

Institute for Public Policy Research



THE STATE OF END OF LIFE CARE

**BUILDING BACK
BETTER AFTER
COVID-19**

Chris Thomas

April 2021

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ABOUT THIS PAPER

This report advances IPPR's charitable purpose of educating the public and preventing disadvantage as a consequence of illness or disability.

This paper and its recommendations are aimed at the NHS in England and the Westminster government, recognising devolution of health system in the UK.

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SUMMARY

Covid-19 has caused serious disruption to end of life care provision in England.

Excess deaths have spiked due to the pandemic, putting more strain on providers. The hospice sector has seen their fundraising disrupted, putting beds and continuity of care at risk. Place of death has shifted from acute to community settings, without the time for proper proactive planning and resourcing. And the well documented difficulties in social care – where life expectancy of residents is between 12 and 24 months – have impacted wellbeing and quality of life for many at the end of their lives.

We cannot just focus on recovery – we need to build back better. Of course, we need to meet the unique challenges posed by the on-going pandemic. To that end, there have been welcome policy announcements, including £200 million of financial support for hospices per quarter. However, recovery alone is not enough. In the next two decades, strain on end of life care services could increase substantially. Deaths are projected to be higher in 2031 than in 2020 in England, even accounting for Covid-19. We need to prepare for the challenges and disruption ahead of us, both short and long-term.

We have the right reform agenda. The problem is not a lack of direction. Since the 2008 end of life strategy, the NHS in England has consistently prioritised a community-focused, personalised and more integrated approach to end of life. This is the right approach. The evidence shows that a shift to the community could mean more appropriate care, higher quality of life and better use of resource.

But we still have a way to go on delivery. New Imperial College London analysis, released in this report, highlights areas for improvement.

- **Acute-led:** Despite evidence that it is not optimal, inpatient acute care remains dominant, accounting for £6 in every £10 spent on end of life care.
- **Unequal:** Despite spending more time in hospitals, normally a more expensive setting, people in the most deprived parts of the country are getting £400 less healthcare investment per person in their last year of life.
- **Variable:** The shift to a more primary/community-led end of life care model is happening unequally across the country. The South Central region has a better practice care model, and spends 20 per cent less per person – money which can be reinvested in healthcare.
- **Workforce:** Qualitative work with carers shows continued variation in quality of communication between health and social care professionals, and dying people.

Without action, end of life care could face an ‘eternal 2020’. In 2020, and looking at non-Covid-19 cause of death, there were over 35 per cent more deaths in private homes and 25 per cent more deaths in care homes, with corresponding declines in hospitals and hospices. On the surface, this looks like an acceleration of reform towards community-led care. In reality, it created huge difficulties, because an increase in deaths was not matched by an increase in resource, infrastructure, staff and capacity. Going further on delivery is about avoiding an ‘eternal 2020’ in end of life care, as demand increases.

We must go further and faster on end of life care in the coming years. This should be based on delivering a managed shift to community-led end of life care. This would not be one size all – rather, it would be about a model led by the community, and through which people receive the specialist and non-specialist services that are right for them.

Policy recommendation: “Providing everyone the right care, from the right person, at the right time”

Providing everyone... Good end of life care is a right that should be afforded to everyone, equally, in line with the founding principles of the NHS. This means significant and measurable progress against the inequalities that have often defined this agenda. We recommend that the UK government breaks the link between someone’s ability to advocate for good care and outcomes, by hiring 2,700 new ‘end of life care advocates’ – based on care coordinator roles. We also recommend a duty of inclusion is places on end of life care providers, to ensure compassion and dignity for dying people.

The right care... The shift to a community-led model should not be indiscriminate. Rather, it should be seen as a way to get people the care they need, both specialist and non-specialist. We recommend significantly more resource for social, community and home care – including a specific ‘end of life care premium’ for the care of those living in the most deprived part of the country. This should aim to correct long-standing inequalities in the English end of life care system.

From the right person... Access to appropriate care from a suitably qualified and trained professional has been considered an enabler of high-quality end of life care across 15 years of strategy. Yet, our analysis highlighted that dying people and their carers still have concerns. We recommend that significant efforts are made to ensure quality training for all, through a new end of life care academy – aimed not only at NHS and social care staff, but also informal carers. We also recommend efforts to increase staff numbers, and greater efforts to ensure adequate emotional, mental health and financial support is available to workers and carers alike.

At the right time... Personalised care has the potential to transform end of life care. However, there is space to go further in ensuring personalised care is flexible. We recommend providing people a formal review of their care plan every three months, to ensure their wishes are well represented. These reviews should formally include informal carers, to ensure their needs are represented. We also recommend further work to embed use of digital care coordination – such as the Coordinate my Care service in London.

Recommendations in this report are aimed at the Westminster government and England, recognising devolution of health in the UK nations. This project also generated insights on Scotland, which are presented throughout. It is hoped this report and its conclusions will prove useful beyond the England focus.

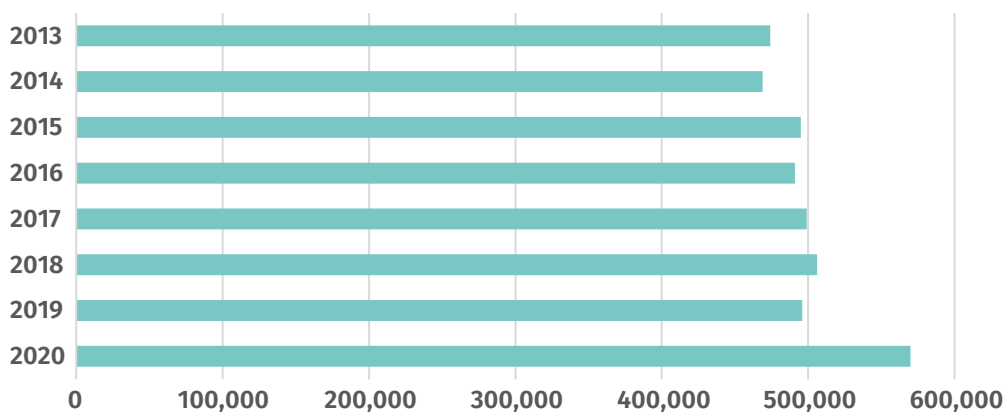
1. DISRUPTION IN END OF LIFE CARE

It has been a challenging year for end of life care. An August 2020 survey showed that 93 per cent of hospice leaders were worried about their ability to provide adequate end of life care (Whitehead 2020). In nursing homes – a setting where life expectancy is 12 months – there were severe outbreaks of Covid, and restrictions on family visits (British Geriatrics Society 2020). Early in the pandemic, a significant media discourse emerged around people dying alone in hospitals – or with their relatives only present via video link (Nelson-Becker and Victor 2020).

One of the biggest drivers of these difficulties is, simply, the number of excess deaths experienced in 2020. In a normal year, around half a million people die in England of around 600,000 in the UK. In 2020, the number of deaths in England rose to 570,000 – one of the largest increases on record.

FIGURE 1.1. DEATHS ROSE SUBSTANTIALLY IN ENGLAND IN 2020

Age-standardised mortality, 2014–2020



Source: Author's analysis of ONS 2021

Qualitative interviews with carers made clear the tangible consequences of these disruptions. One interviewee – a carer for their husband – described an emergency admission during Covid-19, and the impact this had on who could visit during the dying period:

“Although visiting was restricted, I was allowed to go in. I mean I had to be all with – masked and all the rest of it, with the PPE, but yeah, and I was allowed an hour a day. What was quite – was very distressing was the fact that our son wasn’t – I said, “Couldn’t I give one of my hours to him, so he could see his dad?” And, they said “no” and that was quite upsetting for both of us, as you can imagine.”

Interview with carer

There is a clear need to support end of life care providers through the pandemic and ensure swift recovery after it. However, the evidence also indicates that recovery is unlikely to be enough to ensure good end of life care in the years to come. As challenging as the pandemic has been, there are three mid to long-term challenges that put significant onus on policymakers to look beyond just what happened in 2020/21. A failure to do so may expose end of life care to the pressures of 2020, every year from 2030 onwards.

