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Tony Hockley & Alison Leary - January 2021

Health charities and the NHS
A vital partnership in peril?

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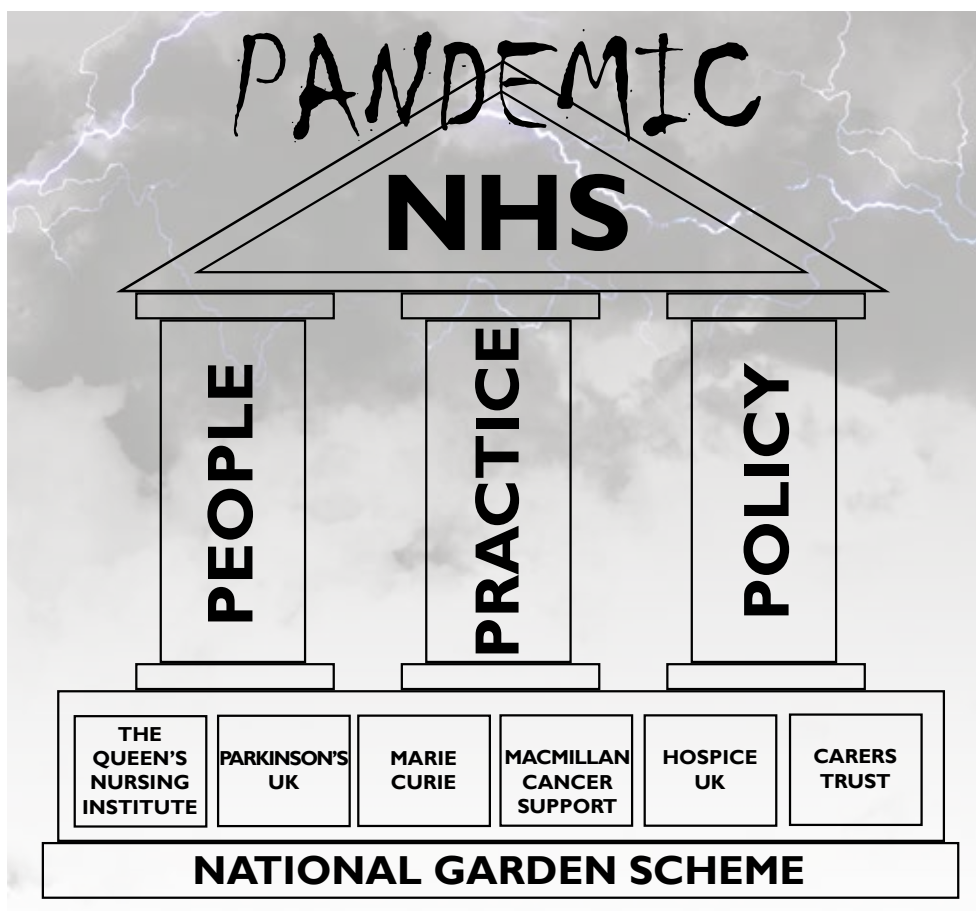
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1.   Foreword

Health charities and the NHS. A vital partnership in peril?

"Health charities need to be at the table in planning how the NHS will face the future. The pandemic of 2020 accelerated the onset of the health and social care systems' biggest challenges. It was a wake up call about coping with rising daily deaths. It should also remind policymakers of how much health and care relies upon health charities. We have heard inspirational stories of agility to keep services going during the pandemic. They have done this despite a fundraising crisis, infection controls and weak partnership planning in health policy. Given what lies ahead a much stronger partnership between the NHS and these major charities is imperative."

Tony Hockley & Alison Leary, January 2021

We first met with the National Garden Scheme (NGS) to discuss ideas for a paper in early March 2020. Within two weeks the UK was in an unprecedented lockdown due to the coronavirus pandemic. Our original plan was to produce a paper developing the themes from the 2019 King's Fund report *Investing in Quality* that the NGS commissioned, which broadly linked the work of charities supported by the NGS to public policy ambitions, particularly the 2019 *NHS Long Term Plan*[2] . From this point on, however, it was inevitable that this paper would have a very different focus.

In mid-March the beneficiary charities themselves should have been attending the National Garden Scheme annual media launch at London's Royal Festival Hall, to celebrate the £4 million raised by NGS gardens in 2019 and to hear the details of the donations they would receive. Instead they were working urgently on plans to maintain their vital nursing and health services whilst coping with the impact caused by the cancellation of their major fundraising events.

This paper is, therefore, partly the story of their incredible agility in rising to this challenge, whilst other services closed down and care needs increased. 2020 will long be remembered as the year when the gaps between longstanding policy rhetoric and policy delivery came to the forefront of public attention.

In part this is a very positive story of how the major health charities supported by the NGS adapted quickly and rose to the challenge, not only filling huge gaps in public services but also offering real leadership in how to rise to the challenge of a pandemic. Despite all of this they were still forced to make the case for their own services. We heard for example, how The Queen's Nursing Institute (QNI) was instrumental in implementing a policy of 'Everyone In' to meet the needs of the homeless during the lockdown. The QNI also freely provided vital advice to the health system on how best to provide care at home amidst the risks posed by COVID-19. Similarly, Hospice UK had to assume a national leadership role on behalf of the dying, and make the case to the Treasury for funding to support these essential services during the pandemic. In so many crucial areas of care these nursing charities led the way, albeit with little evidence of recognition of their role in sustaining the health and social care system. Their contribution to the pandemic response in priority areas of care was huge. At the time of writing any credit from policymakers for this contribution is notable by its absence.

The pandemic showed how central high-quality and motivated expert nursing is in meeting the most challenging of health needs. Personal care delivered with empathy was at its hardest to achieve, but also its highest value to recipients. The stories from the response to the pandemic by these charities highlight very starkly how they 'protect the NHS' every year and will be needed to continue to do so in the future. We summarise this in three strategic areas:

1.   **People**
New ways were found to enable and motivate a workforce under incredible stress, providing guidance and support around the clock. Alongside the organisational challenge these health charities wasted no time in adapting and enhancing their systems for peer support, in order to sustain motivation and wellbeing amongst frontline professionals.

2.   **Practice**
'Intelligent' services adapted to the circumstances. The policy for the homeless of 'Everyone In' was supported not only as a practical challenge, but also as an opportunity to deliver services to those who had long been hard to reach. Up and down the country nurses and other staff supported by the charities found new ways to deliver care, maintain human contact, and secure personal protective equipment.

3.   **Policy**
The care of the dying, of people living with cancer, and those being cared for in care homes or at home, all required new guidance to keep service providers and users safe. The charities in these areas led by example and did not hesitate in also taking a lead to develop and deliver practical advice to benefit all providers.

The year 2020 simply accelerated the advance of the major challenges that the health and social care system needs to address. In particular it is a 'wake up call' around dying. Death rates seen at the height of the pandemic in spring 2020 will become the norm within the next 20 years. The need for personalised care will continue to increase, as will expectations of personalised care. Nursing will be central to meeting these demands. This is particularly true of specialised nursing, as seen now in meeting the needs of people with cancers or with Parkinson's Disease. The system will not only need to recruit and retain these nurses, but also do much more to retain the support of the charities that do so much to make this personalised care possible within the context of a rather centralised, impersonal health system.

The pandemic also highlighted the financial challenge faced by these major charities. They clearly do what they do very well, but the opportunity to scale up to meet rising demand cannot be based on charity alone. Above all 2020 should bring about restoration of a culture that respects charities as important partners in care planning and delivery, and an honest discussion of a shared role in filling the gaps now laid bare.

2.   Background

This paper was written in the summer of 2020, between the first and second waves of the coronavirus pandemic. Whilst commissioned by the National Garden Scheme the authors benefitted enormously from direct access to the leadership teams of the beneficiary charities. We are deeply grateful to them for their time, particularly given the huge practical and financial challenges they were dealing with at the time. Their willingness to participate in the project bears testimony to the extraordinary levels of motivation within their organisations to do whatever they could to maintain the essential services they provide and to maintain their partnership working and long-term relationships.

This has also offered us an insight into the strength of these partnerships. Not only between the NGS and the charities that benefit from their consistent fundraising activities, but also between the beneficiary charities as they have worked together to support our writing in our many video calls and other correspondence. We are grateful for both the valued input and experience.

We think it worth sharing a little of the story of the relationship between the National Garden Scheme and the other charities, which is extraordinary. It is linked to the 1887 creation of The Queen's Nursing Institute, set up to co-ordinate national standards for district nursing. The NGS, in turn, was the brainchild of the QNI in 1926, as a way to fundraise in order to better support district nursing. The following year 600 gardens opened to visitors, they all charged one shilling admission and they raised £8,000. It was not until 1980 that the NGS became a charity independent of the QNI, to raise funds not only for the QNI but also a range of other nursing and health charities. In 1984 Macmillan Cancer Support became a beneficiary and the NGS has been, for some years, Macmillan's longest-standing supporter; by 2020 NGS donations to Macmillan Cancer Support had reached a total in excess of £17m. In 1996 the charities well-known today as Marie Curie, Hospice UK, and Carers Trust were taken on as beneficiaries. They remain part of the Scheme today with the NGS as the largest cumulative funder of them all.

Alongside sustained support to its core beneficiaries the National Garden Scheme also selects and supports guest charities, which benefit from the Scheme's donations for two or three years. Parkinson's UK became a guest charity in 2013, but was subsequently adopted as a permanent beneficiary, taking the total to six.

Prior to its 90th anniversary in 2017 the NGS decided to strengthen the link between its fundraising activity and health. It commissioned from The Kings Fund the now influential 2016 report *Gardens and Health* and created a Gardens and Health funding stream supporting charities to use garden projects for health benefit, some of which we will examine in this paper. This was a particularly fortuitous decision given the hugely elevated importance of gardens to support wellbeing, particularly amongst the most vulnerable, during the 2020 pandemic. Whilst public policy first recognised[3], and acted upon[4], the need for green space in response to urbanisation and industrialisation in the mid-nineteenth century, appreciation of the value in access to nature appears to have diminished over time. During the pandemic, surveys for the NGS[5] and for Natural England showed huge public attachment to green spaces for mental health and wellbeing, but poor levels of access for those who could benefit most[6]. The NGS Gardens and Health initiative had been incredibly timely in its creation.

Putting the charity sector in context

The year 2020 will always be remembered for the coronavirus pandemic. In the early spring a health and care system that was already under great strain faced the prospect of overwhelming care needs, as had already been witnessed in China and in Italy. During the following months extraordinary measures were taken to 'protect the NHS', including an extensive lockdown on normal activities. Those worst affected by these

measures were those who were already most vulnerable, particularly residents in care homes, as well as those with other care needs for which services were either delayed or made extremely difficult by the limitations on face-to-face support. The lockdown also had a dramatic impact on fundraising activities for the many charities that do so much to supplement the UK's health and care system. But 2020 will also be remembered as a year of real innovation, when charities showed their great agility in adapting to these changing circumstances and changing needs. Far from simply 'plugging gaps' in the welfare state these charities often lead the way in improving standards of care, in professional collaborations, in reaching out into the community, and in making rapid adaptations when necessary. In this paper we consider, within the extraordinary circumstances of 2020, how charities supported by the National Garden Scheme are changing lives, and in doing so helping to meet some of the most important strategic goals of public policy.

