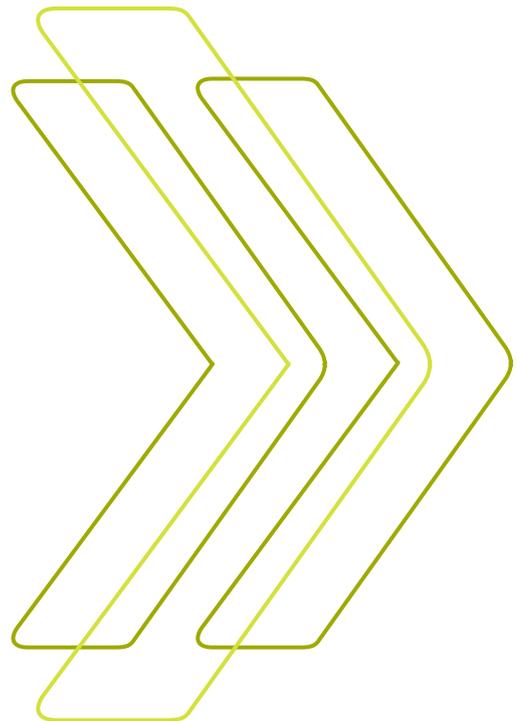# The King's Fund>

Ideas that change health care

Investing in quality

The contribution of large charities to shaping future health and care

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This independent report was commissioned by the National Garden Scheme. The views in the report are those of the authors and all the conclusions are the authors' own.

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1 Introduction

More than 37,000 charities work in the health and social care sectors (NCVO 2018). The government's review of partnerships and investment in voluntary, community and social enterprise organisations in health and care states that:

> *…at their best these organisations do not just deliver to individuals, they draw upon whole communities: for volunteering and social action which addresses service-resistant problems like loneliness and stigma, and for the expertise of lived experience in designing more effective, sustainable services and systems.*
> (Department of Health *et al* 2016)

The UK Civil Society Almanac estimated the income of voluntary sector organisations in health and social care at more than £16 billion in 2015/16 (NCVO 2018). Its analysis also shows that their incomes are increasing, largely due to a growth in income from individuals. This varies between different types of care. For example, if we consider hospice care in England, in 2016 the government funded only 32 per cent of the costs of providing adult hospice care, and 15 per cent of the costs of children's hospices (Hospice UK 2017a). This highlights the vital contribution that voluntary sector organisations make, not only in providing quality care but in sourcing the required funding.

Money raised from individuals comes from multiple sources: from donations from members of the public; money left to charities as part of a legacy; and money raised by the charity through its own activities. It is safe to say that all of us are likely to benefit at some point in our lives from health and care funded by money donated by members of the public to charity.

While most charities raise funds to support their own activities, around 9 per cent of the money raised by charities in health and social care is redistributed through grants to derive impact. In both cases, how that money is spent and its contribution to the quality of health and care is a marker of the partnerships those charities make and the strategic decisions they take.

2 About the National Garden Scheme

The National Garden Scheme was founded in 1927 by The Queen's Nursing Institute to raise money for district nursing by inviting the owners of outstanding gardens to open them to the public. In 1980 the National Garden Scheme became an independent charity, continuing the work with the aim of funding a range of nursing and health charities.

Its main activity – opening up private gardens to visitors – has remained largely unchanged, although the number and variety of participating gardens has increased significantly. In 2017, some 3,000 gardens opened to visitors, raising more than £3.8 million.

The charity focuses its annual donations on support for nursing and caring charities. The main beneficiary charities include:

- Macmillan Cancer Support

- Marie Curie

- Hospice UK

- The Queen's Nursing Institute

- Parkinson's UK

- MS Society.

Because the National Garden Scheme has been donating to these organisations for many years, it is the largest charitable funder of all except Parkinson's UK (which was only added to the group in 2016) and the MS Society (which became a guest charity of the National Garden Scheme between 2016 and 2018).

To date, the National Garden Scheme has donated more than £58 million to its beneficiary charities, making it the most significant cumulative charitable supporter of nursing in the country.

This report

In 2018, the National Garden Scheme commissioned The King's Fund to undertake a piece of work to capture its contribution to six of its main beneficiaries, and how this fits within the context of the future direction of policy development in health and social care. The starting point of the work was the National Garden Scheme's original aim to support community nursing, but this was extended to consider its current and broader remit to support nursing and caring charities. The six beneficiary charities (*see* above) each have a history of working with or supporting nursing.