THREE DISRUPTIVE TRENDS IN THE 2020S

1. The pandemic's aftershock: The 'end of life care backlog'

One consequence of the pandemic was significant disruption to care for non-Covid-19 conditions. This included:

- 50,000 missing diagnoses for cancer (Macmillan Cancer Support 2021)
- a 50 per cent drop in A&E presentations for heart attacks (British Heart Foundation 2020)
- a significant worsening of symptoms amongst people living with dementia, including great difficulty concentrating, greater agitation/restlessness, stress and depression, and memory loss (Alzheimer's Society 2020a).

More recently, IPPR's landmark annual *State of health and care* report showed further disruptions ahead. These include 4,500 more cancer deaths this year and 12,000 more heart attacks and strokes over the next five years (Patel, Thomas and Quilter-Pinner 2021).

This is indicative of the fact that disruption to health will not go without consequences in the years to follow the pandemic. There will be many people with more serious health conditions, seeking help. In turn, this will mean more strain on end of life provision for several years to come.

2. More deaths in 2031 than in 2020

Until recently, most years since the advent of the NHS have seen a reduction in mortality. For example, less people died from one year to the next between 1974 and 2003 (Gomes and Higginson 2008) This was driven by the continued success of universal health provision, vaccination programmes, progress of major killers like cancer and cardiovascular disease, amongst other factors. However, the opposite is now true. More people are dying year on year.

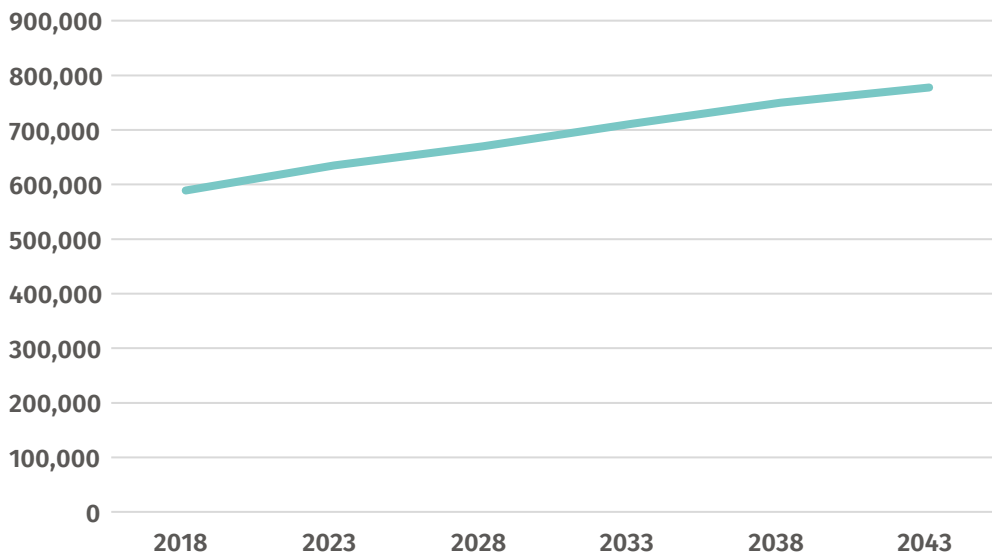
In an average year, around 600,000 people die each per annum in the UK.¹ By 2040, that figure is expected to reach nearly 800,000 (ONS 2019b), of which 653,000 will die in England (ONS 2019a).² This means that total mortality will rise faster than the population grows over the coming decades (figure 1.3).

1 Excluding the impact of unpredictable health shocks, like pandemics.

2 This does not take account of Covid-19 figures, which increase 2020 deaths in England and Wales by 70,000, over and above the projections displayed in these charts.

FIGURE 1.2: TOTAL DEATHS ARE PROJECTED TO RISE IN THE NEXT 25 YEARS

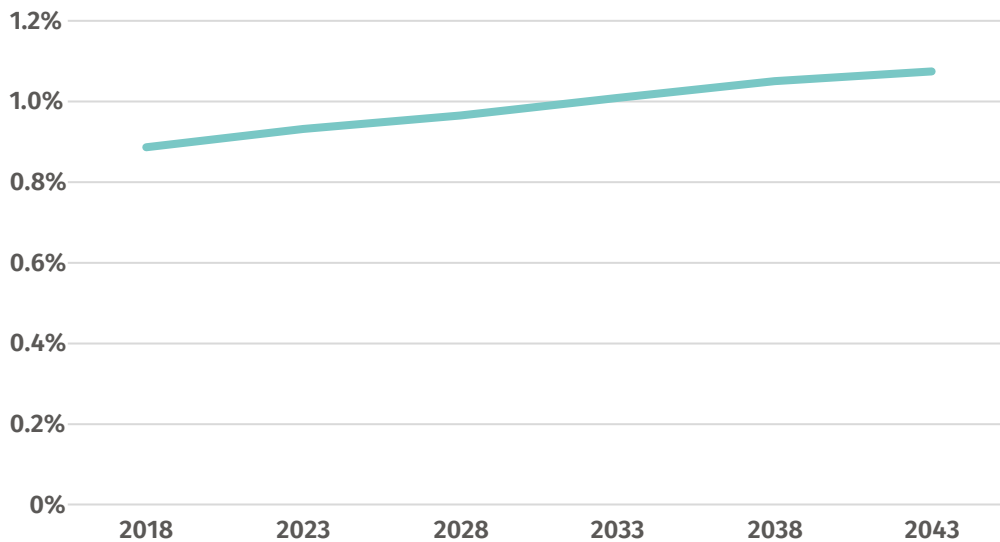
Projected number of deaths in the UK per annum, total, 2018–2043, not including Covid-19³



Source: Author's analysis of ONS 2019b

FIGURE 1.3: TOTAL DEATHS WILL RISE FASTER THAN THE POPULATION GROWS

Number of deaths as a per cent of the UK population, per annum, 2018-2043



Source: Author's analysis of ONS 2019b

This will mean significant strain for end of life provision. Once accounting for the impact of Covid-19 – not shown in the above graphs – 614,000 people died in England and Wales. This figure that made for a very difficult year for health and care generally, and end of life providers specifically. It is worrying, therefore, that on current projections, more people will die in 2031 than died in 2020. This

³ Projections are made on the basis of census data, so do not include unpredictable spikes such as Covid-19. This would make total deaths significantly higher for both 2020 and 2021 years.

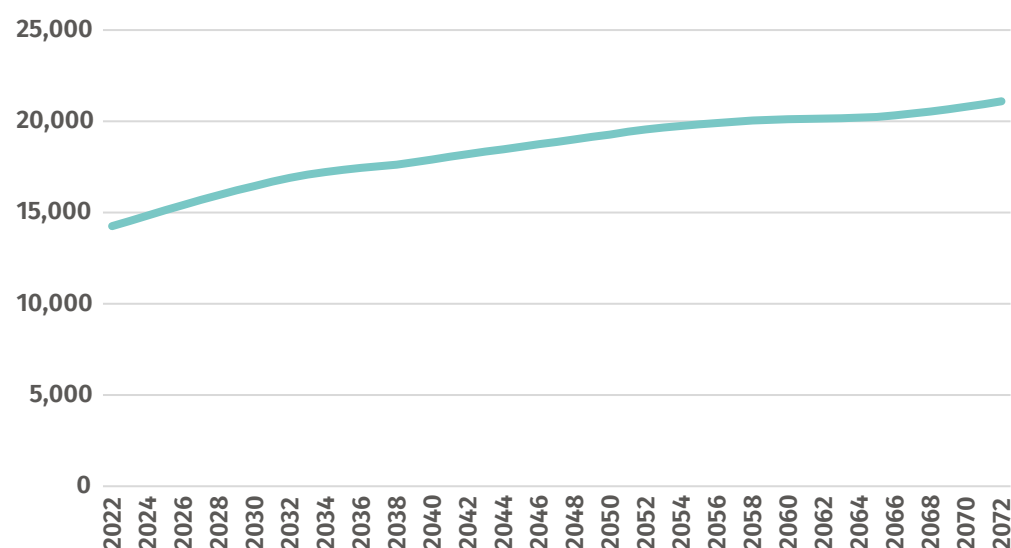
underscores the need for more capacity in end of life and palliative care, without which the experience of the pandemic in 2020 could become the ‘new normal’.