The pandemic has brought new attention to how people live their lives, at home, at work, and at leisure. Questions are being asked particularly about housing, about inequality, residential care of the elderly, the health and care workforce and, of course, death. These are questions that the charities we consider here deal with day-in day-out. We should, perhaps, learn from the pandemic of 2020 not only to better understand and appreciate the crucial role of the charitable sector, but also consider how much public policy can learn from charities' adaptability and innovation in order to better face the coming decades.

We set this in the context of five priority areas in which the UK needs to do much better:

- Wellbeing
- Workforce
- Inequality
- Ageing
- Dying

In each of these we look at the extraordinary contribution of the charities, both in 'normal' times and in the circumstances of a pandemic. It is a story of human motivation to help others, of agile and imaginative leadership, of expertise of working with populations and of a real determination to match ambitions and delivery.

Charities can, however, only deliver on their extraordinary ambitions if they are able to fund their services. Financial support from the National Garden Scheme, not least because it is sustained with substantial donations from one year to the next, clearly plays an important part in supplementing the charities' own fundraising activities. In 2020 these activities suffered a huge blow due to restrictions required to combat the coronavirus pandemic. Nonetheless the charities demonstrated the same determination to do whatever possible in fundraising innovation as they did in service delivery. No amount of innovation, however, could replicate the scale of their usual fundraising activities. At the same time that these charities were demonstrating the value they bring to the UK health and care system, the events of 2020 also highlighted the vulnerability that is inherent in reliance upon the third sector to meet core needs of increasing importance.

The pandemic should be the spur to development of a stronger and more sustainable partnership between public services and the charitable sector. Faced with growing needs and high aspirations in these priority areas of public policy it would be both disingenuous and dangerous to assume that charities will forever be able to fill gaps in health and social care under 'business as usual'.

Participation within the National Garden Scheme appeals to the full range of human motivation, from personal fulfilment to public altruism[7]. The outcome, however, is closely focused on the health and wellbeing of those served by the charities supported by the NGS. It is this human impact that is the primary focus of this paper.

We have approached it with three general questions in mind.

1. What difference have these charities made during the worst pandemic to strike the UK since the Spanish Flu more than a century before?
2. How have they adapted and managed a situation of high need with most of the usual fundraising options closed?
3. What lessons are there from this experience for the future of UK health and social care?

The pioneers of district nursing at The Queen's Nursing Institute, who created the National Garden Scheme in 1927, could not have imagined either the scale or the breadth of the impact that the Scheme would have during the following century. The Scheme's fundraising activities involving the opening of more than 3,500 gardens, generate financial support for nursing and health charities (including the QNI) amounting to £60m since the Scheme started, and £3m in 2019 alone[8] . Even at a time when much of the world was locked down to tackle a viral pandemic in 2020 the NGS and its charities found new ways to meet some of the exceptional needs of the time, showing again the value of a determined and effective charitable contribution. The rapid recruitment of a million NHS Volunteer Responders[9] in the early stages of the pandemic showed that the *Gift Relationship*[1] is still as strong as it ever was in British society. But it also showed the scale and intricacies of the task of harnessing volunteers to maximum effect[10]. The initial call for Volunteer Responders was closed when 750,000 had come forward, and after essential checks and administrative requirements the total available fell to less than half the original number[11]. Nevertheless, the 2019 *NHS Long Term Plan* set a three-year target to double NHS volunteer recruitment and increase diversity[12]. Both were achieved, at least for the short term, in just three months during the 2020 pandemic[13].

The United Kingdom offers its population a universal welfare systems, based upon a twentieth century ambition to provide 'cradle to grave' support, with health care funded mostly from general taxation with very few direct charges. As well as being largely free at the point of use it is also largely state-provided, making the National Health Service one of the World's largest organisations. The risk of a welfare system run by a quite centralised state is that the human, personal dimension can be lost. Secondly, it would be hard for any state-funded and delivered system to ensure that it is truly comprehensive, with no gaps, given the inevitable limits on funding, or for it to be nimble in times of unusual or localised need.

Charities have always played a part in supplementing gaps in care and extending the reach of health and social care. Indeed, district nursing was left to local authorities upon the creation of the NHS, and the QNI bore the responsibility for accreditation of training centres[14]. As health need has expanded so charities have taken a lead in ensuring that health services expand to meet these needs. This is particularly evident in relation to cancers and other diseases associated with increasing longevity.

A dramatic improvement in life expectancy in developed countries has, of course, been one of the greatest achievements of the past century. It has brought with it the challenge of meeting daily physical, social, and mental health needs in a growing number of people so that longer lives can be lived to the full. But the charitable contribution is much more than simply filling gaps in the welfare system by harnessing volunteers; charity staff, particularly nursing staff, deliver services under contract for the NHS and other agencies, because of the added value they bring to care:

- Firstly, charities add a unique dimension in meeting people's needs. Volunteering is, of itself, a valuable source of wellbeing for participants.
- Secondly, good outcomes are almost always core to the motivation of those who work within or volunteer for charities. This provides a focus on outcomes that large businesses or public agencies struggle to sustain amidst the pressures of processes and finances.
- Finally, charities (even large charities) are free to act more nimbly when the need arises than a large organisation such as the NHS.

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[1] The Gift Relationship book by Richard Titmuss was published in 1974. Titmuss argued that people possess a sociological and biological need to give. He made the case for the retention of a blood donor system based on altruism.

Each of these strengths of the charitable contribution to care was tested to the extreme during the 2020 coronavirus pandemic, even though charitable fundraising all but stopped. The time of maximum value coincided with minimum income, but rather than freeze activities these charities chose to meet the challenge head on and to deliver for those who needed their services more than ever. The gulf between the rigidity of state rules and the adaptability of even the most well-established charities was highlighted when pleas for special flexibility for charities in the use of furlough arrangements (under the Coronavirus Job Retention Scheme) were deemed impossible by the government: Macmillan found itself with staff unable to do their usual jobs under the lockdown rules, but who would have willingly volunteered for other tasks and to fundraise, but were not allowed to do so if the charity used the scheme to help its survival[15].

The 2020 coronavirus pandemic generated a huge disruption to care across the full spectrum of needs. This was particularly true of cancer care. It was reported that cancer care was impacted in multiple ways[16]:

- The risk of infection and poor outcomes amongst those with compromised immune systems is particularly severe. Cancer patients, therefore, needed to be shielded from infection risks, making treatment more difficult and more isolating than usual.
- Pandemic pressure on health systems meant that diagnosis was delayed, both by design and by a natural reluctance to call on health systems at a time of crisis. As in many countries, routine screening services were reduced or even suspended.
- Treatment pathways were altered to limit patients' exposure to the exceptional viral risks within hospitals treating COVID-19 patients.
- The usual priority attached to cancer care was reduced, with substantial disruption to patients' established treatment routines.
- The priority attached to COVID-19 clinical trials meant that other trials were suspended during the pandemic.

These undesirable changes, at a time of general uncertainty and fear in the population, presented an immediate additional burden for those living with cancer, their families and carers and, of course, those carrying the symptoms of as yet undiagnosed cancers. The health and social effects of this period can be expected to last for a long time. Cancer Research UK, for example, estimated that the extraordinary 20% fall in attendances at hospital accident and emergency departments (A&E) in March 2020 (where one-fifth of cancers in the UK population are diagnosed) and a 70% fall in general practitioner referrals, would mean thousands of new cancers were left undiagnosed every week that this situation persisted[17].

Charities played a vital role in adapting to the pandemic in order to provide continuity of care and vital support to some of those most impacted by the indirect effects of the coronavirus pandemic. In this paper we consider this important complementary role played by charities and the people who support them, focused on the real difference that their interventions can make. The lockdown used to tackle the COVID-19 virus had a particular impact on charity finances, just when the human touch of voluntary support was most needed. In the same week that the Prime Minister raised a mug for the 30th annual Macmillan Coffee Morning[18] , the charity found itself having to announce plans for 310 redundancies amongst its staff when faced with a forecast £175m drop in its voluntary income by the end of 2022[19].

In this paper we try to document the value of some of this work in the charitable sector, not only in terms of its contribution to the delivery of vital public policy ambitions, relieving pressure on tax-funded services or filling gaps in these services, but also in terms of its exceptional capacity to have a positive impact on lives, even in the most challenging times. Now, more than ever, does this contribution need recognition and much stronger engagement in policy decisions. The alternative is that taxpayers will be paying more, and for lower levels of care.

3.   Policy Priorities

Charities supported by the National Garden Scheme are meeting needs around core areas of public policy priority and playing major leadership roles. But they appear generally, and illogically, to be excluded from policy planning; a concern that we heard time and again during the course of this project.

The coronavirus pandemic has pushed these further into the policy spotlight. The burden of the spring 2020 pandemic outbreak fell particularly heavily on some of the UK's most disadvantaged communities and on care homes. Older people were far more likely to die than the young. The poor more than the rich. Those with Black, Asian and Minority Ethnic heritage more than the white majority. Daily headlines reporting the latest death toll made dying a topic of conversation in homes around the world. The lockdown also highlighted a widespread lack of accessible local green space and generated a new popular awareness of the value of opportunities to connect with nature. Charities supported by the National Garden Scheme are working across all of these issues, innovating in the delivery of their services as circumstances change. The links to national policy ambitions are considerable.

We have chosen to focus on the charities' contribution in relation to five important public policy priorities:

- Wellbeing
- Workforce
- Inequality
- Ageing
- Dying

These five priorities are, of course, not mutually exclusive. A focus on wellbeing underpins the other four. It is certainly arguable, based on the stories that are retold in this paper, that charities are best able to deliver a holistic approach across all five priorities, when the tendency in policymaking is often to tackle each as a separate topic. We hope that the separate consideration that follows shows that this separation is both artificial (as here) and increasingly unhelpful to good service delivery.

Finding service solutions in the pandemic © Parkinson's UK

3.1 Wellbeing

Considerable effort has been invested in the development of measures of wellbeing for incorporation into public policy decisions. From the macro consideration of 'gross national happiness' to micro measures of personal wellbeing, the search is on for policies that promote and protect wellbeing. The UK government first asked the Office for National Statistics in 2010 to start measuring wellbeing. At the time the then Prime Minister, David Cameron, said: *"from April next year, we'll start measuring our progress as a country, not just by how the economy is growing, but by how our lives are improving; not just by our standard of living, but by our quality of life"*[20].

The 2014 Care Act made the promotion of individual wellbeing a statutory duty for English local authorities[21], and an independent What Works Centre on Wellbeing was established in the same year, following the work of a commission on the topic chaired by the former Cabinet Secretary, Lord O'Donnell[22].

In addition to the integration of wellbeing as a priority in the delivery of state-run public services, research on the topic has also emphasised the crucial role of the third sector. There is, for example mounting evidence that volunteering activity has a significant positive impact on wellbeing and on the self-perceived health of the volunteers themselves, as well as on the beneficiaries of their efforts[23]. Evidence-based policy approaches that target wellbeing as an outcome can be expected to lead to the breakdown of barriers between those involved in delivering on these ambitions.

Conversely, poor health, disability, and social isolation all tend to have a negative impact on wellbeing and the most vulnerable are the most susceptible. Research by the Office for National Statistics found that:

"Self-reported very bad or bad health was the strongest factor associated with the poorest wellbeing. Those reporting a disability were almost twice as likely to have the poorest personal wellbeing as those who said they were not disabled."[24]

Illness often has lasting effects on wellbeing, making it likely that the pandemic of 2020 will have a sustained effect on many of those who needed treatment for the virus. Whilst cancer survival rates have improved significantly, cancer's negative impact on wellbeing can be enduring. A 2011 study found that cancer survivors tend to be in significantly poorer health than the general population, with similar level of health to someone with a chronic disease. The authors found that:

"cancer survivors tend to have ongoing health problems, reporting poor general health, physical wellbeing and pain. They also report making greater use of health services than individuals who do not have a cancer diagnosis or chronic condition. The differences extend beyond health per se and into social and economic dimensions of life …"[25]

As survival with or after cancer continues to improve, and incidence grows with demographic changes the wellbeing of survivors will become increasingly important in public policy.

