily available in all areas and all times of the day.
- Housing being made suitable through specialist equipment or adjustments.
- A culture of dignity and respect being promoted throughout end of life pathways through a workforce that is adequately supported.

Two enablers need to be in place for more people to experience personalised end of life care. Firstly, a universal personalised approach must place choice at the heart of policy and practice. Secondly, health and care professionals must have the resources to record and respond to individual preferences, with enough time to support difficult conversations with patients and families.

Macmillan believes there must be an honest assessment about what personalised care means for a patient, based on what local services are available to support a patient in the last year of their life. What matters to a patient and their family might not be necessarily place of death but avoiding repeated emergency admissions that can result in a chaotic and distressing death. If the choice of a national policy target is between an abstract promotion of 'choice' or promoting dignity and limiting distress through reducing the number of unnecessary admissions to hospital a patient has in their last months of life, it should be the latter.

What can be done?

We believe that choice does not have to be a 'myth', as one professional described it, but there may need to be a reassessment of what patient choice in the last year of life realistically means and what type of care this affords. We welcome the Long Term Plan continuing to emphasise the policy priority of choice at the end of life. But professionals clearly set out to us the changes that need to happen in the wider system to realise this policy ambition:

- The upcoming Governement Spending Review must provide urgently needed funding for social care.

- In the longer term there needs to be a sustainable funding settlement for social care.

- The NHS must also work with social care partners to ensure that recruitment to the NHS, especially for nursing positions, compliments plans underway to recruit and retain professionals in social care.

POLICY PRIORITY SEVEN:
Seeking quality improvement in primary care

As stated in the NHS Long Term Plan[71] Paragraph 1.11: 'we will agree significant changes to the GP Quality and Outcomes Framework (QOF). This will include a new Quality Improvement (QI) element, which is being developed jointly by the Royal College of GPs, NICE and the Health Foundation. The least effective indicators will be retired, and the revised QOF will also support more personalised care.'

At the heart of delivering good care is the ability to continually innovate and improve. Macmillan has always placed importance on quality improvement initiatives and was pleased to see the inclusion of a Quality Improvement domain in the new five-year GP Contract framework from 2019/2020.

We were particularly pleased to see as part of these changes that, for 2019/2020, the Quality Improvement domain is addressing end of life care, specifically early identification and support for people who might die within 12 months. The focus is on well-planned and coordinated care that is responsive to patient needs', and those of family and informal care-givers as part of a patient's core support.

Professionals told us that they see the Quality Improvement module as an opportunity to encourage all GP practices to think about how they serve their end of life care patient populations and enhance their systems to improve care. However, there were some professionals who had already worked on some level of quality improvement, and it was felt this did not enable further innovation.

Therefore, Macmillan believes that the core focus for policy makers and GPs must be how to ensure improvements made through the incentive of QOF are sustainable for the future. We know it's possible and have heard about areas of great practice. However, both clinicians and Macmillan believe there is a way to go to ensure any quality improvement is sustainable and continues in years to come.

What can be done?

Based on what professionals have told us, there is a real opportunity to improve end of life care in primary care through the 'QI module', through providing coordinated personalised care. It is essential that improvements are sustained.

- After completion of QI 2019-2020 activity in end of life care, a new indicator must replace the removal of regular MDT meetings for palliative patients and be included in the Quality Outcomes Framework.

- NHS England must report on progress made against the quality improvement module for end of life care, set for 2019-20, and demonstrate the success of this module in further encouraging quality improvement activities.

Best practice

Milton Keynes - Increasing the number of people identified at end of life and offered an advance care plan

The GP Advance Care Planning pilot started in February 2018 with eight Milton Keynes practices. The idea behind the project was to increase the number of people identified at end of life and therefore increase the number of people offered an advance care planning conversation. There were a significant proportion of patients in the final years of life being admitted to and dying in hospital unnecessarily. By extrapolating national data, the pilot estimated that around four people a week were dying in Milton Keynes General Hospital who had no medical need to be there.

While the GP practices mostly had a palliative/supportive care register and claimed QOF money for keeping this register, they varied in terms of how often monthly Multi-Disciplinary Team (MDT) meetings were held, what disease groups were identified and the overall number of people on that list. This meant that few patients had an advance care plan, despite a locally produced document developed by the local hospice and hospital to support these conversations.