3. An ageing population means more complicated health needs

The UK population is ageing, quickly. Projections show a significant increase in the over 60-population in the next half a century.

FIGURE 1.4: ENGLAND’S POPULATION IS SET TO GET SIGNIFICANTLY OLDER IN THE NEXT 50 YEARS

Projected changes in the over-60 population in England, 2018-2128, thousands of people



Source: Author’s analysis of ONS 2019a

One consequence of this change is increasingly complicated health needs. Research across causes of death shows that multimorbidity and comorbidity are becoming more common (Tran et al 2018, van Leersum et al 2013). Estimates suggest that 15 to 30 per cent of the population now live with more than one chronic condition, and that that this proportion is rising (Richmond Group 2019). People with multiple conditions often need a different type of care – which is more personalised, which makes a wider range of community and preventative services available, and which helps them develop coping mechanisms. This is a challenge for end of life care, which has historically been organised around specialist care in acute settings (ibid).

The causes of death are also changing. In particular, we are witnessing a rise in conditions where care is primarily provided by social care, unpaid care and community settings – rather than (primarily) hospitals. One example is the rise of Alzheimer’s and dementia, which is now the leading cause of death in the UK (Alzheimer’s Society 2020b). By contrast, cancer mortality is falling – and is expected to reduce by a further 13 per cent by 2030 in the UK (Cancer Research UK 2020).

Even then, the nature of some conditions are changing. Cancer is a very different condition in 2021 than in 1921. Today many cancers are ‘treatable but not curable’ – meaning people living with a diagnosis for many years. According to Macmillan Cancer Support, 130,000 people are living with this kind of chronic cancer (Macmillan Cancer Support 2020). Again, this increases the complexity of the care that the average person needs, including in the last year of life.

SCOTLAND'S DECADE OF DISRUPTION

The same trends in England will put pressure on end of life care services, including Scotland. Currently, 54,000 people die in Scotland each year. As in the UK more widely, this is projected to rise sharply in coming years; with 64,000 deaths in 2030/1, 68,000 deaths in 2040/41 and 71,000 deaths in 2050/51 (ONS 2019c). As in England, dying people are likely to have more complicated, multiple needs – driven by a significant increase in the average age of the population. Indeed, by 2033, estimates suggest Scotland's over 60 population will be 50 per cent higher compared to 2010 (Scottish Government 2010).



2. A MANAGED SHIFT TO COMMUNITY-LED END OF LIFE CARE

The government have long accepted the need for reform of end of life care services in England. It has put forward a number of relevant strategies on reforming and improving end of life care, to ensure it can meet future challenges. Four key themes are consistent within the strategies.

1. **A shift to the community:** Community-led care to ensure a wider array of support, avoid over-treatment and prioritise quality of life outcomes – while reducing costs.
2. **More personalised care:** To ensure care is tailored to the person's needs (and those of their carers), recognising that people have different perceptions, objectives and priorities.
3. **More integrated care:** To ensure that care providers work seamlessly around the person, whether primary, secondary, social or community.
4. **A more skilled workforce:** To improve communication and care planning skills, recognising how important this is to outcomes.

THE REFORM CONTEXT

End of Life Care Strategy (2008): This strategy identified a number of key areas to improve end of life care – including many that are still being focused on by strategies today. These include coordination and personalisation of care, workforce training, identifying people at the end of their lives, high quality care regardless of location and funding.

Ambitions for Palliative and End of Life Care 2015–2020 (2015): This strategy outlined a national plan for local action on end of life care. It gave a commitment to personal care planning, shared records, better evidence, and greater involvement of the people supporting and caring for the dying person. Key enablers were co-design of care and services, local leadership, 24/7 access to services, and better education and training for professionals.

Our commitment to you for end of life care (2016): This contained a commitment to every person, by the Westminster government, on what they could expect at the end of their life. It included a commitment to honest conversations, informed choice on care, personalised care plans, carer and family involvement and a clear point of contact. To deliver this, the strategy committed to spread innovation, improve care in all settings, train the workforce and to ensure transparency in reporting.

The NHS Long Term Plan for England (2019): This strategy, covering NHS priorities for the next decade, reiterated commitments to both integrated and end of life care. It also outlined commitments to train staff in end of life care, provide personalised care plans to all, and to work more closely with hospices, local authorities, patients, families and the voluntary sector.

The strategy made a wider commitment to moving more care into the community and primary settings – and to upgrading urgent community response for those who need it.

The Comprehensive Model for Personalised Care (2019): Outlined a series of actions that the NHS would take to embed personalised care in business-as-usual delivery, particularly for those at the end of their lives. The six components of the plan were shared decision making; personalised care plans; supported self-management; social prescribing; enabling choice and personal health budgets.

This shift towards community-led, integrated and person-centred care is the appropriate ambition in the face of future pressures. It is thought to be good for outcomes – because it avoids over-treatment associated with hospitals. Evidence also indicates that it is cost effective. A forthcoming review by Imperial College London shows that home-based teams may generate substantial savings for the healthcare settings, while benefitting both patients and caregivers (Higginson et al 2003, Tamarin et al 1992, Spilsbury and Rosenwax 2017). Marie Curie estimates suggest a day of community care at the end of life is £280 cheaper than a day of in-patient specialist palliative in-bed care (Marie Curie no date).⁴

As such, a strong business case can be built for a shift towards a model of community-led palliative care, in the face of growing demand pressures. That is not to say that specialist care will never be appropriate in the future – not least, because it comes in many guises and can be delivered in hospitals, hospices and community settings. Rather, it is to say the direction of challenge should be towards more community care and less hospital care at a population level. The challenge is to identify a way to get there.

In 2017, modelling in the journal *Palliative Medicine* looked at trends in end of life care up to 2040 (Bone et al 2017). The research showed that demand for end of life care services was likely to increase substantially in the next two decades. It also showed that, on current trends, twice as many deaths would take place in care homes, hospices and private homes as do today – meaning these settings would account for 76 per cent of all deaths.

However, as the research points out, this move to a community-led model will *only be possible if there is the community infrastructure in place to provide it*. At the time of the study, significant gaps included a vast lack of social care capacity (both domiciliary and care home beds), a lack of capacity to provide home support, and a small number of hospice beds relative to the population.

One possible outcome should deaths increase, without concordant community investment, is a regression to a more acute-led model of end of life care:

“If care home capacity does not increase and these additional deaths instead occur in hospital, the [historic] decline in hospital deaths will reverse by 2023, rising to 40.5 per cent of all deaths by 2040. New approaches to caring for people will need to be considered. If people are to be supported to die outside hospital, input from the NHS, social care and the voluntary sector will need to be considered.”