Those with cancer and cancer survivors will have been highly affected by the COVID-19 pandemic. This will come from direct health concerns, particularly amongst those with compromised immune systems, and from the indirect effects of reduced hospital care, increased isolation, and additional challenges in obtaining the community support needed. As the NHS prepared for the second phase of its response to the pandemic, following the April 2020 peak of infections, an increased demand for aftercare and support was predicted[26] . Guidance to the NHS asked the service to *"make best use of voluntary and care sector organisations to support people, including through social prescribing".*[27]

Lockdown restrictions have meant that many people receiving clinical and emotional support from charity staff were physically cut off from these services. Furthermore, many of their clinical staff were redeployed onto the NHS coronavirus front line as part of the national effort to ensure that the NHS was not overwhelmed as the

caseload peaked. Charities had to adapt quickly to continue to understand and support the wellbeing of their service users within these extraordinary circumstances. Parkinson's UK, for example, turned to data analytics to guide ongoing service provision. Working with the University of Lancaster they surveyed more than 2000 people affected by Parkinson's in April and May 2020. This highlighted severe needs as people living with Parkinson's were excluded from the government's 'extremely vulnerable' population group. As a result, carers found themselves having to take on more responsibilities, for example because exclusion meant no priority for shopping deliveries; for people living with Parkinson's exclusion meant that they were not treated as shielding, affecting expectations of their capacity to work and confusion around their level of coronavirus risk. Reduced exercise opportunities and increased anxiety was leading to exacerbated symptoms of Parkinson's. Unsurprisingly the study revealed lower than normal wellbeing amongst the family, friends and carers of those with Parkinson's, particularly when those people were themselves unwell during the pandemic[28]. In response Parkinson's UK sought to raise additional funds in order to be able to reach these people in new ways, pivoting its Parkinson's Connect project to achieve this, increasing nurse capacity on the helpline and bringing in expert pharmacist support.

Gardens and Wellbeing

Enjoyment of green space and connections with nature became vitally important to a nation in lockdown, allowed outdoors for non-essential purposes only for a dose of daily exercise . The National Garden Scheme has, of course, done much over the years to enhance public access to private gardens, and garden spaces feature regularly in initiatives amongst beneficiary charities. This is not a random link. The association between green space, nature connectedness[29] and human wellbeing has long been known, linked to the Biophilia Hypothesis from the 1980s[30]. A study in 1984 suggested direct benefits on physical health even from remote access to green spaces; that patients after surgery appeared to make a faster recovery from their treatment if they could view a natural scene from their ward window rather than see only other buildings[31]. An NGS survey in the pandemic summer of 2020 found that 95% of those with access only to a public outdoor space said that a key benefit of this access was that it 'helped relieve stress', and 92% of those with their own outdoor space described it as 'extremely important' to their health and wellbeing during the pandemic[32].

Interest in the use of green space as a tool for good health has increased over recent decades. The *Marmot Review*[33] of 2010 provided an evidence base regarding the impact of green and open space on health inequalities. The review noted that:

> *"Living close to areas of green space … can improve health, regardless of social class. Numerous studies point to the direct benefits of green space to both physical and mental health and wellbeing. Green spaces have been associated with a decrease in health complaints, blood pressure and cholesterol, improved mental health and reduced stress levels, perceived better general health, and the ability to face problems. The presence of green space also has indirect benefits: it encourages social contact and integration, provides space for physical activity and play, improves air quality and reduces urban heat island effects".*

The findings of the *Marmot Review* were developed to assist practical policymaking[34] and incorporated into government policy[35].

The pandemic of 2020, and the associated lockdown on public activity served to highlight the value of local green space and the paucity of access to sufficient green space in many communities.

The 2019 evidence review *Space to Thrive*[36] highlighted six areas of social benefit from access to green space:
1. Physical health, mental wellbeing and life satisfaction
2. Opportunities for social integration
3. Opportunities for community engagement in green space improvements

[2]Those deemed "clinically extremely vulnerable" were instructed to stay indoors from 16th March to 1st August 2020

4. Highlighting inequalities
5. Connecting with nature
6. Economic returns, in jobs and encouraging investment

In October 2020 the government in England launched a £4.27m scheme to test projects to scale-up green social prescribing[37], given the evidence that equal access to green space could save the NHS £2.1bn in treatment costs.

> *"I only have a path at the front and side of my house. Just watching the bees in the pots of lavender was lovely"*
>
> *NGS 'Gardens & Coronavirus 2020'*

As we said earlier, in addition to the main NGS beneficiary charities, to which it has given sustained financial support over years and decades, the Scheme now gives additional annual donations with a focus on "gardens and health". This has included a long-term commitment to fund the Horatio's Garden charity, which designs, creates and cares for accessible gardens in the NHS regional spinal centres[38] and which to-date has received £330,000 from the NGS.

In just a few years Horatio's Garden has played a pioneering role in demonstrating and, crucially, monitoring the life-changing benefits that access to a garden and gardening activity offer to people who have suffered the personal crisis and immobility caused by a spinal injury. Previously confined to a ward for many months, often years, patients are able to get out into the fresh air for time alone or with their families, to take part in productive activities and to enjoy the simple but crucial benefits of fresh air, sunshine and a natural environment. The impact on their mental, emotional and physical state of health is often dramatic.


Artists in residence at Horatio's Garden Salisbury providing outdoor therapy for spinal injury patients

The restrictions and anxiety that people faced through the pandemic and particular during enforced lockdown highlighted the benefits of access to a garden or green space for everyone. At the end of the summer the National Garden Scheme conducted a survey and gathered up the responses into a report, 'Gardens and Coronavirus 2020'. The report contains a multitude of comments from people setting out what their garden did for them and the graph below sets out the details for just one of the questions.

Q6 What benefits did you gain from access to your garden / outdoor space during lockdown (tick as many as apply)
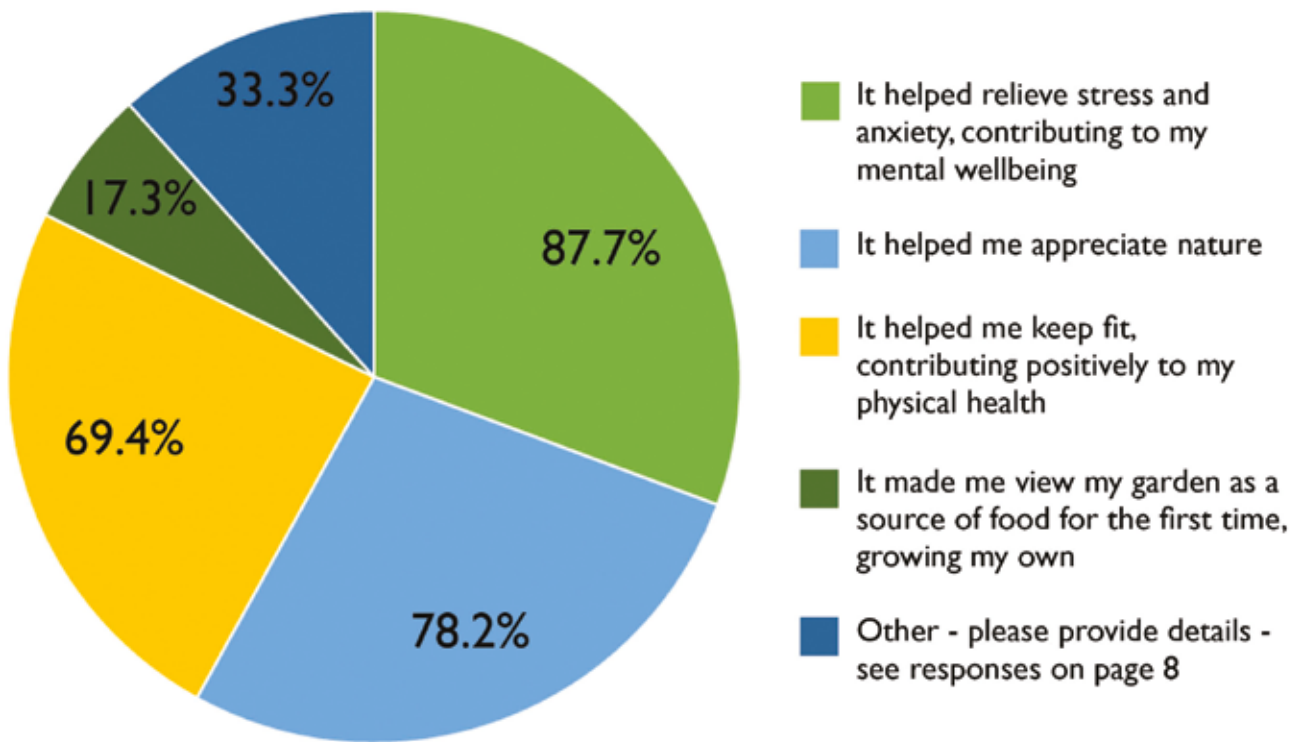
"Gardens and Coronavirus 2020" - National Garden Scheme report

3.2 Workforce

For all the advances in medical science and communications technology, the provision of care remains hugely dependent upon the people who manage and provide it. The health and social care workforce account for almost 12% of total employment in the UK[41]. Staff costs account for about two-thirds of NHS providers' total spending[42], and growing demand for social care has seen the number of jobs in adult social care in England rise to more than 1.6 million[43]. However, despite rising demands for care the policy response to the economic crash of 2008 produced exceptional restraints on workforce numbers and incomes, which affected recruitment and retention. This has inevitably affected standards of care. In early 2020 NHS England had calculated a shortage of more than 100,000 full-time equivalent (FTE) staff, and the gap was put at 122,000 FTEs in adult social care; equating to a vacancy rate of 8% across both sectors of care[44].

Staff shortages and pay restraints appear to have negatively affected morale, as would be expected. Care workers have described themselves as "dissatisfied, stressed, and undervalued"[45].

Agile professionals

The coronavirus pandemic changed this situation, probably temporarily; an NHS porter told ITV News he'd "never been so pleased to work for the NHS"[46]. A Thursday evening 'clap for carers' was quickly adopted in the UK and became a social norm, albeit with a heavy focus on the NHS alone. Whilst hospitals were prepared for the overwhelming demand on services already seen in Italy, the care sector seemed to be much less central in pandemic planning. The care workforce faced the trauma of unprecedented death rates amongst those they cared for, particularly amongst care home residents with dementia and Alzheimer's disease, and at much higher rates than in the general population[47]. Care workers themselves faced particularly high death rates from the coronavirus[48].

Amidst these extraordinary practical and emotional pressures new ways were found to provide valuable support many of which were devised by charities. Hospice UK stepped up work to support the frontline workforce providing end-of-life care, ensuring that some form of help was available to those who needed it at any time. The whole workforce was taking on new and untested ways of working, additional hours and responsibilities, working to meet the exceptional needs of patients and families, and within a situation of a COVID-19 infection risk to themselves and high rates of bereavements. The charity quickly combined its efforts with others, including the Samaritans and Mind, to provide a single support service Our Frontline[3] to millions of key workers. The service would provide round-the-clock support, by call or text, from trained volunteers, as well as offering online resources and tips.