A lack of clinical time to have an advance care planning conversation was identified as the probable cause of this as a ten-minute consultation was simply not long enough. Staff in the practices also lacked the confidence to have these important conversations

So funding was used to free up clinical time for a practice nurse and a GP per practice to allocate to advance care planning discussions. In addition, there was a significant education and training component to increase confidence in professionals, including a 2-day training course ran by a Macmillan GP.

By freeing up staff time, they were able to significantly increase the total number of advance care plans in place for patients at end of life from a total of 2 across the pilot sites in 2017 to more than 130 advance care plans completed in 2018 – a huge improvement.

With such positive results, the pilot team were able to demonstrate to the CCG the significant impact these changes had. The CCG then agreed to fund the project for the remainder of GP practices in Milton Keynes. While there are still some practices that are not able to participate, over 75% of the primary care population now benefit from increased clinical time to support advance care planning conversations and more chance of being identified as being in end of life.

Conclusion

This report concludes that we are at a crossroads for end of life care in England. The Long Term Plan provides a number of opportunities to make end of life better for people in the future, and we have built our analysis in this report around the specific commitments in the Plan that we have identified as having particular potential to improve care.

There have been national policy commitments before, but many improvements in care have been hindered by these not being followed up by delivery plans. We heard from many professionals during this research that while it's hard to find someone who disagrees with the principles of the Government's National Commitment on end of life care, there has not been the buy-in from senior health leaders to ensure that local health systems are mandated to follow through on these commitments.

That is why the main recommendation of this report is for every STP or ICS to state explicitly how they intend to fulfil the commitments in the Long Term Plan that relate to end of life when they draw up their five year delivery plans in 2019.

This report is rooted in the conversations we had with health professionals across the country. Despite the professionals spanning different roles and geographical locations, a common story emerges.

We heard that end of life plans are often lost amongst competing priorities, with a lack of mandated delivery plans to see commitments through from high-level ambitions to tangible results. We also heard that there is a lot of work needed to improve communication between the wide range of professionals who are involved in end of life care, with the necessary technology not being in place. It is concerning that communication between health professionals is often badly lacking, despite national policy placing such an emphasis on better communication between patients and professionals about end of life choices.

Wider system pressures, be they workforce shortages or pressures on social care, mean that some professionals are deliberately not engaging with people about death and end of life care because they know that the system cannot facilitate choice. This is troubling and needs to be addressed urgently.

We have honestly addressed both the challenges and the opportunities for end of life care in this report. We have set out clear recommendations for change, basing them on what professionals told us when we asked them 'what needs to happen to make the Long Term Plan a success?' But these recommendations need to happen now, as improvements have stalled for too long. We urge all policy makers who read this report to take action based on these recommendations, and make sure that the next 10 years of the NHS are years that that see England becoming a better place to die.

References

1   NHS England. NHS Long Term Plan. 2019.. Available from: https://www.longtermplan.nhs.uk/ (Accessed May 2019).

2   Department of Health. Our Commitment to you for end of life care. 2016. Available from: https://assets.publishing.
        service.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf. (Accessed
        May 2019).

3   End of Life Care Coalition. End of Life Care in Sustainability and Transformation Plans: an analysis. 2017. Available
        from: http://endoflifecampaign.org/wp-content/uploads/2017/10/STP-one-pager.pdf

4   Sleeman, K. et al. Is end-of-life care a priority for policymakers? Qualitative documentary analysis of health care
        strategies. Palliative Medicine. Available from: https://journals.sagepub.com/doi/full/10.1177/0269216318786333
        (accessed May 2019).

5   Department of Health. Our Commitment to you for end of life care. 2016. Available from: https://assets.publishing.
        service.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf. (Accessed
        May 2019).

6   Department of Health. Our Commitment to you for end of life care. 2016. Available from: https://assets.publishing.
        service.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf. (Accessed
        May 2019).

7   National Palliative and End of Life Care Partnership. Ambition for Palliative and End of Life Care. 2015. Available from:
        http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf

8   Macmillan Cancer Support. No Regrets: Talking about death and dying. Available from: https://www.macmillan.org.
        uk/_images/no-regrets-talking-about-death-report_tcm9-311059.pdf (accessed May 2019).