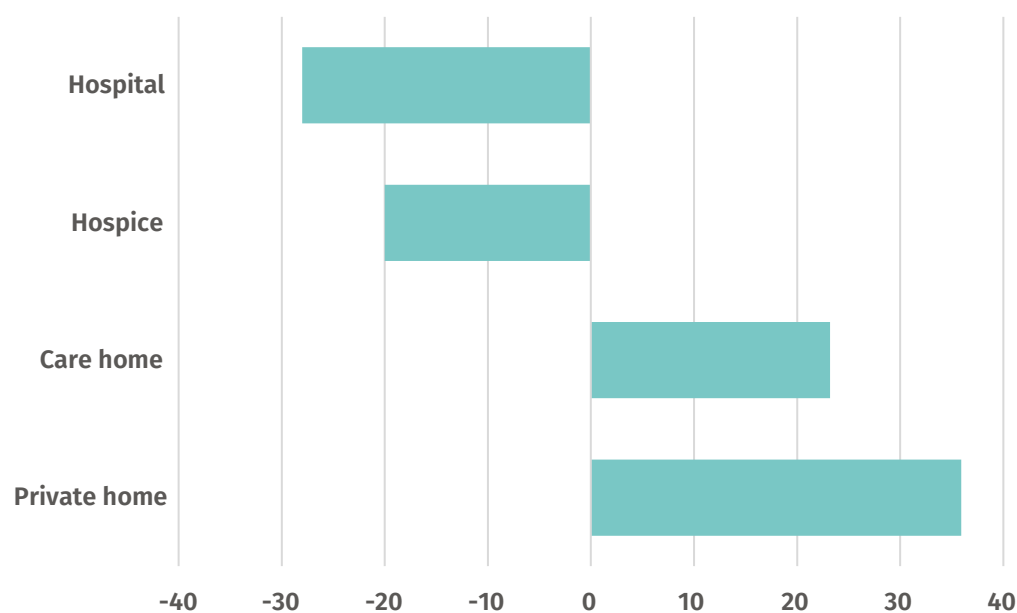
Bone et al (2017)

⁴ Though the cost saving is conditional on the patient receiving care that is right for them – specialist care will still be appropriate to many, including in-hospital specialist palliative care, in the future. It is also important to note that not all specialist care is in-patient specialist palliative care, delivered in hospitals – community/hospice provision also exists.

The Covid-19 pandemic indicates a second plausible scenario - one where care shifts to care homes and private homes, despite insufficient capacity and proactive planning. The 2020 pandemic put significant pressure on hospitals to free up beds, to meet the extra demands associated with Covid. This meant that people dying from a condition that was not Covid-19 were far more likely to die in care homes and private homes, than in hospitals:

FIGURE 2.1: THERE WAS AN UNPLANNED SHIFT FROM ACUTE TO HOME SETTINGS

Changes in place of death for five leading causes of mortality (non-Covid-19), 2020 compared to 2019 (%), England, all genders



Source: Author's analysis of ONS (2020)

This might appear to be a natural and welcome acceleration of community-led care. However, our qualitative research showed that the lack of preparation for a shift of end of life care to social, community and home settings made it hard for care quality to be maintained, and to significant stress amongst workers and carers. Our strategy should not be to allow the strain of the pandemic to become business as usual.

These sub-optimal scenarios reiterate that a shift to community-led end of life care will not simply *happen*. Rather, it will need to be proactively planned and supported by capacity. In other words, what is needed is a *managed* shift to a community-led end of life care model – based on proactively putting capacity in place, as the setting of care changes.

In the next chapter, we identify areas where our efforts should focus, in accelerating delivery of reform. In the final chapter, we look at policies to deliver a managed shift, and to prepare for the challenges facing end of life care in the decade to come.

REFORM IN SCOTLAND

In Scotland, 54,000 people die each year. As in England, there has been significant investment in setting out policy and strategy to help ensure these people receive the best possible care. In 2015, the Scottish government release *Palliative and end of life care: Strategic framework for action*.

This strategy had several key aims:

- to increase access to specialist palliative care, regardless of age, gender, diagnosis, social group or location
- to ensure timely and focused conversations about death and dying, with people dying people and carers
- care from a wider range of health and care staff, providing more coordinated services
- a well-trained a confident workforce, able to have high quality, early conversations about death
- a greater focus on hospices, care at home services, care homes, social care and carers.

This strategy is in line with the wider trend towards a community-led model of care in England. But, as in England, the proof will be in whether resource and planning can support reform in advance of a disruptive decade.



3.

A MANAGED APPROACH: IDENTIFYING AREAS FOR FOCUS

In this chapter, we report on key findings on resource allocation and healthcare utilisation, undertaken by Imperial College London. This analysis identifies areas where we should focus our efforts to accelerate managed delivery of high quality, community-led care in the decade to come.

METHODOLOGY

This report uses a mixed method approach to inform the future of end of life care in England. Quantitative analysis was led by Imperial College London, in collaboration with the University of Edinburgh. The team conducted a retrospective cohort study of people aged 60 years and over – who died between 2010 and 2017. Their analysis used routinely collected and linked data from a nationally representative sample of the English population. Data was sourced from the following places:

- Clinical Practice Research Datalink (CPRD)
- Hospital Episode Statistics (HES)
- death registrations via the Office for National Statistics (ONS).

Analysis allowed identification of healthcare utilisation and resource use amongst decedents broken down by gender, primary cause of death, age, geography, socio-economic status and number of conditions (comorbidities).

This was supplemented by qualitative research undertaken by Imperial and IPPR. The former led formal semi-structured interviews, exploring attitudes to end of life care amongst n=20 carers. IPPR explored attitudes from healthcare leaders, commissioners, professionals and policy experts. Qualitative work was carried out between June 2020 and January 2021. This qualitative work informs interpretation of the quantitative data and the final policy recommendations, presented in this report.

THEME 1: END OF LIFE CARE REMAINS TIED TO HOSPITALS

In 2019, the NHS in England spends an estimated £3.7 billion per year on healthcare for people in their last year of life.⁵ Hospital care remains the biggest site of end of life care costs. Analysis showed that, in the study period, £6 in every £10 spent on end of life care was spent on inpatient care. The sum of hospital costs varied by socio-economic status, age, number of conditions, cause of death and proximity to death.

⁵ In cash terms.

TABLE 3.1: ESTIMATED END OF LIFE CARE COSTS IN THE LAST YEAR OF LIFE, PER PERSON, ENGLAND

Type	Hospital	A&E	Outpatient	Primary care	Prescription	Total
Cost (£)	4,529	329	599	1,094	876	7,426.2
%	61	4	8	15	12	100

Source: Analysis team

The second and third largest costs were primary care and prescriptions. In each case, this was a fraction of the amount spent on inpatient hospital care.

If this reliance on acute care continues, future mortality could mean spiralling costs associated with hospital-based end of life care. Total costs would reach an estimated £4.8 billion by 2043⁶ – of which £3 billion would be hospital costs (compared to £2.3 billion today).⁷

As discussed, this is likely to impact not just cost but outcomes. Qualitative interviews with carers showed hospital as a last resort care setting – and no one who participated in the research actively sought end of life care in a hospital setting. Hospital care was often seen as poor quality and disjointed, particularly in comparison to hospice services. Below are three indicative quotations, from three carer interviewees:

“I said, ‘Well what good will it do? Is there something that the hospital can do that is miraculously greater than we can do here with your help and local help?’ And she said, ‘No, they haven’t got a magic bullet, they will just see that she is alright’, she said, so I said, ‘Well, then no, my choice would be for her not to go into hospital.’”

Interview with carer

“She was in a normal ward and they hadn’t got time, it’s not their fault, they were pushed and they hadn’t got time and they weren’t looking after her properly – well I shouldn’t say “properly” but they just didn’t have time”.

Interview with carer

“I’d always said to him, “Whatever happens, I’ll look after you and I won’t put you in a home” as it were, but the opportunity didn’t arise but I think, of course hindsight is a wonderful thing, that palliative – we had talked about palliative [hospice] care and I think it would have been better in a way, he would have been more comfortable certainly with skilled people looking after him rather than me doing my best”.

Interview with carer

THEME 2: RELIANCE ON HOSPITAL CARE IS HIGHER IN THE NORTH EAST, YORKSHIRE AND THE HUMBER, WEST MIDLANDS AND LONDON

The evidence base and NHS strategy promote a greater proportion of care taking place in the community (when appropriate for the person). Building on this, Imperial analysis shows that there is evidence that reliance on hospital care is greater in some parts of the country than others.