> *"I was on the telephone for hours. She listened. She understood my pain and healed my wounds with her compassion, her love and her positive echoes that I was a good person. I was a good nurse."*
>
> *QNI Talk to Us, 2020*

The Queen's Nursing Institute set up a Talk to Us listening service, with its launch funded by £11,520 raised by the charity's Chief Executive walking a 26-mile lockdown marathon around her garden on 25th April 2020. It is clear from feedback received by the QNI on the listening service that this initiative showed great foresight and proved to be of great value to community nurses working within the exceptional professional and emotional challenges of a viral pandemic. The QNI's renewed focus on supporting nurse wellbeing and its willingness to try new methods led to the production of a video with the cast of the popular TV series *Call the Midwife*[*], targeted as a morale boost for Queen's Nurses and all nurses working in the community.

Macmillan Cancer Support warned that lessons should be learnt from the pandemic's first wave in spring 2020, ahead of the winter. In a report on cancer; *The Forgotten 'C'? The impact of COVID-19 on cancer care,* detailing huge gaps in cancer care they argued that:

"Many staff may have experienced significant physical and emotional challenges working through the peak of the COVID-19 outbreak and it is imperative that there is enhanced support in place to support staff at risk of burnout"[49]

Across the board it is the nursing workforce that is a principal enabler of many of the charitable objectives, often overlapping with service provision in NHS hospitals, hospices, acute community services and primary care. The NGS beneficiary charities are supporters, enablers and employers themselves of a substantial nursing workforce. This clearly deserves much stronger recognition and engagement as an important part of the UK health system. This workforce delivers complex care, often directly to patients and their families.

The nursing workforce is ageing, and retention of suitably skilled registered nurses is a challenge to the provision of high-quality health and social care. District nursing alone has lost almost 50% of its workforce in the last eight years[50] and the work that organisations such as the QNI are doing helps to mitigate this problem. During the pandemic they demonstrated an extraordinary commitment to sustaining workforce wellbeing and motivation alongside service continuity.

Marie Curie Rapid Response Service

"We go to patients homes as and when they need us. If the patient becomes unsettled or they're in pain and the District Nurses are unable to attend, then we would attend. Our response time is within the hour. It is very fulfilling because we can make such a difference."

Dawn, Rapid Response Nurse, Durham

Marie Curie's nursing service and rapid response teams supplement the heavily strained NHS community services in providing clinical and emotional support at home for people at the end of their lives - and for their families - at night and over weekends.

Charities providing support, professional networking and educational opportunities can also help retain an experienced workforce. In the NHS in England there are estimated to be over 40,000 nursing vacancies and this is projected to worsen[51]. This being despite the fact that patients have made it clear that they feel they are best served by nurse-led care. Recently NHS England have prioritised retention of skilled and experienced staff but this has had little impact and the reality is that the crisis in the nursing workforce is primarily a direct result of government policy and poor employment practices. The leadership shown by many of the charities in this sector in terms of supporting this workforce is an exemplar of good practice. For example, Macmillan are major providers of continuing professional development for nurses working in cancer care. They understand that retention of an experienced workforce is essential for good patient outcomes and experience.

This agile workforce also delivers leadership in health and social care using innovative approaches to solve pressing real world problems. They are also essential to delivering on future demand for healthcare. Areas such as end of life care, multimorbidity and frailty are projected to increase in need. Other areas which result from societal issues such as changes to the benefits system and poverty are often mitigated by specialist nurses who can either provide assistance or connect and advocate with other agencies.

3.3 Inequality

Poor health is both a cause and consequence of inequality. Over the past decade life expectancy in the UK appears to have stalled, as it has done in many countries, and inequalities in life expectancy have increased. In fact, life expectancy for women in the most deprived areas of England mostly declined over the decade[52]. There are even larger inequalities in healthy life expectancy (HLE) or 'disability-free life expectancy' than for life expectancy. The gap in healthy life expectancy (HLE) between people living in the most and least deprived areas of England between 2015-2017 was 15.8 years for men and 21.5 years for women and this gap has widened in the last ten years.[53]

Charities play a leading part in tackling inequality and the burdens of disease and disability. This might be through direct help to unpaid carers, for example, whether in meeting immediate needs or in tackling social isolation and other aspects of wellbeing. It can also be through the work of The Queen's Nursing Institute to ensure that vital community services have influential individuals able to lead and speak up for them, and to share best practice.

In 2013 Macmillan published analysis of the financial impact of a cancer diagnosis. It showed that 83% of those affected were, on average, made £570 a month worse off after their cancer was diagnosed. They faced both reduced income and higher living costs[54]. More detailed analysis reveals a lottery in societal costs after cancer treatment, to the NHS, to individual households in their out of pocket expenses and in meeting informal care needs. Whilst some patients face no lasting economic burden, others face very substantial costs.[55]

The coronavirus pandemic highlighted inequalities in the UK. The virus not only hit lower socio-economic groups hardest, but the economic impact of policies to tackle the virus was borne most heavily by low paid workers least able to work from home.[56] In particular it hit those who are homeless or unpaid carers, cut off from their usual face-to-face support systems vital to their wellbeing.

Homelessness

In late February 2020, shortly before the coronavirus lockdown and on the eve of a data release on rough sleeping, the Prime Minister announced additional funding and appointed Louise Casey to undertake a review. He said: *"We must tackle the scourge of rough sleeping urgently, and I will not stop until the thousands of people in this situation are helped off the streets and their lives have been rebuilt"*.[57] The official data showed more than 4,000 people sleeping rough in England. This was in excess of double the number a decade earlier. The latest data on homeless deaths (2018) had shown a 22% year-on-year increase, mostly men and at a mean age of just 45 years.[58] The government's Rough Sleeping Strategy of 2018 established an ambition to halve rough sleeping by 2022 and to end it by 2027[59].

When the pandemic struck the Government implemented an 'Everyone In' scheme, housing almost 15,000 homeless people, including most rough sleepers, in emergency accommodation, including hotels, universities, and caravan parks. In June, Louise Casey reflected that, in addition to providing a safe haven during the pandemic:

"It has also presented an extraordinary opportunity, to prevent people going back to the streets even after COVID has receded. Out of the darkness of this disease has come a small but significant silver lining. The chance to work with rough sleepers on this scale has come sooner than expected".[60]

Analysis of this period suggests that the 'Everyone In' initiative directly saved almost 300 lives amongst rough sleepers, given their high risk from the virus.[61]

> *"I stayed supporting this 150 bedded hotel, City Travelodge, for six weeks. During that time we managed around 25 symptomatic clients ... I had to source everything over the first few days and make them safe."*
>
> *Sam Dorney-Smith*
> *Homeless Health Programme Lead, QNI*

The QNI supports a network of nurses who work in the community including in homeless health services. When the pandemic struck, rough sleepers were taken into hotels under the government's "Everyone In" programme in England. The QNI seized the opportunity to take steps to improve the health and wellbeing of this particularly vulnerable group served by the nurse-led Homeless Health Service Programme[62]. Innovation by the QNI had to address important legal and governance issues in order to deliver service differently within the context of the pandemic. Being a charity allowed the QNI to be highly responsive to the needs of nurses working in inclusion health, offering good practice blogs and supporting mutual learning within the network. The QNI created two online professional support groups for Health Visitors, meeting every fortnight facilitated by the network manager and the Director of Nursing Programmes.

The QNI Homeless Health Programme also provided a basis for vital outreach to help Health Visitors adapt to meeting the needs of homeless families with young children during the pandemic. By creating a network for them Health Visitors could discuss and share challenges and innovations; for example, supporting families in temporary accommodation to adhere to infection control in shared kitchens and bathrooms, book GP appointments without access to a smartphone, and enable home-schooling in the absence of broadband internet.[63]

Carers

There are estimated to be 5.5 million unpaid carers in the UK. The 2019 *NHS Long-Term Plan* noted that the demands of caring make them twice as likely to suffer from poor health as the general population. It says that this is due to: 'a lack of information and support, finance concerns, stress and social isolation'. Up to 40% of young carers report mental health problems[64].

Evidence gathered during the pandemic raised serious concerns for the health of carers, at a time when they found themselves with greater caring responsibilities and more people found themselves with unpaid caring roles. Survey data revealed that almost 9 in 10 carers had their NHS treatments cancelled or postponed in April 2020 compared to 77% of the general public, and more than half had been unable to get through to the NHS 111 helpline. Almost half requiring psychotherapist services were unable to receive these[65].

During the pandemic the Carers Trust and its network of local partners worked quickly to ensure that these causes of ill-health could continue to be addressed despite the exceptional constraints of a national lockdown. Within weeks unpaid carers were supported to gain the skills to use digital tools to maintain their vital human connections.

One of Carers Trust's network partners, the Scarborough and Ryedale Carers Resource charity, shifted from a system of fortnightly meetings of otherwise dispersed rural unpaid carers to online engagement. This was despite many of those involved having never been online before and lacking an internet connection. Hours on the phone to each carer, the provision of equipment including tablets and internet dongles, meant that the online network was up and active within weeks. For the VE Day celebration in early May 2020 the charity ensured that the carers received their celebration pack of bowler hats, flags, cupcakes and bunting ahead of the group video call. Before a 'Musical Memories' call they received blow-up microphones and guitars, and

song sheets. The carers can now catch up with each other and other friends as often as they wish. The charity reports that the initiative appears to have had a significant and lasting impact on the carers' wellbeing, because getting connected has opened up a new world for them to enjoy.

"I've never forgotten the laughter and sheer joy on the faces of all those carers when they turned on their screen for that first call and saw all their friends there as well."

Elizabeth McPherson
Scarborough & Ryedale Carers Resource

Chris Montgomery - Unsplash

3.4 Ageing

Increasing life expectancy has been one of the greatest post-war achievements. But it brings with it a range of practical challenges. Whilst medicine has improved survival rates and some health-related behaviours have improved significantly, the burden of ill-health is increasing.

In 2010 the public health strategy for England set out a plan for 'ageing well'. It said:

"As individuals grow older, key moments such as retirement or bereavement can be a catalyst for decline. However, this decline is not an inevitable part of ageing"[66]

In 2013 the Big Lottery Fund decided to provide a £50m 10-year endowment to create a Centre for Ageing Better in 2015 to 'promote the changes needed so that more people will benefit from their longer lives'.[67]

The UK government Industrial Strategy[68] of 2019 identified the ageing society as one of four 'Grand Challenges' that lay ahead; the global trends that will transform the future. It said: *"We have an obligation to help our older citizens lead independent, fulfilled lives, continuing to contribute to society".*[69] The Industrial Strategy set a mission to: *"drive improvements in public health and innovation across the social care sector".*

The changing profile of the population means that increasing numbers of people act as informal carers. The Office for National Statistics (ONS) has estimated that this informal care had a value of £59.5bn in 2016, providing support to around 2 million UK adults[70]. The time and physical demands of informal care provision directly affect the capacity of care-givers to continue to work in later life[71]. The number of sandwich carers, caring for both their older relatives and their children, will grow as the population grows and ages. More than one-in-four sandwich carers experience symptoms of mental ill-health. Its prevalence increases with the amount of care given[72]. Relieving some of these care demands, on individual health and on economic activity, and providing support to carers will be of increasing value over the coming decades.