9   Economist Intelligence Unit [EIU]. The 2015 Quality of Death Index Ranking palliative care across the world. 2015.
        Available from: http://www.eiuperspectives.economist.com/healthcare/2015-quality-death-index

10   Death Registrations Summary Statistics, England and Wales, 2017 (Table 3). ONS. Available from https://www.ons.gov.
        uk/file?uri=/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/dataset s/
        deathregistrationssummarytablesenglandandwalesreferencetables/2017/deathsummarytables2017final.xls (Accessed
        April 2019)

11   Mortality statistics for England in 2001-2016, Office for National Statistics. Available from: https://www.ons.gov.uk/
        peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datase ts/
        cancerregistrationstatisticscancerregistrationstatisticsengland (Accessed April 2019). Figures include malignant
        cancers excluding non-melanoma skin cancer (ICD10 codes C00-C97, excl. C44).

12   Etkind, SN, Bone AE, Gomes B et al. (2017) How many people will need palliative care in 2040? Past trends, future
        projections and implications for services. BMC Medicine 15:102 https://doi.org/10.1186/s12916-017-0860-2 available at:
        https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-017-0860-2

13   Hunter J with Martina Orlovic. End of life care in England: A briefing paper. IPPR. 2018 Available from: https://www.ippr.
        org/files/2018-05/end-of-life-care-in-england-may18.pdf (Accessed April 2019).

14   Mortality statistics for England and Wales in 2017, ONS. Place of death available from table 8. Available from: https://
        www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/
        deathsregisteredinenglandandwalesseriesdrreferencetables (Accessed April 2019)

15   YouGov Plc. (2017). Macmillan commissioned YouGov Plc. to survey UK adults with a cancer diagnosis. Total sample
        size was 2,005 people with a previous cancer diagnosis. Fieldwork was undertaken between 20 and 29 March 2017.
        The survey was carried out online. The figures presented have been weighted and are representative of the population
        of those living with cancer in the England only. Respondents (n=1,584 in England) were asked, 'If the right care and
        support was available in any of these locations, where would you prefer to spend your final days?'

16   YouGov Plc. (2017). Macmillan commissioned YouGov Plc. to survey UK adults with a cancer diagnosis. Total sample
        size was 2,005 people with a previous cancer diagnosis. Fieldwork was undertaken between 20 and 29 March 2017.
        The survey was carried out online. The figures presented have been weighted and are representative of the population
        of those living with cancer in the England only. Respondents (n=1,584 in England) were asked, 'If the right care and
        support was available in any of these locations, where would you prefer to spend your final days?'

17   National Survey of Bereaved People (VOICES): England, 2015. Office for National Statistics, released April 2016.
        Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/
        bulletins/na tionalsurveyofbereavedpeoplevoices/england2015 (Accessed April 2019).

18   National Survey of Bereaved People (VOICES): England, 2015. Office for National Statistics, released April 2016.
        Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/
        bulletins/na tionalsurveyofbereavedpeoplevoices/england2015 (Accessed April 2019).

19   Vidrun, C. et al. Dying in the hospital setting: A systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. Palliative Medicine. (2015). Available from: https://journals.sagepub.com/doi/10.1177/0269216315583032

20   Hunter, J. End of life care in England: A briefing paper. 2018. IPPR. Available from: https://www.ippr.org/files/2018-05/end-of-life-care-in-england-may18.pdf (Accessed April 2019).

21   National Survey of Bereaved People (VOICES): England, 2015. Office for National Statistics, released April 2016. Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/na tionalsurveyofbereavedpeoplevoices/england2015 (Accessed April 2019).

22   Emergency admissions. Data briefing. Marie Curie. 2018. Available from: https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2018/emergencyadmissions-briefing-paper-2018.pdf (Accessed April 2019).

23   Macmillan Cancer Support/Public Health England. How many emergency hospital visits do cancer patients make towards the end of their life? June 2017. Poster presentation at the 2017 Cancer Data and Outcomes conference.

24   National Survey of Bereaved People (VOICES): England, 2015. Office for National Statistics, released April 2016. Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/na tionalsurveyofbereavedpeoplevoices/england2015 (Accessed April 2019).

25   The state of health care and adult social care in England 2017/18. Care Quality Commission (CQC). 2018. Available from: https://www.cqc.org.uk/sites/default/files/20171011_stateofcare1718_report.pdf (Accessed April 2019)

26   National End of Life Care Intelligence Network. What we know now 2013. Available from: http://www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now_2013 (Accessed April 2019).

27   Department of Health. Our Commitment to you for end of life care. 2016. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf. (Accessed May 2019).

28   Department of Health. Our Commitment to you for end of life care. 2016. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf. (Accessed May 2019).

29   Etkind, SN, Bone AE, Gomes B et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Medicine. 2017. 15:102> Available from: https://doi.org/10.1186/s12916-017-0860-2 available at: https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-017-0860-2

30   Department of Health. Our Commitment to you for end of life care. 2016. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf. (Accessed May 2019).