6 In cash terms – the cost once accounting for inflation would be significantly higher.

7 Assuming hospital share of healthcare utilisation remains constant.

TABLE 3.2: HEALTHCARE UTILISATION BY REGION (RED = NEGATIVE INDICATION, GREEN = POSITIVE INDICATION)

	Hospital admissions	Hospital days	A&E visits	ICU length of stay	Outpatient visits	Primary care visits
North East	2.4	26.7	1.2	0.6	4	26.7
North West	2.6	22.7	1.9	0.4	5.6	23.4
Yorkshire and the Humber	2.6	23.4	1.7	0.4	4.5	23.5
West Midlands	2.5	26	1.7	0.4	4.8	23
East of England	2.4	23.7	1.7	0.6	4.2	22.3
South West	2.2	21.5	1.4	0.3	4.4	26.6
South Central	2	20.9	1.4	0.4	5.5	23.3
London	2.8	27	2.2	0.7	6.7	21.8
South East Coast	2.3	22.3	1.7	0.4	4.8	23.2

Source: Analysis team

This table indicates that some places are further on the reform journey than others. London has the highest use of acute care and a below average utilisation of primary care. The North East and Yorkshire and the Humber also had a greater reliance on hospital care, across this dashboard. The reverse is true in the South central and South West regions.

This aligns with aggregate resource costs. During the study period, significantly more money was spent on end of life care in the last 12 months of life in areas with a bigger reliance on acute care.

TABLE 3.3: RESOURCE ALLOCATION BY REGION, LAST YEAR OF LIFE, ENGLAND

Region	Total cost (Average per patient, last year of life, £)	Difference to highest cost region
London	8,276.1	0
Yorkshire and the Humber	8,192.1	84
North West	7,888.8	387.3
North East	7,888.7	387.4
West Midlands	7,445.4	830.7
East of England	7,341.8	934.3
South East	7,329.9	1,036.2
South West	7,051.2	1,224.9
South Central	6,692.2	1,583.9

Source: Analysis team

If every English region has the same care model and costs as the South Central region, quality and efficiency would both improve. Moreover, these savings would likely come in the parts of the country where health need is highest - meaning it could be reinvested equitably (Thomas et al 2020).

THEME 3: THERE IS EVIDENCE OF HEALTHCARE INEQUALITIES IN HEALTHCARE AND RESOURCE USE

Care intensity varies significantly by age

Age has a large impact on the kind of care received. The youngest in our sample experienced significantly more care across the board – they spent more time in hospital, had more medications, were more likely to stay on in the ICU and were more likely to visit primary care.

TABLE 3.4: HEALTHCARE UTILISATION BY AGE, LAST 12 MONTHS OF LIFE, ENGLAND

Age	Hospital admissions	Hospital days	A&E visits	ICU admissions	ICU stay
60-69	3.9	25.1	1.8	0.2	1.2
70-79	2.9	25	1.8	0.1	0.7
80-89	1.9	23	1.7	0	0.2
90+	1.3	17.6	1.4	0	0
Difference	+ 2.6	+ 7.5	+ 0.4	+ 0.2	+ 1.2

Source: Analysis team

TABLE 3.5: HEALTHCARE UTILISATION BY AGE, LAST 12 MONTHS OF LIFE, ENGLAND

Age	Outpatient visits	Primary care visits	Prescriptions
60-69	9	27.2	79
70-79	6.6	26	86.9
80-89	3.9	22	87.2
90+	2.1	18	76.6
Difference	+ 6.9	+ 9.2	+ 2.4

Source: Analysis team

In line with this, the resources invested in people aged 60-69, in the last year of their life, were much higher than the resources invested in people over 80 or 90 years old.

TABLE 3.6: HEALTHCARE COSTS BY AGE, LAST 12 MONTHS OF LIFE, ENGLAND

Age	Hospital costs	A&E costs	Outpatient costs	Primary care costs	Prescription costs	Total costs
60-69	5,477.5	356.5	1,116.2	1233	980.8	9,164
70-79	5,002.1	355.6	785.3	1,192.9	974.8	8,310.8
80-89	4,288.5	324.8	427.2	1,040.5	831.2	6,912.3
90+	3,205.7	247.3	221	887	667.7	5,228.7

Source: Analysis team

There are good reasons why this would not be a simple or good idea. For example, people at an older age may be less likely to benefit from intensive treatments with a curative intent. Moreover, there is a strong argument that incessantly chasing cure and longevity over quality of life does more harm than good. It may be that people over 90 are better served by non-curative options.

However, given that utilisation of care was lower across all metrics, there may also be an element of age discrimination. This was highlighted as a problem in the system through our qualitative interviews with practitioners, commissioners and professionals. In turn, this may indicate that improving the options available to older people may be beneficial from a resource perspective.

Variation by socio-economic status

Socio-economic status may have an impact on the kind of care people can expect to receive in the last year of life. Analysis shows that people living in the most deprived parts of the country receive more care in acute settings (though, the differences are relatively small)

TABLE 3.7: HEALTHCARE UTILISATION BY SOCIO-ECONOMIC STATUS, LAST YEAR OF LIFE, ENGLAND

IMD decile	Hospital admissions	Hospital days	A&E visits	Outpatient visits	Primary care visits	Prescriptions (GP only)
1 (least deprived)	2.3	22.6	1.6	6	24.3	79.7
2	2.3	23	1.6	5.3	23.2	82.8
3	2.4	22.7	1.6	5	23.9	85
4	2.3	24	1.8	4.6	22.9	86
5 (most deprived)	2.5	24.5	1.9	4.4	22.5	94
Difference	+ 0.2	+ 1.9	+ 0.3	- 1.6	- 1.8	14.3

Source: Analysis team

Hospital costs are by far the most expensive part of end of life care provision – usually, because they provide access to specialist care. A natural hypothesis would be, therefore, that people living in the most deprived parts of the country have more money invested in their care in their final year of life. This is not the case.

People in the least deprived parts of the country had £385.50 more spent on their care, on average, than people in the most deprived.

TABLE 3.8: DIFFERENCE IN RESOURCE ALLOCATION BY MOST/LEAST DEPRIVED, AVERAGE PER PERSON

	Total care cost
Most deprived	£7,393.70
Least deprived	£7,779.20
Difference	£385.50

Source: Analysis team

THEME 4: PEOPLE DO NOT FEEL CONFIDENT IN THE WHOLE WORKFORCE

Workforce training and communication has been a UK government aim for over a decade. It has appeared in a number of strategies – including large, specific end of life care ambitions. This is in line with interviews with carers from this project, which showed good interactions with health and care professionals could transform the dying process:

“So, they obviously realised probably about a month before she died that she was really – she’s going to die soon, I think one of them actually said to me, you know you get to know them who’s coming in and the owner of [care company] care had actually come and had said to us, “Right, your mum is very near the end of her life now and she doesn’t really have very long, you need to be prepared for this.”

Interview with carer

It is also in line with the evidence, which endorses the importance of the workforce in good end of life care. NICE report that good communication between worker and dying person improves their prognosis, stressing the role of good communication training amongst staff (NICE 2015).

Yet, it is not always easy. End of life care has not been immune to the impact of wider shortages in the workforce. For example, a survey by Marie Curie and Nursing Standard showed that 65 per cent of nurses found it hard to give good care to dying patients due to staff shortages in the NHS and the social care sector (Hospice UK 2019). Shortages and strain in general practice and the social care workforce are likely to cause further problems.

Access to training can be difficult. Qualitative work with professionals by Macmillan Cancer Support has shown that workforce pressures make access to end of life training difficult (Macmillan 2019b). This means that data showing availability of training, such as a 2014 audit which showed that 96 per cent of trusts in England had a formal in-house continuing education programme on end of life care, does not tell the whole picture (Macmillan 2019b).

Qualitative research with carers showed that interactions with health and social care professionals had a significant impact on the end of life care received. In some cases, this included descriptions of negative interactions, leaving carers unprepared for the treatment and management course across the illness and dying trajectory. Those who did not have effective discussions with their health and social care professionals felt unable to plan effectively for the future.

“To be honest with you, no-one had ever told, certainly me, the life expectancy as such, so no, to be quite truthful and honest with you, I didn’t have a clue what the end of life would be, so it was a real shock to me. And as I say, you know, he was more or less abandoned, we didn’t know where to turn to for advice or help or anything ... [he] wasn’t given really any proper information when he was diagnosed either, you know, who to go to, who to speak to, you know, the experts, all this sort of thing. And I think the GPs need to be held accountable to, you know, to get that information out there once the person has been diagnosed.”