One of the core challenges facing policymakers is to better integrate care, which is separated both physically and financially. This makes it extremely difficult for the system to provide continuity of care, or care that meets whole needs. The 2019 *NHS Long-Term Plan* promised that the reforms that had been set in train would result in *"the creation – for the first time since the NHS was set up in 1948 – of fully integrated community-based health care".*[73] One of five tests by which the NHS would be judged on its success against the plan was to be a reduction in demand for care through better integration and prevention[74].

Changing the basis of funding for social care was left out of the welfare reforms of 1946, leaving social care as a means-tested responsibility of local authorities. Whilst a more appropriate, sustainable and equitable system of funding is widely recognised as an important policy objective, decades have passed without agreement upon a solution. The closest that England has come to a shared solution was the publication of the report from the Commission on Funding of Care and Support, known as The Dilnot Commission, in the summer of 2010. The approach taken by the Commission was to use additional public funding to 'unlock greater private resources': Capping individual care costs and raising the assets limit on means-tested support was intended to help people better plan for potential social care costs[75]. A decade later the proposals had not been implemented.

On his first day as Prime Minister in 2019 Boris Johnson said:

"I am announcing now – on the steps of Downing Street – that we will fix the crisis in social care once and for all with a clear plan we have prepared, to give every older person the dignity and security they deserve"[76]

A year on, in October 2020, he appeared to narrow the ambition to the development of a system for protection against extreme costs for residential care. He said in his party conference speech: *"We will fix the injustice of care home funding, bringing the magic of averages to the rescue of millions".*[77]

This leaves the largest gap in the welfare system, with an unusually large role for families, informal carers, and in particular, charities. The coronavirus pandemic put an intense spotlight on the challenges faced by care homes and carers, and on the importance of these services. Care homes and care workers were much less protected from the burden of the virus than the hospital sector, which was reflected in the number of Excess Deaths registered[78]. Until 16th April, a month after the first COVID-19 deaths were registered, there was no requirement for NHS hospital patients to be tested for the virus prior to discharge into a care home[79]. This was, perhaps, the most extreme signal yet of the lack of integration in the care system.

> *"It's been really helpful to know what others were doing, to share experiences. One of the more helpful Facebook groups, and professional."*
>
> *QNI Care Home Nurse Network Pandemic Facebook Group*

The Queen's Nursing Institute has been working to support nurses working in care homes, who are often overlooked in comparison to their peers elsewhere in the health and care system. When the pandemic lockdown was put in place the QNI established a closed Facebook group for its Care Home Nurse Network. At the same time the QNI took a leading role in communicating the needs and experience of care homes to policymakers, and ensuring that senior nurses with community responsibilities across the country were kept up-to-date on changing guidance; the normal twice-yearly meetings of the Community Nurse Executive Network were taken online and their frequency increased to monthly.

Keeping people healthy, independent, and supported as they age is of increasing importance. Growing old within an ageing population has important policy implications, as the ratio between the working age population and those in old age, known as the 'old age support ratio' declines. This ratio is forecast to decline rapidly over the coming decade[80]. The situation is, of course, worsened when people have to leave the workforce in order to care for a relative. This is most likely for people aged 50 to 69, amongst whom one in five people have become informal carers[81]. It is also estimated that 1.5 million people aged 16 and over are caring for someone with cancer, usually a parent, spouse or friend. Cancer places exceptional time demands on carers in comparison to other conditions[82]. The declining support ratio, however, means that it is desirable that people stay longer in the workforce, rather than leave it prematurely.

In addition to the relative growth in the population of pension age compared to the working age population, social changes can also be expected to affect care needs and provision, particularly the availability of informal care within families. The 2016 report on ageing by the Government Office of Science (GOS) noted that:

"There have been important declines in the permanence and homogeneity of long-term relationships between couples… These changes have led to new social risks relating to population ageing – for example, how to meet the increasing demand for unpaid care. One likely outcome is that there will be an increase in the level of responsibility and risk borne by individuals."[83]

The number of people age 75 or older receiving informal care is forecast to be 87% higher in 2032 compared to 2007, from 890,000 people to almost 1.7 million[84]. Estimates suggest a shortfall of 160,000 unpaid carers in England by 2032.[85]
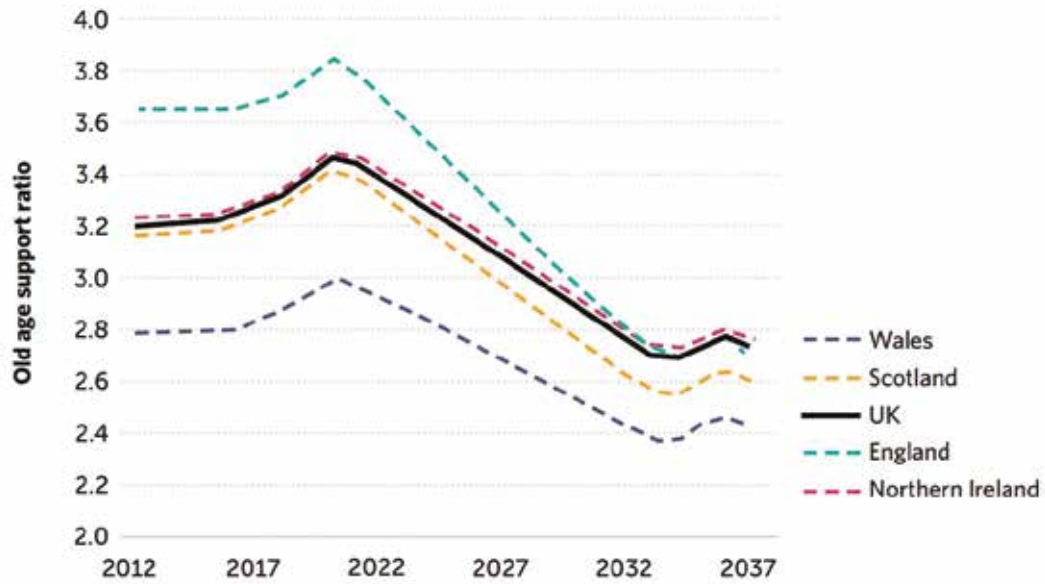
Figure 1.5: Estimates and projections of old age support ratios (number of working age people divided by number of people eligible for the state pension) UK 2012-2037[10]


Andreea Popa - Unsplash

3.5 Dying

The coronavirus pandemic of 2020 propelled UK mortality well beyond the normal expected range. At the April 2020 peak the number of deaths registered in England and Wales exceeded 22,000 in a single week. This was more than double the weekly average for the time of year[86].

Number of deaths registered by week, England and Wales 28 December 2019 to 23 October 2020
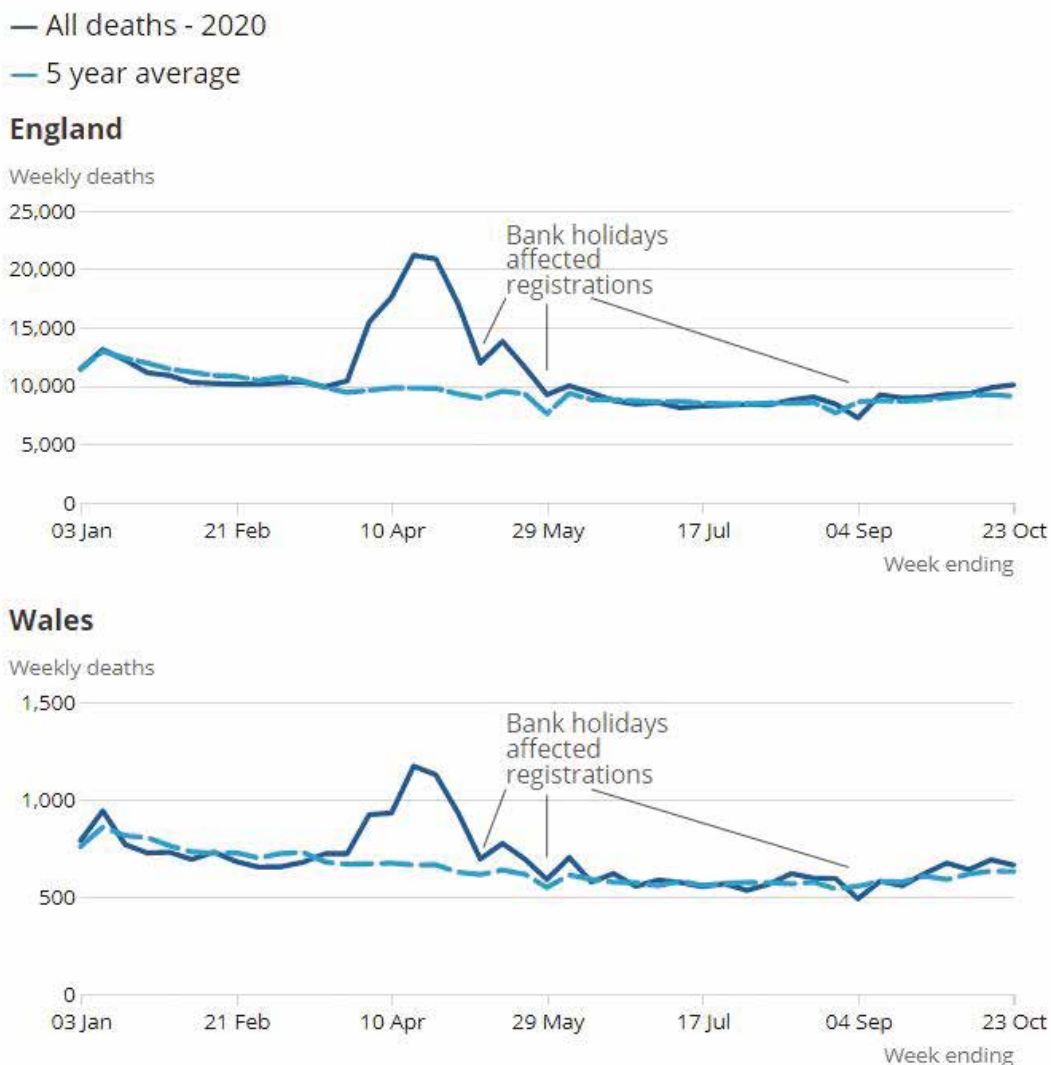
The peak in excess deaths during the pandemic followed a period in which concern was beginning to grow that the progress in life expectancy of the late 20th century appeared to have slowed in the 21st century, with particular spikes in excess winter deaths during the period 2015 to 2018. A study by Public Health England of this change of trend in mortality noted:

"There has been a substantial shift in the age structure of the population in recent decades: the number and proportion of people at older ages has increased. This indicates that there are likely to be more people living with dementia and other long-term conditions that may make them particularly vulnerable to the effects of flu and other winter risk factors, and who may be particularly reliant on health and social care services"[87]