31   Department of Health. Our Commitment to you for end of life care. 2016. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf. (Accessed May 2019).

32   Macmillan analysis of Office for National Statistics, NHS England. (2015). National Survey of Bereaved People, 2014.

33   YouGov Plc. (2017). Respondents were asked: "Have you thought about the possibility that you may die of your cancer?" Answers included constantly (6%), often (16%), sometimes (27%), occasionally (26%), never (24%) and prefer not to say (0%).

34   YouGov Plc. (2017). Respondents who hadn't shared their thoughts or feelings about death with anyone were asked: "You said that you have not ever shared your thoughts or feelings about death or dying with anyone. Could you tell us why this is? Please select all that apply."

35   Macmillan Cancer Support. Missed Opportunities. 2018. Available from: https://www.macmillan.org.uk/_images/missed-opportunities-end-of-life-advance-care-planning_tcm9-326204.pdf

36   Royal College of Physicians and Marie Curie Palliative Care Institute, End of Life Care Audit – Dying in Hospital, 2014 and End of Life Care Audit – Dying in Hospital National report for England 2016

37   BMA. 2019/20 General Medical Services (GMS) contract Quality and Outcomes Framework (QOF) Available from: https://www.england.nhs.uk/wp-content/uploads/2019/05/gms-contract-qof-guidance-april-2019.pdf - Page 20

38   Department of Health. Our Commitment to you for end of life care. 2016. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf. (Accessed May 2019).

39   Independent evaluation of Electronic Palliative Care Co-ordination Systems (EPaCCS) in England – Final Report. Whole Systems Partnership. 2016. Available from: https://www.thewholesystem.co.uk/wpcontent/uploads/2017/03/EPaCCS-Evaluation-Report-Final.pdf (Accessed April 2019)

40   YouGov Plc. (2014) survey GB adults. Total sample size was 2,343 people, and 1,4648 people answered the question 'You said that you have been referred by your GP to a consultant or other specialist clinician for treatment of medical condition(s)... Which, if any, of the following statements apply to you in regards to your experience(s) of this?'. Fieldwork was undertaken between 26 and 27 June 2014.

41   Coordinate my care. CMC Data Overview for London. 2019. Available from: https://coordinatemycare.co.uk/downloads/cmc-data-overview-april-2019.pdf

42   Ibid.

43   Ibid.

44   Macmillan estimate of deaths between February 2015 and February 2016 based on Office for National Statistics. 2015. National Population Projections, 2014-based projections. http://www.ons.gov.uk/ons/rel/npp/nationalpopulation-projections/2014-based-projections/index.html (accessed January 2016); and 10% of the bereaved (all conditions) reporting that the overall, taking all services into account, they would rate the deceased care in the last three months of life as poor. Office for National Statistics. 2015. National Survey of Bereaved People (VOICES), 2014.

45   Office for national statistics, 2016. National Survey of Bereaved People 2015 (VOICES). 10% of all respondents disagreed or strongly disagreed that the cancer patient had sufficient pain relief in the last two days of life (Q35), among those who had pain (88.5%). Excludes those who are not sure. https://www.ons.gov.uk/fileuri=/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/datasets/nationalsurveyofbereavedpeoplevoices/2015/referencetablesvoices2015.xls and Macmillan (June 2017) estimation of over 12,000 people each year calculated by applying 10% to England 2015 cancer mortality figures of 122,580 deaths (88.5% of the total of 138,509 deaths, to represent those who had pain relief). Office for National Statistics, 2016, Cancer Deaths registered in England and Wales in 2015 https://www.ons.gov.uk/fileuri=/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/adhocs/006211cancerdeathsregisteredinenglandandwales2015/cancerdeathsenglandandwalesseparately2015.xls

46   Macmillan Cancer Support/Public Health England. How many emergency hospital visits do cancer patients make towards the end of their life? June 2017. Poster presentation at the 2017 Cancer Data and Outcomes conference

47   Ibid

48   Brettel, B. et al. What proportion of patients at the end of life contact out-of-hours primary care? A data linkage study in Oxfordshire. BMJ Open. Available from: https://bmjopen.bmj.com/content/8/4/e020244

49   Care Quality Commission. The state of health care and adult social care in England, 2017/18. 2018. Available from: https://www.cqc.org.uk/sites/default/files/20171011_stateofcare1718_report.pdf

50   Phillips D, Simpson P. National standards, local risks: the geography of local authority funded social care, 2009–10 to 2015–16. IFS. Available from: https://www.ifs.org.uk/publications/9122

51   Macmillan Cancer Support. North Manchester Macmillan Palliative Care Support Service: Learning Report. 2017. Internal report.