Interview with carer

THEME 5: QUALITY AND ACCESS TO CARE

Quality is high in hospices across the country – with 90 per cent rated good or above. Moreover, the Economist Intelligence Unit’s ‘Quality of Death Index’ ranks the UK top, out of the 80 countries included in the study (Economist Intelligence Unit 2015). However, there remain areas where improvement is possible. Studies of carers suggest as many as seven in 10 people with a terminal illness do not get the care they need – with those whose loved ones die in hospitals and care homes least likely to be satisfied with the quality of care. Moreover, 42 per cent of end of life services in acute hospitals are rated inadequate or require improvement by the Care Quality Commission (CQC 2016).

There is no one size fits all approach to end of life care – meaning it should happen in a range of acute, community and home-based settings. Nonetheless, access to expert end of life care remains patchy in England. While hospices are the gold standard for quality end of life care for many, they have relatively few beds. There are just under 3,000 hospice beds, while 500,000 people die in England each year on average. More generally, Hospice UK estimate that one in four families are not able to access expert end of life care, that they may need (Hospice UK no date) – while the national VOICES survey shows that one in 13 did not receive any pain relief at the end of their life.

Patchy care provision extends into the community. Carers described problems with integration and coordination of services meaning, while a community-led approach is evidenced, it needs proper and proactive planning from policymakers:

“You need to get all the right people in because of waiting and referrals and equipment ordering and all that it takes... so the minute you knew that things weren’t right so it was just to call the GP, get them to come and do a home visit, on there he just had to say what he wanted and he needed district nurse support and he needed all the other stuff that goes with it, it might be night district nurse or day district nurse or whatever that is so you’ve got that and then at the same time a referral too would have been generated from district nursing to social care, they came round and did an assessment so the bed got sorted, the personal carers came round, the district nurse came round, all within a week it was like a Tuesday and I did all of it and by the Thursday.”

Interview with carer

FINDINGS IN SCOTLAND

The analysis also covered end of life care in Scotland, a component of the project led by the University of Edinburgh. This found that inpatient hospitalisation was increasingly common in the last year of life – becoming more common when the person was close to death. This finding was consistent across cause of death, age and rurality. In fact, the average time spent in hospital, in the last year of life, was 12 months. This underpinned a mean cost of secondary care of £10,134 per person in their last year of life – almost twice that observed in England.

Overall, around 50 per cent of people in Scotland currently die in hospital – which may mean many dying in a place not of their preference. This indicates a culture of ‘over medicalisation’ – as observed in England – where people receive hospital care that either doesn’t benefit them or does them harm.

As in England, costs in the last year of life decreased with age. Costs for those in the youngest group in the study were twice that as for those 90 years old and over. People living in large urban areas had the highest use of healthcare. This may represent the ease of access to hospitals – a factor which was highlighted in our qualitative work as a factor in whether someone received more or less acute care.

Overall, this indicates that a similar shift to community-led care would be beneficial in Scotland – and is perhaps even more urgent than in England. Improving the quality and appropriateness of care for people in their final stage of life is a national and international priority – and Scotland have an opportunity in their move towards more integrated healthcare to improve outcomes.



4. POLICY RECOMMENDATIONS

Based on the need to prepare for future pressures, and on the basis of where Imperial analysis identifies areas for large marginal gains, this chapter outlines a new framework for end of life care. This aims to ensure a managed and well-resourced shift to community-led care in England.

TABLE 4.1: A FRAMEWORK FOR THE SHIFT TO COMMUNITY-LED END OF LIFE CARE IN ENGLAND, SUMMARY

Theme	Definition	Relevance to community-led care
Providing everyone	Good end of life care is should be available, equally, to everyone. This means significant and measurable progress against the inequalities that have often defined this agenda.	Community-led care means more providers and more diverse care settings. If this means patient advocacy defines care quality, inequalities will emerge.
The right care	This report argues for community-led care. However, that care needs to be properly funded, to ensure supply meets demand.	If community and social care does not receive resource, either those sectors will come under huge strain, or care will not shift out of hospitals.
From the right person	People have been key parts of end of life strategies, but more needs to be done. In particular, we need to ensure training and communication skills are more consistent.	Moving to the community means ensuring people can get access to the right people, with the right skills – outside highly specialised units.
At the right time	The focus on personalised care that has been embedded in the last six years of policy is a welcome shift. End of life care must continue to have the ability to shift to individuals' preferences and context – and to adapt care as those preferences and contexts change through their care.	Community-led end of life care revolves around many providers supporting one person. Without personalisation, this care will not be properly coordinated – making it liable to delay or low quality.

Source: IPPR analysis

PROVIDING EVERYONE...

Providing for everyone means that any reform agenda should begin with equality. Beyond the analysis outlined in this report, the literature is rich with examples of inequality at the end of life (as in health more widely) – based on socio-economic status, ethnicity, sexual identity, gender identity and age.

Recommendation 1. Recruit 2,700 'end of life care advocates' in the community, as an extension of current link worker recruitment

Our qualitative work with carers highlighted the importance of advocacy in ensuring people get the best end of life care. Carers often described their role as being an advocate for the dying person. That could mean co-ordinating care across

providers; filling in staff members on medical history; pushing for preferences to be met; or making difficult decisions. In some cases, for example were caring for a dying person with dementia, the carer would have little input beyond decisions made in advance of the onset of the disease.

Carers often needed better support. Participants in qualitative interviews described feeling duty bound to provide care, and in some cases a significant impact on their lives, including living arrangements and work:

"And both dad and I knew she didn't want to go into a care home, she'd made that decision a long time ago on her own so it was really, it was... and dad didn't want to go against her wishes so guess who got lumbered with that one."

Interview with a carer

"You've got to look at it holistically. You've got to think of everybody that's involved, you know. I wanted to look after my mother, but I still... that would have affected my husband."

Interview with a carer

"And I don't think that my work were particularly helpful either. I work for the local council and I don't think that they're... they might have had policies but they certainly didn't offer anything helpful particularly. So it was always a struggle with appointments and things taking... Because obviously I... Well, not obviously, but I went to everything and it was always a juggle making that time back. So yeah, it was a logistical nightmare, looking back."

Interview with a carer

The link between good care and strong patient/care advocacy might explain the sub-optimal care observed amongst the most deprived people in England in the Imperial analysis. The evidence is clear that people from more affluent parts of the country are more likely be able to advocate effectively for their care – particularly, when that care is complexed. Those who cannot call on knowledgeable friends and family; who's carers have less time or resource; or who simply have less social capital are less likely to get the best care.

The NHS in England has already try to address this. For example, the comprehensive model of personalised care commits to every person with a long-term condition being allocated a named care coordinator. Moreover, link workers have been introduced, to help coordinate community-based support. However, end of life care has unique challenges, that may require additional support:

- link workers at the end of life may not have specialist awareness of the community and voluntary services available for those at the end of life, for both patients and carers – such as bereavement, respite, mental health or hospice services
- care can be more intensive and more complicated in the last year of life. It may mean more time receiving care, from more care providers, than usual. This may mean more time is needed from care coordinators – and for those care coordinators to be active in different settings
- studies have shown that people's objectives for their end of life care are context dependent – and that that context can change very quickly. This means care plans may need to be regularly reviewed and care re-coordinated rapidly.

The implication is that end of life care requires a far more specialist and intensive process of coordination and advocacy than would be catered for by existing models. These challenges could be increased by a shift to a community care model, based on diversifying services, and with more reliance on coordination.

As such, we recommend that the NHS in England recruits new end of life care advocates, based in community settings, to ensure everyone has access to the coordination and personalisation of care they need. Advocates should play a coordinating role in the care system – for example, by identifying appropriate services and managing care transitions. However, they should also provide case management for needs outside the remit of the NHS. They should have the ability, for example, to navigate welfare applications, home office processes and the justice system (within reason, and where formal legal representation isn't essential).

In England, around 500,000 people die every year – with around half a million of those living in England. To cater for this, we recommend central funding is allocated to allow every primary care network to hire two end of life care coordinators by 2023/24, and more thereafter.⁸ Assuming that these roles are hired at Band 4, the cost would be an estimated £120 million per year. (Curtis and Burns 2020).