Figure 2: Over time, births and deaths reach similar levels so net international migration causes most growth - Projected births, deaths and net migration, UK years ending 2019 to mid 2043
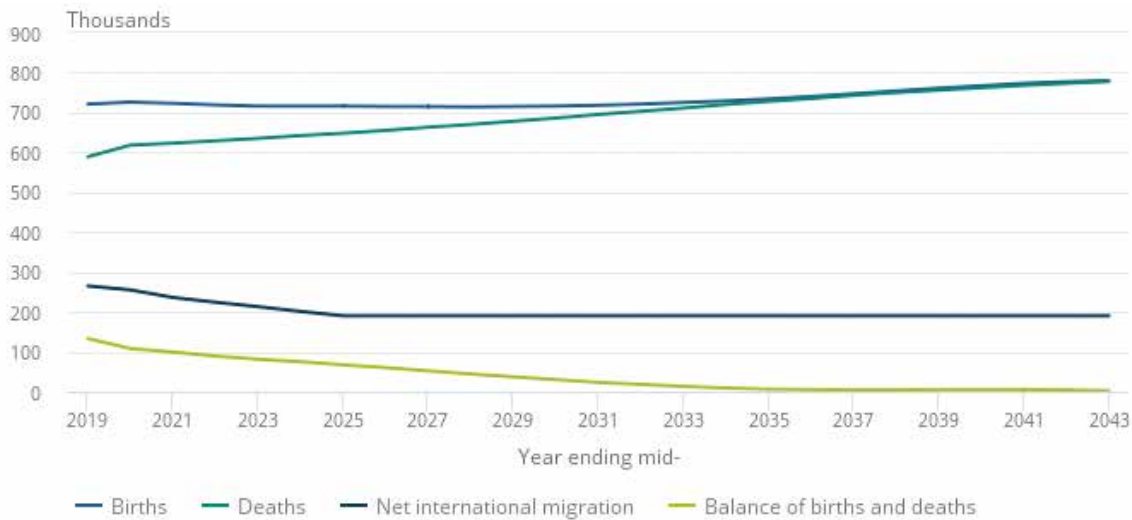
Source: ONS - National population projections

Whilst mortality rates for cancer, circulatory and respiratory disease have declined, those for mental, degenerative and behavioural conditions, including dementia, have 'increased sharply'.[88] Current forecasts are that the number of UK deaths annually will increase by 200,000 over the next 20 years. This implies an average of almost 2,000 additional weekly deaths in 2030[89]. Dealing with the dying and bereaved, and supporting carers was a major challenge during the pandemic, and it will be increasingly important that death is better incorporated into health and social care policies. The scale of end-of-life need is set to increase steadily over the next 20 years, as well as the intensity of these needs in an ageing population with a changing mix of co-morbidities. Furthermore, the economic consequences of the 2020 pandemic will strain the public finances and public services, making partnership between government and policy makers with the charities upon which end-of-life care is already largely dependent, even more important than today.

Partnership is, of course, the established core of palliative and hospice care, the frontline of dealing with human mortality. In the UK the hospice care sector supports more than 225,000 people a year with terminal and life-limiting conditions. A report prepared for Hospice UK and published in March 2019 confirmed that hospice care is almost exclusively provided by charities in all countries in the UK; it involved total spending of £1.5 billion in 2017-18 and employed 40,000 people. The vast majority of the money is raised locally for individual hospices and does not come from government. However, demographic change and the economic climate since the 2008 crash mean that fundraising can struggle to keep pace with rising demand and rising costs, increasing pressure for a reappraisal of both funding system and relations between hospice care and the NHS.

Pam:
"I thought I'd never see my husband again ... but then he skyped me from the hospice."
Marie Curie

During the course of writing this paper we heard from Hospice UK about their lobby to secure additional government funding whilst fundraising was limited. Whilst success with this led to funding for 6,800 palliative care bed days and 82,000 community contacts per day, this amounted to just half of what the charity was delivering[92]. This demonstrates the considerable value provided by the charitable sector within a priority policy area.

In 2008 the NHS developed its first End of Life Strategy[93], in response to the rising number of people dying in hospital, despite a common desire not to do so. A reappraisal of how the NHS in England and Wales provided end of life care was also necessitated by growing controversy around an Integrated Care Pathway (ICP) known as the Liverpool Care Pathway. This dealt policymakers an uncomfortable lesson in the challenges of scaling up local care knowledge to fit a whole health system, whilst retaining sensitivity[94]. The pathway had been described by the NHS End of Life Care Programme as being developed: *"to take the best of hospice care into hospitals and other settings".*[95]

In 2011 NICE produced a Quality Standard for End of Life Care. This was followed in 2014 with a set of NHS England commitments on 'dying well'. Attention was turning to the crucial issue of how people die, having made some progress on addressing concerns over where they die. In 2016 NICE produced a guideline for the end of life care of children with life-limiting conditions, and a service guideline for adult end of life care in October 2019[96].

> *"I felt many anxieties after not working on a ward for 20 years ... I had the privilege of looking after a patient who had been an outpatient ... I looked after him on the ward for weeks. Because I had looked after him for a year prior to this I knew him very well ... I was privileged to sit with him in his final hour and play him the music that I knew he loved. We were able to let his family know that we were with him at the end."*
>
> *Donna, Marie Curie nurse*

During the coronavirus pandemic hospices showed renewed determination to minimise the impact on those receiving end of life care. They would innovate, for example, to help patients use Skype not only to remain in touch with their families when visits were not possible, but also so that partners could still 'be there' for the doctor's round[97]. Day patients at Liverpool Hospice did not lose their valued contact with the occupational therapies team; regular virtual exercise classes were quickly introduced, alongside a weekly quiz session. The team understood the importance not only of their physical service but also of a need to ensure some continuation of peer-to-peer emotional support amidst the lockdown and shielding needs. For inpatients matching handmade hearts were shared between each patient and their close family, maintaining some physical and emotional connection whilst kept apart.

During hospice at home visits carers were encouraged and helped to use video-calling apps, so they could participate in support groups. One hospice took to delivering Hearty Hospice Meals, providing patients and carers with a homemade 2-course meal 3 days a week. We were also told of a hospice taking responsibility for end of life care for anyone discharged from hospital in their local area (as many as 40 extra people a week), and hospices funding palliative care in NHS hospitals.

The first virtual children's hospice was launched, supporting families across Scotland throughout lockdown, directly delivering professional advice by video or phone. Other technology deployed included an interactive app to monitor people's symptoms, helping prioritise caseloads, and supporting the use of video and telephone.

In addition to the practical steps taken to adapt services the pandemic also pushed existing charity-led campaigns to the fore. Since 2017 Hospice UK has led the Dying Matters coalition[4], a membership organisation comprising charities, individuals, the NHS and other partners. It works to help people talk more openly about dying, death and bereavement and to make plans for the end of life. It says that:

"This will involve a fundamental change in society in which dying, death and bereavement will be seen and accepted as a natural part of everybody's life cycle".[98]

In March 2020 Dying Matters responded to the pandemic with the launch of a #BeforeTheirTime online campaign to help people share their experiences and talk through concerns.

The pandemic has started important conversations about death. It has also generated an unexpected shift towards dying at home, usually the stated preference of most people, although it is not yet possible to determine whether this has been by choice or accident. During the national lockdown of March and April the majority of excess deaths (above seasonal norms) occurred in care homes and hospitals. By June this had reversed, so that there will still almost 1000 excess deaths each month at home, and correspondingly negative figures for hospitals and care homes.[99]

Ryan Crotty - Unsplash

"For many years we have been aware that, tragically, many people do not get end-of-life care, and over the coming years this problem will be amplified by the increasing number of people reaching the final chapter of their life.

The higher death rates we have experienced in the UK during COVID have been shocking, but they are but a foretaste of how many people will be dying each month in but a few years' time, notwithstanding COVID through the changing demographics.

The pandemic has therefore also vividly exposed the urgent need for sustainable end-of-life care for all and funding of it, so it is there when we and our loved ones need it."

Matthew Reed, CEO, Marie Curie

4. A Partnership Renewed

At a time of unprecedented financial and emotional stress these charities, their professional workforce, their volunteers and supporters, have shown incredible agility in rising to extraordinary challenges. The coronavirus pandemic of 2020 highlighted major gaps in the UK health and care system, and also the importance of a focus on wellbeing throughout life rather than a piecemeal approach for each 'episode of care'. The NHS and other large public bodies will always struggle to replicate the examples of frontline innovation given in this paper, ensuring that care and wellbeing needs are met in ways that are personal, at a high standard, and professional.

The charities covered in this paper not only rearranged their own services in response to the pandemic but often also helped guide NHS services through the coronavirus challenge. However, the initiative to do so came almost invariably from the charities themselves, with little or no forethought from the NHS, policymakers, or other public service leaders. The QNI leadership on managing homeless health during the lockdown is just one example.

The health and care system faces huge challenges over the next two decades, not only due to an ageing population, but also changing aspirations for wellbeing and equity. The coronavirus pandemic has, if anything, heightened these challenges and added significant additional economic considerations for taxation and spending. It has also shone a fierce light on those areas of the nation's health and care that are heavily dependent on the charities, such as end of life, which would struggle - if not collapse - if they were not there. Charities such as those supported by the National Garden Scheme are clearly willing and able to play a major part in meeting these challenges, given a supportive policy environment.

The very real and stark challenges that the charities are now faced with, which are unlikely to recede in the foreseeable future were clearly set out by Lynda Thomas, Chief Executive of Macmillan Cancer Support. She explained in October 2020, when the charity was chosen as the charity partner for the 2021 London Marathon, that the charity is simply not able to do everything it wants. She said:

"Right now, Macmillan can only be there for one in four people when they're diagnosed with cancer, but we want to be there for everyone. The coronavirus pandemic has impacted our ability to fundraise at a time when people are waiting longer to get a cancer diagnosis and start treatment and desperately need support to help them navigate through this anxious period".[100]

This paper offers an insight into the value being provided by health charities, through normal and abnormal times, and against some of the most pressing policy priorities. The UK has important aspirations to make progress in each of the priority areas covered. This is, however, within the context of rising need and severely strained public finances. Ambitious visions to improve wellbeing, recruit and retain a well-motivated workforce, tackle inequalities laid bare by the pandemic, and improve the experience of ageing, and of dying can only realistically be realised in partnership with appropriate charity engagement. Charities are leading the way on service innovation and value, yet they seem to be ignored in the policy discourse.

Whilst writing this paper the English government, in response to the care home crisis revealed by coronavirus, decided to recruit its first Chief Nurse for Social Care, within a new Adult Social Care Group. The advertisement[101] emphasised partnership working with statutory bodies, the public, and the independent sector, but with no mention of the crucial role of charities within social care nursing.

In contrast the charities themselves are keen to work as partners to deliver on priorities, whenever they have the resources to do so. Dr Crystal Oldman Chief Executive of The Queen's Nursing Institute told us:

"I am immensely proud of the ways in which Queen's Nurses responded to the pandemic, undertaking not only hugely pressured work to support their communities, but also to support the QNI in advising the government on the production of national guidance regarding infection prevention and control, PPE, and the care of people in the community".

Tracey Bleakley, Chief Executive of Hospice UK said:

"From securing £200m funding for hospices, setting up an England-wide PPE distribution network from scratch, organising weekly clinical ECHOs to update over 200 clinical teams, and trauma and bereavement support to NHS, social care and frontline teams, the team has done so much to support palliative and end of life care during the pandemic."

Katherine Crawford, Director of Services at Parkinson's UK commented:

"Parkinson's UK services are directly in touch with around 35,000 of the UK's vulnerable families every year. Around 100,000 people use its website resources. The charity's ambition is that every single person with Parkinson's is directly referred to the charity at the point of diagnosis, establishing it at the heart of a person's professional support network from the get go. The charity's response to the pandemic demonstrates it has the depth and expertise to fulfil that role."

Amidst the major policy challenges highlighted by the pandemic, the threat to charity-funded services has not produced the crises experienced elsewhere in health and social care. Charities supported by the National Garden Scheme have found innovative ways to maintain some fundraising activities and equally innovative ways to maintain vital services. They have neither neglected those nor passed them on to the NHS. In addition to the value delivered to those professionals and service users during the pandemic, their speed of response and its scale, will have played a significant role in limiting the backlog of need that will be faced by the NHS and social care system.