52   Royal College of Physicians (RCP) and the Marie Curie Palliative Care. National care of the dying audit for hospitals, England. 2014. Available from: https://www.rcplondon.ac.uk/projects/outputs/national-caredying-audit-hospitals (Accessed April 2019).

53   National Council for Palliative Care (NCPC).Staff prepared to care? Capacity and competence in the end of life care workforce. 2016. Available from: https://www.ncpc.org.uk/sites/default/files/workforce_report_May_2016.pdf (Access April 2019). RCN survey available from: http://www.independentnurse.co.uk/news/nurses-concerned-about-provision-ofpalliativecare/65725.

54   National Council for Palliative Care (NCPC).Staff prepared to care? Capacity and competence in the end of life care workforce. 2016. Available from: https://www.ncpc.org.uk/sites/default/files/workforce_report_May_2016.pdf (Access April 2019). RCN survey available from: http://www.independentnurse.co.uk/news/nurses-concerned-about-provision-ofpalliativecare/65725.

55   Marie Curie. Training in palliative care. 2019. Accessed April 2019. Available from: https://www.mariecurie.org.uk/media/press-releases/marie-curie-calls-for-more-training-in-palliativecare/103226

56   Ibid.

57   NHS England. NHS Long Term Plan, 2019. NHS England. Available from: https://www.longtermplan.nhs.uk/ (Accessed May 2019).

58   nfpSynergy, Primary Healthcare Monitor, 2017, From the Frontline. Workforce pressures in the NHS. Macmillan Cancer Support (September 2017).

59   N NHS Digital. GP Primary Care Workforce. September 2015 to March 2018. 2018. Available from: https://app.powerbi.com/view?r=eyJrIjoiNzFmMzM2ZTEtMmQ2Zi00NDdjLThhNmYtMmQxMDI5MGE3YjQwIiwidCI6IjUwZjYwNzFmLWJiZmUtNDAxYS04ODAzLTY3Mzc0OGU2MjIlMiIsImMiOjh9&pageName=ReportSection1b8cc727338a02512894

60   NHS Providers. The State of the Provider Sector. 2018. Available from: http://nhsproviders.org/state-of-the-provider-sector-05-18

61   Nuffield Trust. Shifting the balance of care. 2017. Available from: https://www.nuffieldtrust.org.uk/ files/2017-02/shifting-thebalance-of-care-report-web-final.pdf. For example, in England it has been found that access to community-based end of life care could save £104 million per year for cancer patients alone as a result of fewer emergency admissions and reduced length of stay.

62   Macmillan Cancer Support. Cancer workforce in England. 2017. Available from: https://www.macmillan.org.uk/_images/cancer-workforce-in-england-census-of-cancer-palliative-and-chemotheraphy-speciality-nurses-and-support-workers-2017_tcm9-325727.pdf

63   Macmillan Cancer Support. Cancer care development project. 2019. Available from: https://www.swast.nhs.uk/assets/1/macmillan_swast_newsletter_issue_3_2019.pdf)

64   Ibid.

65   Marie Curie. When time really matters: Fast track care at the end of life. Available from: https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2019/d393_when-time-really-matters-24-pages_web.pdf

66   NHS England. NHS Continuing Healthcare and NHS-funded nursing care report. 2019. https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2019/02/CHC-and-FNC-Report-Q3-2018-19_nM8WBH.pdf Section 3 - The total number of people eligible for NHS CHC was 54,754 as at the last day of Q3 2018-19. Of these, 36,603 were eligible for Standard NHS CHC and 18,151 were eligible for Fast Track NHS CHC. (accessed June 2019).

67   Ibid.

68   NHS England. NHS Long Term Plan.2019. Available from: https://www.longtermplan.nhs.uk/ (Accessed May 2019).

69   ADASS. Budget Survey Report 2018. Available from: https://www.adass.org.uk/media/6434/adass-budget-survey-report-2018.pdf

70   Skills for Care. The State of the adult social care sector and workforce in England. 2018. Available from: https://www.skillsforcare.org.uk/NMDS-SC-intelligence/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/The-state-of-the-adult-social-care-sector-and-workforce-2018.pdf

71   Ibid.

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