Recommendation 2. Create a 'duty of inclusion' for all providers delivering both specialist and non-specialist end of life services

There is a growing body of evidence on 'inclusion health', and on inclusive end of life care more specifically. As discussed above, non-inclusive services can make it hard to give people the care they live, and to ensure good care transitions to the most appropriate settings. If end of life care is to be delivered in different, new or more diverse settings, it is right that these learnings are kept at the forefront of our mind.

As such, we recommend that a duty of inclusion is placed on end of life providers to accelerate this process at the end of life. This should go beyond the expectations set in existing legislation, such as the Equality Act 2010. The duty should focus on four, evidence-based principles in the first instance.

- 1. An identifiable commitment to inclusion:** evidence has shown that making a clear and easily identifiable commitment to inclusion can have a positive impact on care. This could be as simple as posters displayed within a care setting, badges worn by staff, extra text added to forms and adherence to best practice inclusive language.
- 2. Inclusive communication training:** It is often highlighted, by workers and worker representatives, that training on meeting diverse needs is often lacking. An ambition should be set for every healthcare professional to receive training on inclusive care, including for those with serious health conditions and end of life care.
- 3. A pathway to psychosocial support:** In a Lancet review of evidence on inclusion health, access to psychosocial support was listed as the third most important intervention for ensuring inclusive health. This means access to services relating to severe mental ill health, substance misuse and addiction. Providers should have a clear pathway to psychosocial support services, proactively communicated to relevant healthcare professionals.
- 4. Zero-tolerance of discrimination at all levels:** Discrimination happens in NHS services. Studies show that more than one in five trans people report having experienced discrimination, transphobia, homophobia or unfair treatment from a GP surgery staff (Macmillan Cancer Support 2014) – and other studies have shown discrimination in ward settings (Bristowe et al 2018). A zero-tolerance staff should cover both professionals (as regulated by their employer) and organisations and leaders (as regulated by the CQC) (Cloyes et al 2019).

⁸ In line with wider plans to expand the number of social prescribing link workers.

This standard should be set in collaboration with workforce regulators and unions and overseen by the Care Quality Commission on a 'comply or justify' basis.

THE RIGHT CARE...

Our research showed that there is more to be done to move away from an acute-led to a community-led model of end of life care. The shift to the community-led care does not have to mean an obsession with ensuring people can die at home – our qualitative work highlighted that this had been unhelpful in the past. Rather, it should mean an approach based on getting people the care they need – specialist and non-specialist.

Making this shift will mean properly resourcing those we ask to provide more care. If that does not happen, we risk failing to move care out of the hospital, or exposing community, social and at home providers to the kind of strain experienced in 2020. Given that a shift from hospital care generates cost savings, this can be seen as a long-term, cost-effective investment.

Recommendation 3. Match the shift to community and social care with resources

The ambition to shift care into the community needs to come with a strategy. Between 2010 and 2020, the UK government's approach has been to close hospital beds – based on the idea that 'an open bed is a filled bed'. The ambition is sound, but it will only work in practice if reduced hospital capacity is pre-empted by a corresponding increase in community or primary care capacity.

Put simply, the amount of NHS funding provided to community and primary care will need to increase. The NHS Long-Term Plan for England committed extra funding to these sectors, however more is likely to be needed. In particular, previous IPPR research has presented the case for £2 billion more investment in community care capacity per year (Thomas 2020). This would constitute a full re-allocation of monies saved from hospital bed closures since 2010 (ibid).

This needs to be supported by proper resourcing of the social care system. In 2021, social care already provides services for many in their last year of life. In fact, nursing home residents have a life expectancy of 12 months, highlighting the need for the right support in care as well as health.

In 2018, IPPR released a briefing paper as part of this programme of work, where we argued:

“...significant additional investment in social care is necessary, in order to provide a sustainable and effective ecosystem of support that allows people to maximise their quality of life outside of acute medical settings where appropriate and where desired...This would require significant and radical change. Spending on social care has experienced a significant decline year on year and local authorities, who are responsible for designing and commissioning social care, have seen their budgets dramatically reduced annually since 2010.”

Hunter and Orlovic (2018)

There we argued for a sustainable funding settlement, to be delivered through the social care green paper.

As of 2021, the social care green paper has not been published and the funding of the sector has not been put on a sustainable footing. The 2019 election saw the new Prime Minister reiterate his commitment to solving the social care crisis, and 2021 offers two tangible opportunities for his UK government to do so. We recommend that the Westminster government look to provide immediate funding for the sector at the Spring budget, followed by long-term funding and reform at

autumn's comprehensive spending review. The best reform would deliver free personal care for all, based on IPPR's 2019 proposals (Quilter-Pinner and Hochlaf 2019).

Recommendation 4. Commit to 'hospice quality' to all settings and an end of life care premium

As care moves into the community, the unequal distribution of hospice beds will become clearer and clearer. Hospices provide by far the highest quality care – with the CQC showing that four times as many acute hospitals providing end of life care services are rated 'inadequate' or 'require improvement'. Yet, despite a trend of greater access to hospice care, there are widening inequalities (Sleman et al, 2015). A large 2015 study showed that people living in the least deprived parts of the country are more likely to access hospice care (Ibid).

A key reason for the lack of supply of hospice services is the slightly different way end of life care has evolved compared to other NHS services. Hospices, despite being the end of life gold standard, are funded by charitable donations. This means that places are limited, compared to demand. And it means hospices are more likely to thrive in more affluent parts of the country – where local donors have more disposable income.

It is the only part of the health system where this is the case – at least, at such scale. There would be outcry, for example, if maternity services were similarly reliant on charity and, for that reason, access to high quality care was unequal. That is not to say we should not be grateful the hospice movement, or the philanthropy that supports it. Rather, it is to say that the public sector should make sure that the standards of hospice care are afforded to everyone, in line with the founding principles of the NHS.

As such, we recommend new resource comes alongside an explicit commitment to creating 'hospice quality care' across the whole country. That means ensuring wider access to hospice-level home services, by making more progress on the shift to 24/7 end of life home support – which is currently inconsistent (End of Life Care Programme Board 2015). Every community should develop a 24/7 community end of life service with access to specialist and non-specialist clinical time, and telephone support.

We also recommend that resource is allocated to areas that have not traditionally benefitted from the extra investment and capacity the nation's hospices provide. We recommend an end of life version of the 'pupil premium' is introduced, to help support better end of life care for the most disadvantaged people. Our finding shows on average, people in the most deprived parts of the country receive nearly £400 less investment per person in their last year of life. As such, we recommend the end of life care premium is set at this level.

Importantly, this fund need not be used to fund intensive care beds. Instead, it could be used to fund capacity for more home care and community services from across care providers and integrated care systems. Equally, it could be allocated to personal care plans and personalised health budgets, to help support people to get the care that is right for them. Either way, this would directly address our finding that people in the most deprived parts of England a) receive less investment and b) have higher utilisation of acute-led care.

FROM THE RIGHT PERSON...

A skilled and sustainable workforce has been highlighted throughout end of life strategies as a key enabler to better end of life care. The right workforce, with the right skills, can be an evident enabler to good end of life care. But a stretched

workforce, without the training and competencies they need, can make good and dignified end of life care all but impossible.

The right person means two things. It means the right professional for your needs – regardless of where you are. That might mean someone who can prescribe pain relief. That might be a specialist in palliative care. Or it might mean someone who can facilitate your care. It also means access to someone with the right training and information – someone who can communicate with you honestly and openly, or who does not need you to repeat your case history, because they have the right data and records available.

Recommendation 5. Enhance training in communication skills around end of life care through a new end of life care academy

Good communication and relationships with professionals remain a barrier to good end of life care. However, the policy reacting to this needs some nuance. First, it does not necessarily follow that the availability of training is the problem. Audit data suggests relevant training is available in the vast majority of health settings do offer training. And since the last audit data was made available, yet further training resources have been developed on this agenda, by organisations like Skills for Health.