However, the extraordinary motivation and determination within these charities to support care professionals and service users may induce a false confidence in policymakers. There is no guarantee that these charities can sustain themselves if faced with an extended restriction on their main fundraising activities. Similarly, there is no guarantee, indeed it seems highly unlikely, that the charities will be able to fill the growing gap between public services and public needs in these priority areas. They can lead the way in innovation and partnership working, and can offer a unique quality of care, and they can play a part in a partnership to meet current and future needs. To do so they will need to be fully integrated into policy development as well as policy delivery.

This paper makes clear the decisive role played by charities during the pandemic and the particular qualities of their work and ethos; providing vital services in the face of extreme needs and constraints; leading adaptation and innovation to ensure that care can continue and that it can be delivered safely. Whilst many publicly-provided services stopped, the charities sought to find ways to continue and it is clear that they can - and should - do this in the future.

In conclusion, the significant contribution made by health and care charities must be better acknowledged by our public services and policymakers and better integrated into planning for future challenges. In health and social care the UK faces the prospect of a more aged and vulnerable population, with much higher death rates than is currently the norm outside a pandemic. At the same time expectations are rising that services will be better personalised and delivered with empathy for each of us. Charities will be essential partners in delivering against these needs. The pandemic of 2020 has been a wake up call on the need for stronger partnership that cannot be ignored. Charities need to be back at the heart of future planning, no longer left out on a limb until the next crisis hits.

References

[1] Gilburt H, Ewbank L "Investing in quality: The contribution of large charities to shaping future health and care" The King's Fund, London, May 2019 https://www.kingsfund.org.uk/publications/charities-shaping-health-care Accessed online 7 July 2020

[2] NHS England "NHS Long Term Plan" January 2019 https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/ Accessed online 7th July 2020

[3] Select Committee on Public Walks (1833) See: House of Commons, Hansard, HC Deb, 21 February 1833, Vol 15, Cols 1049-59

[4] Taylor, H. (1995). Urban Public Parks, 1840-1900: Design and Meaning. Garden History, 23(2), 201-221. https://www.jstor.org/stable/1587078 Downloaded 4th November 2020

[5] NGS "Gardens and Coronavirus 2020" National Garden Scheme, 1st September 2020 https://ngs.org.uk/new-report-gardens-and-coronavirus-2020/ Downloaded 4th November 2020

[6] Spain, M "People and nature survey: How are we connecting with nature during the coronavirus pandemic?" Natural England blog, 12th June 2020 https://naturalengland.blog.gov.uk/2020/06/12/people-and-nature-survey-how-are-we-connecting-with-nature-during-the-coronavirus-pandemic/ Accessed online 4th November 2020

[7] Čakovska, B "Garden tourism: reasons for opening private gardens in the UK National Garden Scheme" Current Issues in Tourism, 21:12, pp1344-1348 https://doi.org/10.1080/13683500.2016.1276521 Accessed online 6 July 2020

[8] NGS "Impact Report 2019" National Garden Scheme (2020), p2

[9] Butler P "A million volunteer to help NHS and others during Covid-19 outbreak" The Guardian, 13th April 2020 https://www.theguardian.com/society/2020/apr/13/a-million-volunteer-to-help-nhs-and-others-during-covid-19-lockdown Accessed online 4th August 2020

[10] Butler P "NHS coronavirus crisis volunteers frustrated at lack of tasks" The Guardian. 3rd May 2020 https://www.theguardian.com/world/2020/may/03/nhs-coronavirus-crisis-volunteers-frustrated-at-lack-of-tasks Accessed online 4th August 2020

[11] Churchill N "Micro-volunteering at scale can help health systems respond to emergencies, such as the Covid-19 pandemic" 2020, Patient Experience Journal, Vol 7 Issue 2, p161 https://pxjournal.org/cgi/viewcontent.cgi?article=1498&context=journal Downloaded 7th August 2020

[12] NHS "The NHS Long Term Plan" January 2019 https://www.longtermplan.nhs.uk/online-version/chapter-4-nhs-staff-will-get-the-backing-they-need/8-volunteers/ Accessed online 7th August 2020

[13] Churchill N "Micro-volunteering at scale can help health systems respond to emergencies, such as the Covid-19 pandemic" 2020, Patient Experience Journal, Vol 7 Issue 2 https://pxjournal.org/cgi/viewcontent.cgi?article=1498&context=journal Downloaded 7th August 2020

[14] QNI Heritage website https://qniheritage.org.uk/history/the-queens-nursing-institute/ Accessed online 5th October 2020

[15] Macmillan Cancer Support "Written evidence" EIC0755 https://committees.parliament.uk/writtenevidence/7619/pdf/ June 2020, Downloaded 5th October 2020

[16] Richards M et al "The impact of the COVID-19 pandemic on cancer care" https://www.nature.com/articles/s43018-020-0074-y Nature Cancer, 1: 564-567 (2020). Accessed online 16th July 2020

[17] CRUK "Cancer Research UK's response to the Health and Social Care Select Committee Inquiry on 'Delivering Core NHS and care services during the pandemic and beyond" April 2020 https://www.cancerresearchuk.org/sites/default/files/april2020_cruk_hsc_submission_covid_cancer_final_public.pdf Accessed online 16th July 2020

[18] Johnson B, Twitter post https://twitter.com/BorisJohnson/status/1309437920907005952?s=20 25th September 2020, Accessed online 5th October 2020

[19] Thomas L "A truly difficult decision …" Blog post, 22nd September 2020 https://medium.com/@lyndathomasmac/a-truly-difficult-decision-6d8b05196943 Accessed online 5th October 2020

[20] Cameron D "PM speech on wellbeing: 25th November 2010" https://www.gov.uk/government/speeches/pm-speech-on-wellbeing Accessed online 4th August 2020

[21] HMG, "Care Act 2014" Legislation, https://www.legislation.gov.uk/ukpga/2014/23/section/1/enacted Downloaded 6th October 2020

[22] What Works Wellbeing "Commission on wellbeing and policy report" March 2014 https://whatworkswellbeing.org/resources/commission-on-wellbeing-and-policy-report/ Downloaded 7th October 2020

[23] Lawton RN, Gramatki J, Watt W "Happy Days: Does volunteering make us happier or is it that happy people volunteer?" Jump Projects, 2019 https://jump-projects.com/our-work/ Downloaded 4th August 2020

[24] ONS " Understanding well-being inequalities: Who has the poorest personal well-being?" Office for National Statistics, 11 July 2018 https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/understandingwellbeinginequalitieswhohasthepoorestpersonalwellbeing/2018-07-11#:~:text=Three%20groups%20of%20people%20at,reported%20health%20problems%20or%20disability Accessed online 4th August 2020

[25] Elliott, J., Fallows, A., Staetsky, L. et al. The health and well-being of cancer survivors in the UK: findings from a population-based survey. Br J Cancer 105, S11–S20 (2011). https://doi.org/10.1038/bjc.2011.418 Accessed online 4th August 2020

[26] Stevens S, Pritchard A "NHS Dear colleagues letter" 29th April 2020 https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/second-phase-of-nhs-response-to-covid-19-letter-to-chief-execs-29-april-2020.pdf Accessed online 4th August 2020

[27] NHS "Aftercare needs of inpatients recovering from COVID-19" Version 2, 3rd August 2020 https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/06/C0705-aftercare-needs-of-inpatients-recovering-from-covid-19-aug-2020.pdf Accessed online 4th August 2020

[28] Simpson J, Eccles F, Doyle C "The impact of coronavirus restrictions on people affected by Parkinson's" Lancaster University 7 Parkinson's UK (undated) https://www.parkinsons.org.uk/sites/default/files/2020-07/Parkinson%27s%20UK%20Covid-19%20full%20report%20final.pdf Downloaded 12th October 2020

[29] Martin L et al "Nature contact, nature connectedness and associations with health, wellbeing and pro-environmental behaviours", April 2020, Journal of Environmental Psychology, Vol 68, https://doi.org/10.1016/j.jenvp.2020.101389 Downloaded 13th October 2020

[30] Kellert SR & Wilson EO (eds) "The Biophilia Hypothesis" (1993) Island Press

[31] Ulrich RS "View through a window may influence recovery from surgery" Science, 27 April 1984, 224:4647 pp420-421

[32] NGS "Gardens and coronavirus 2020" (2020) National Garden Scheme https://ngs.org.uk/wp-content/uploads/2020/08/Survey-Results-September-2020.pdf Downloaded 14th October 2020

[33] Marmot M "Fair Society, Healthy Lives: The Marmot Review" 2010 http://www.instituteofhealthequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review/fair-society-healthy-lives-full-report-pdf.pdf Downloaded 2nd August 2020

[34] Geddes I et al "The Marmot Review: Implications for Spatial Planning" Institute of Health Equity http://www.instituteofhealthequity.org/resources-reports/spatial-planning-and-health-nice/spatial-planning-and-health-report-nice.pdf Downloaded 2nd August 2020

[35] HMG "Healthy Lives, Healthy People: Our strategy for public health in England" CM7985 30 November 2010 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216096/dh_127424.pdf Downloaded 2nd August 2020

[36] Dobson, J et al "Space to Thrive: A rapid review of the benefits of parks and green space for people and communities" Heritage Fund, 2019 https://www.heritagefund.org.uk/sites/default/files/media/attachments/Space%20to%20thrive_2019-A%20rapid%20evidence%20review%2014102019-accessible.pdf Downloaded 2nd August 2020

[37] Gov.uk "Green social prescribing pilots open for applications" Press Release, 5th October 2020, https://www.gov.uk/government/news/green-social-prescribing-pilots-open-for-applications Accessed online 14th October 2020

[38] NGS "Impact Report 2019" National Garden Scheme, p18

[41] OECD "Health at a Glance 2019" http://www.oecd.org/health/health-systems/health-at-a-glance-19991312.htm Accessed online 7th September 2020

[42] NHSI "Submission to the NHS Pay Review Body and the Review Body on Doctors' and Dentists' Remuneration" NHS Improvement, September 2016, p5 http://www.oecd.org/health/health-systems/health-at-a-glance-19991312.htm Downloaded 7th September 2020

[43] SkillsforCare "The size and structure of the adult social care sector workforce in Englandm 2019" https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/documents/Size-of-the-adult-social-care-sector/Size-and-Structure-2019.pdf Accessed online 7th September 2020

[44] House of Commons Library "The health and social care workforce gap" 10 January 2020 https://commonslibrary.parliament.uk/social-policy/health/the-health-and-social-care-workforce-gap/ Downloaded 7th September 2020

[45] CQC :The state of health care and adult social care in England 2018/19" Care Quality Commission, p40 https://www.cqc.org.uk/sites/default/files/20191015b_stateofcare1819_fullreport.pdf Downloaded 7th September 2020

[46] Watson L "I've never been so proud to work for the NHS: Hospital staff on the coronavirus crisis" news report, 23rd April 2020 https://www.itv.com/news/2020-04-23/i-ve-never-been-so-proud-to-work-for-the-nhs-hospital-staff-on-the-coronavirus-crisis Accessed online 7th September 2020

[47] ONS "Deaths involving COVID-19 in the care sector, England and Wales: deaths occurring up to 12 June 2020 and registered up to 20 June 2020 (provisional) Updated 3rd July 2020 https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvingcovid19inthecaresectorenglandandwales/deathsoccurringupto12june2020andregisteredupto20june2020provisional Accessed online 7th September 2020care

[48] ONS "Coronavirus (COVID-19) related deaths by occupation, England and Wales: deaths registered between 9 March and 25 May 2020" 26 June 2020 https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/bulletins/coronaviruscovid19relateddeathsbyoccupationenglandandwales/deathsregisteredbetween9marchand25may2020#deaths-involving-covid-19-among-men-and-women-health-and-social-care-workers Accessed online 7th September 2020

[49] Macmillan Cancer Support "The forgotten C? The impact of Covid-19 on cancer care" Macmillan, October 2020, p20 https://www.macmillan.org.uk/assets/forgotten-c-impact-of-covid-19-on-cancer-care.pdf Downloaded 2nd November 2020

[50] QNI "District Nursing Today" Queen's Nursing Institute (2019) https://www.qni.org.uk/wp-content/uploads/2019/11/District-Nursing-Today-The-View-of-DN-Team-Leaders-in-the-UK.pdf Downloaded 24th September 2020

[51] ibid

[52] Marmot M et al "Health equity in England: The Marmot Review 10 years on" Institute of Health Equity (2020), p18 http://www.instituteofhealthequity.org/resources-reports/marmot-review-10-years-on/the-marmot-review-10-years-on-full-report.pdf Downloaded 5th August 2020

[53] ONS Health state life expectancies, UK: 2015 to 2017 The number of years people are expected to spend in different health states among local authority areas in the UK. Accessed 9th November 2020 https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/healthstatelifeexpectanciesuk/2015to2017

[54] Macmillan "Cancer's hidden price tag" (2013) https://www.macmillan.org.uk/_images/Cancers-Hidden-Price-Tag-report-England_tcm9-270862.pdf Accessed online 5th August 2020

[55] Marti J., et al "The economic burden of cancer in the UK: a study of survivors treated with curative intent". Psycho-Oncology, (2016) 25: 77– 83. doi: 10.1002/pon.3877. Downloaded 5th August 2020

[56] Xu, X & Blundell R "Covid-19: The impacts of the pandemic on inequality" Institute for Fiscal Studies, presentation, June 2019 https://www.ifs.org.uk/inequality/wp-content/uploads/2020/06/Covid-and-inequality.pdf Downloaded 8th October 2020

[57] HMG "Prime Minister sets out new measures to end rough sleeping" Press Release, 27th February 2020 https://www.gov.uk/government/news/prime-minister-sets-out-new-measures-to-end-rough-sleeping Accessed online 8th October 2020

[58] ONS "Deaths of homeless people in England and Wales: 2018" Office for National Statistics, 1st October 2019 https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsofhomelesspeopleinenglandandwales/2018 Accessed online 8th October 2020

[59] MHCLG "The Rough Sleeping Strategy" Ministry of Housing, Communities, and Local Government, 13th August 2018 https://www.gov.uk/government/publications/the-rough-sleeping-strategy Downloaded 8th October 2020

[60] Casey, L "We can stop the most vulnerable becoming rough sleepers" Local Government Chronicle, 24th June 2020 https://www.lgcplus.com/services/housing/louise-casey-together-we-can-stop-most-vulnerable-becoming-rough-sleepers-24-06-2020/ Accessed online 8th October 2020

[61] Lewer D et al "Covid-19 among people experiencing homelessness in England: a modelling study" The Lancet, 23rd September 2020 https://www.thelancet.com/journals/lanres/article/PIIS2213-2600(20)30396-9/fulltext#seccestitle170 Accessed online 8th October 2020

[62] QNI "Everyone In – Supporting Homeless Clients on the Frontline during Covid-19" item dated 18th June 2019 https://www.qni.org.uk/2020/06/18/everyone-in-supporting-homeless-clients-on-the-frontline-during-covid-19/ Accessed online 24th September 2020

[63] Private communication, Crystal Oldman, Chief Executive, Queen's Nursing Institute, 2nd October 2020

[64] NHS England "The NHS Long Term Plan" January 2019, p42 https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf Downloaded 14th October 2020

[65] Carers UK "Covid-19 leaves unpaid carers without physical and mental health treatment" Press Release, 4th August 2020. Accessed online 14th October 2020

[66] HMG "Healthy Lives, Healthy People: Our strategy for public health in England" CM7985 30 November 2010 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216096/d ph_127424.pdf Downloaded 2nd August 2020 p47

[67] CfAB "Trustees Report and financial statements for the year ended 31 March 2017: Chairman's preface" Centre for Ageing Better Ltd, 2017,p4 http://apps.charitycommission.gov.uk/Accounts/Ends41/0001160741_AC_20170331_E_C.PDF Downloaded 2nd August 2020

[68] BEIS "The Grand Challenges" Policy paper, Department of Business, Energy & Industrial Strategy,13th September 2019 https://www.gov.uk/government/publications/industrial-strategy-the-grand-challenges/industrial-strategy-the-grand-challenges Downloaded 4th August 2020

[69] ibid

[70] ONS "Living longer: Caring in later working life" Office for National Statistics, 15th March 2019 https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglongerhowourpopulationischangingandwhyitmatters/2019-03-15#what-does-this-mean-for-the-future Accessed online 4th August 2020

[71] ONS "Living longer: Fitting it all in – working, caring and health in later life" Office for National Statistics, 18th December 2018 https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglongerhowourpopulationischangingandwhyitmatters/fittingitallinworkingcaringandhealthinlaterlife Accessed online 4th August 2020

[72] ONS "More than one in four sandwich carers report symptoms of mental ill-health" Office for National Statistics, 14th January 2019 https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/articles/morethanoneinfoursandwichcarersreportsymptomsofmentalillhealth/2019-01-14 Accessed online 5th August 2020

[73] NHS "The NHS Long-Term Plan", NHS England, January 2019, p14 https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf Accessed online 12th August 2020

[74] Ibid, p018

[75] Dilnot A "Final Report of the Commission on Funding of Care and Support: Letter to the Chancellor and

the Secretary of State for Health" (National Archives) July 2010 https://webarchive.nationalarchives.gov.uk/20130221121534/http://www.dilnotcommission.dh.gov.uk/our-report/ Accessed online 4th August 2020

[76] Johnson B "Boris Johnson's first speech as Prime Minister" 24th July 2019 https://www.gov.uk/government/speeches/boris-johnsons-first-speech-as-prime-minister-24-july-2019 Accessed online 4th August 2020

[77] Conservatives, Prime Minister's speech to Conservative Party Conference, 6th October 2020 https://www.conservatives.com/news/boris-johnson-read-the-prime-ministers-keynote-speech-in-full Accessed online 8th October 2020

[78] ONS "Deaths registered weekly in England and Wales, provisional: Week ending 24 July 2020 https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredweeklyinenglandandwalesprovisional/weekending24july2020#deaths-registered-by-place-of-occurrence Accessed online 7th August 2020

[79] NHS "New requirement to test patients being discharged from hospital to a care home" NHS England, 16th April 2020 https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0324-New-requirement-to-test-patients-being-discharged-from-hospital-to-a-care-home.pdf Downloaded 7th August 2020

[80] GOS "Future of an Ageing Population" Government Office of Science, 2016, p22, Fig 1.4, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/816458/future-of-an-ageing-population.pdf Downloaded 8th October 2020

[81] ONS "Living longer: Caring in later working life" Office for National Statistics, 15th March 2019 https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglongerhowourpopulationischangingandwhyitmatters/2019-03-15 Accessed online 8th October 2020 82 YouGov/Macmillan "Estimating the population of cancer carers in the UK" (Phase One and Two), 2016. Cited in: Macmillan "The Rich Picture: Cancer Carers" 2016. https://www.macmillan.org.uk/_images/carers-of-people-with-cancer_tcm9-282780.pdf Downloaded 8th October 2020

[83] ONS "Living Longer …" op cit, p26

[84] GOS, op cit, p73, Table 5.2

[85] Pickard L "A growing care gap? The supply of unpaid care for older people by their adult children in England in 2032" Ageing & Society, 35(1), pp96-123, 2015 http://eprints.lse.ac.uk/51955/1/Pickard_Growing%20care%20gap_2015.pdf Downloaded 8th October 2020

[86] ONS, "Deaths registered weekly in England and Wales, provisional: week ending 19 June 2020", 30th June 2020 https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredweeklyinenglandandwalesprovisional/latest#main-points Accessed online 6th July 2020

[87] PHE "A review of recent trends in mortality in England" Public Health England, December 2018, p72 Accessed online 16th July 2020 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/827518/Recent_trends_in_mortality_in_England.pdf

[88] ONS "Changing trends in mortality: A cross-UK comparison, 1981 to 2016" Office for National Statistics, 7th August 2018 https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/articles/changingtrendsinmortality/acrossukcomparison1981to2016 Accessed online 5th August 2020

[89] ONS "National Population Projections – 2018 Based" Office for National Statistics, 21st October 2019 https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/nationalpopulationprojections/2018based#births-deaths-and-migration Accessed online 16th July 2020

[90] HospiceUK "Facts and Figures" Webpage https://www.hospiceuk.org/about-hospice-care/media-centre/facts-and-figures Accessed online 5th August 2020

[91] HospiceUK "Eight in ten charitable hospices planning a deficit budget this financial year says Hospice UK" Press Release, 7th October 2019 https://www.hospiceuk.org/about-hospice-care/media-centre/press-releases/details/2019/10/06/eight-in-ten-charitable-hospices-planning-a-deficit-budget-this-financial-year-says-hospice-uk Accessed online 5th August 2020

[92] Private communication, Tracey Bleakley, CEO, Hospice UK. 1st October 2020

[93] DH "End of Life Care Strategy" July 2008 https://webarchive.nationalarchives.gov.uk/20130104214035/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_086345.pdf Downloaded 5th August 2020

[94] Seymour J & Clark D. "The Liverpool Care Pathway for the Dying Patient: a critical analysis of its rise, demise and legacy in England". Wellcome open research, 3, 15. https://doi.org/10.12688/wellcomeopenres.13940.2 Accessed online 5th August 2020

[95] NHS "End of Life Care Programme:Progress Reports Summary" March 2006 https://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/assetRoot/04/13/38/64/04133864.pdf Accessed online 5th August 2020

[96] NICE "End of Life Care: Products" Webpage https://www.nice.org.uk/guidance/health-and-social-care-delivery/end-of-life-care/products?ProductType=Guidance&Status=Published Accessed online 5th August 2020

[97] Marie Curie, "I thought I'd never see my husband again …" website blog 3rd April 2020, https://www.mariecurie.org.uk/blog/we-thought-it-would-be-the-last-time-we-saw-each-other/271337 Accessed online 24th September 2020

[98] Dying Matters "About Us" webpage https://www.dyingmatters.org/overview/about-us Accessed online 25th September 2020

[99] ONS "Deaths registered weekly in England and Wales, provisional: week ending 25th September 2020", 6th October 2020, Office for National Statistics, Fig 5 https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredweeklyinenglandandwalesprovisional/weekending25september2020#deaths-registered-by-place-of-occurrence Accessed online 12th October 2020

[100] London Marathon, "Macmillan Cancer Support named as Charity of the Year for 2021 Virgin Money London Marathon" Press Release, 7th October 2020 https://www.virginmoneylondonmarathon.com/news-media/latest-news/item/macmillan-named-charity-of-the-year-2021/index.html Accessed online 7th October 2020

[101] Civil Service Jobs "Chief Nurse for Social Care (Deputy Chief Nursing Officer/DCNO)"

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