Two other factors are likely to be more important than simply the availability of training. Firstly, in a stretched workforce environment, it may be hard for many to put aside the time to do training. Second, it may be that the training – while available – is not of sufficient quality. To this end we endorse the recent Macmillan Cancer Support recommendation that the CQC regulate on the basis of quality end of life training, and the practical ability of professionals to attend it (Macmillan 2019b)

Second, and relatedly, some settings may have less access than others. Of particular concern is access to training for nursing home staff – a community setting where one in five of the population die. A 2016 review of evidence on access to training concluded that education was not of a standard that could reasonably alter behaviour.

Learnings can be taken from the approach to building digital skills within the NHS. For example, the NHS Digital Academy was set up in 2017, following the Wachter review (DHSC 2016). This provides easily accessible courses and materials to support a generation of digital leaders in the NHS. We recommend a new end of life academy is set up, with easily accessible training materials (leaflets through to courses). In contrast to the digital academy, the training should be suitable for a range of audiences – not just NHS professionals, but social care workers, carers, friends, family and the dying person themselves.

Recommendation 6. Ensure staffing levels are sufficient for people to get help from someone with ‘time to care’

Access to the right staff, with time to care, is also an important part of facilitating a move to community care. Moving care out of hospitals only works for people if they can access the right member of staff, with the time and skills to help them. This makes the end of life care reform agenda very hard to deliver in the context of workforce shortages. There are four particular challenges.

- 1. Nurse workforce:** Marie Curie research from 2019 shows that almost two-thirds of nurses struggle to provide good care to dying patients due to staff shortages. This was up from 38 per cent just the year before (Marie Curie 2019). Other research has shown significant shortages in nursing, health visiting, community nursing and other important roles (Health Foundation 2020). A lack of nurses,

particularly those based in the community, would undercut any move to more community-led care.

2. **Elderly care workforce:** The UK has one of the smallest elderly care workforces of any advanced economy. Moreover, it is one of the few where that workforce is decreasing, relative to the size of the over-65 population (Thomas 2020). Skills for Care data further shows significant vacancies and turnover amongst social care employees (Skills for Care 2020) – linked to pay, workplace rights, training and progression.
3. **General practitioner workforce:** The strain on general practice has been well documented, including how this is impacting access to GP appointments for those who need them. Despite growing need and an ageing population, GP numbers (FTE) have stayed stagnant since 2015 (despite a rising headcount) (Thomas and Quilter-Pinner 2020).
4. **Specialist workforce:** Specialist care is crucial, and early involvement is particularly important in ensuring good value, good quality care (NICE 2018). Filling shortages, and ensuring sustainable staffing is important for the future. As the specialty is already popular, this is likely about increasing the number of training places available.

Specifically, we recommend that HEE are commissioned to ensure that palliative care training places are sufficient to meet demand, and that the specialty remains popular with graduates.

Recommendation 7. More holistic support for workers and informal carers

We will never provide the best possible end of life care if we do not support workers and carers properly. First, it is important to recognise that the end of life can be traumatic. There has been a growing recognition during the Covid-19 pandemic that it is hard for staff to lose their patients. Yet, this is the reality of working in end of life care. Equally, end of life is incredibly difficult for the friends and family of the decedents – many of whom will have taken on a caring responsibility.

We recognise that this is addressed through an uplift in mental health and emotional support. We recommend all health and care workers have access to a full offer, including opportunities for clinical supervision; access to psychological, psychotherapeutic and counselling services; access to personalised mental health care plans; and wider access to the NHS mental health service that currently serves doctors and dentists. This should be open to carers, too, recognising the vital and difficult contribution they make to end of life care.

Moreover, we recommend an increase in commissioning of bereavement services. Evidence from 2013 shows that less than half of the bereaved people who wanted to talk about their feelings with a professional, were able to do so (NCPC 2013). Barriers included limited catchment areas, long journey times, waiting lists and limited provision (ibid). We recommend health and wellbeing boards have a duty to consider and commission adequate bereavement services for their populations (alongside appropriate resource to do so).

Beyond emotional and mental health need, informal carers often struggle to combine work, financial and caring commitments. This is compounded by a lack of compassionate leave in the UK. The UK could look to follow the more generous Polish model, where employees who provide care for a relative are entitled to two weeks paid leave per year, with financial compensation set at 80 per cent of average earnings.⁹ The advantage of this scheme is that it follows some of the principles worked out through the experience of furlough during the pandemic.¹⁰

⁹ Note, this is for over-14s. Poland allows more paid compassionate leave for those caring for under 14s.

¹⁰ It does not replace the need for more generous carers allowance and universal credit benefits.

It would also come with economic gain – keeping carers in work, through facilities like care leave – could add £5.3 billion to the economy (Carers UK 2013).

AT THE RIGHT TIME

End of life care is highly context dependent. In the last year of someone's life, their priorities and objective might change substantially, and several times. They might begin by prioritising freedom, relationships, and the ability to do things they enjoy. They might later prioritise fast access to pain relief and spiritual support. This is point should be at the heart of a shift into the community. It stresses the importance of care that has people's needs at its heart, and which can adapt to their priorities.

Recommendation 8. Scale up commitments on personalisation and electronic care coordination systems for end of life care

The comprehensive model of personalised care constitutes a bold and welcome move to a more person-centred health delivery model. From an end of life perspective, it is an important part of ensuring care comes at the right time, and that it is in line with people wishes. However, there are also opportunities to evolve the model further to help ensure people can get the right care at the right time.

The evidence is clear that personalised care plans are best when conversations are honest and early (see, for example, Tavares et al 2017). However, this does make it important to capture when priorities change – and to reassess care. As such, we recommend that the personalised care model offers people at the end of their life the opportunity for a plan review with a trained member of staff every three months. The first of these should include carers, and sections of the plan that relate to the needs of informal carers.

A second priority should be expansion of digital innovations to support care coordination. This is particularly important if the shift is towards a community-led model, with more and more diverse providers giving people care, across a bigger range of settings. Data from the Coordinate My Care programme shows that 2020/21 significantly increased the number of people in London with a CMC plan. This is a positive indicator of data sharing and coordination. However, levels of new CMC plans began to tail off through the year – while variation still exists across London. This is one example of work still to be done to continue the roll-out of electronic care coordination systems – beyond reaching the 2020 target of ensuring they were present in all English regions. Importantly, data shows that outcomes for patients with a plan continue to be predictable, during and after the pandemic, reiterating their value.

Finally, a very clear learning from Covid-19 is that a more personalised approach to 'do not attempt resuscitation' (DNAR)/'do not attempt cardiopulmonary resuscitation' decisions is needed. Recently, a report from the Care Quality Commission found 'worrying variation' in people's experiences of these decisions during the pandemic, including 500 cases where the decision not to resuscitate was taken without conversation with the dying person or their family (CQC 2021). This highlights the difficulty with consent at the end of life. It is needed both to administer treatment, to take away treatment (like cardiopulmonary resuscitation). It is needed early, as 'too late' can happen very quickly at the end of life. And it needs to be refreshed regularly, as needs and priorities change.

Covid-19 shows a much stronger approach to consent is needed within the framing of more personalised care. We agree with the CQC that a ministerial oversight group be created to work with health and care providers, local government and the voluntary sector to ensure improvements. We suggest that the terms of this group should be focused on consent – vital both to the receipt of treatment,

and the denial of treatments like cardiopulmonary resuscitation. The ministerial oversight group should be tasked with developing a national approach to consent, advance care planning, which includes consistent and early conversations with patients and carers about resuscitation decisions.

POLICY IMPLICATIONS FOR SCOTLAND

This report and its policy development has focussed on England and actions that can be taken by the UK government, recognising devolution of health and end of life care elsewhere. However, the policy implications are likely to be relevant to Scotland. Indeed, as shown by the Imperial research used for this report, the need to move to a community-led model could be more pronounced in Scotland than in England. We recommend that the Scottish government consider a refresh of their 2015 strategy, using similar principles to the **providing everyone with the right care, from the right person, at the right time** framework outlined here.



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