Our approach involved a review of the literature on community nursing and community services, and the development of policy and practice in each of the areas that the beneficiaries focus on.

We initiated conversations with each of the beneficiary charities to understand what they do, their relationship with the National Garden Scheme, and areas where they are developing their activities supported by investment from the National Garden Scheme. We worked with each charity to identify an area of their work (such as a service or programme, illustrated where appropriate with a geographically focused example) that:

- is supported by funding from the National Garden Scheme

- is contributing to addressing current policy issues and supporting the future direction of health and care.

These examples form case studies in this report. They have been produced through a series of interviews with the individuals involved in developing, delivering and participating in them, supported by a review of associated documentation and, in some cases, site visits.

Each case study seeks to provide an insight into areas of practice and care that are developing but have far wider relevance. They also seek to inspire, with an opportunity to explore further, rather than offering a comprehensive review.

The report concludes with The King's Fund's own analysis of how the work of the National Garden Scheme and its beneficiaries contributes to supporting and shaping current and future health and care.

3 Community health care – policy and practice

This section provides a brief overview of the sectors in which the National Garden Scheme's beneficiary charities operate: community services, end-of-life care, and specialist care for long-term conditions. Although some of the beneficiaries operate across the UK, we mainly focus on the policy agenda in England.

Community services

Community health services occupy a curious position in today's health and care debate: simultaneously central to the national agenda yet somewhat obscured from view. A lack of comprehensive national datasets and access targets contributes to their relatively low profile, as does (arguably) the fact that these services are delivered in clinics, general practices and people's homes rather than in hospitals.

Community health services typically include district nursing, community matrons, physiotherapy, tissue viability services, and children's health services such as health visiting for new parents, and school nursing (for a more extensive list *see* Charles 2019). Specialist nursing for long-term conditions has often been included in conversations about community services, although the practical reality of these services is changing over time.

Few of these services operate in isolation. They exist alongside – and in practice need to collaborate with – acute hospitals and mental health providers, and primary care services such as general practice and pharmacies. Because they deliver care wherever people are (often in their place of residence), they also work alongside nursing and care homes and hospices; they may also interface with voluntary provision being delivered in people's homes.

Users of community health services are drawn from all parts of society, but those most likely to receive such services are newborns, children, people with long-term conditions, people who have recently spent time in hospital, and those nearing the end of their life.

Thanks to a history of policy experimentation, and particularly the Transforming Community Services initiative beginning in the late 2000s, community services are today provided by a range of organisations. Some services are run by dedicated community trusts (of which there are 17) (NHS Improvement 2019); others form part of combined trusts alongside mental health and acute hospital provision. NHS Providers estimates that overall, there are around 100 NHS provider organisations delivering substantial amounts of community services (NHS Providers 2018). Independent sector providers and community interest companies (a form of social enterprise) are also particularly active in this sector. Spending on care delivered by these non-NHS providers increased substantially in the years up to 2017 (Gershlick and Firth 2017).

Responsibility for commissioning community services is divided between clinical commissioning groups (CCGs), local authorities and NHS England. CCGs cover adult services, local authorities commission children's services and some public health functions, and NHS England is responsible for some related areas, including national screening programmes and health care in prisons. Overall, it is estimated that there are around 100 million patient contacts delivered by community services each year at a cost of approximately £10 billion (Monitor 2015).

End-of-life care

The UK is fortunate in its end-of-life provision when compared to other countries: comparative studies have put it above many other advanced health systems for the quality of care in this area (Economist Intelligence Unit 2015). The most recent National Survey of Bereaved People in England found that 75 per cent rated their loved one's care as 'outstanding', 'excellent' or 'good' (Office for National Statistics 2016).

End-of-life care involves a range of sectors within the NHS and beyond. People who are approaching death often have complex needs and draw on a range of services – different types of health care (eg, GPs, hospital specialists, community nurses), social care, the voluntary sector, and informal care provided by family and friends. Particularly in the final months of life, people can be interacting with several different types of care provider (National Audit Office 2008); co-ordinating this provision is a key challenge.

While death can occur anywhere, generally people die in one of four locations: their home, a care home, a hospice, or a hospital. Over the past decade,

fewer people have been dying in hospital, with more people dying in their own homes or care homes (see Figure 1). These shifts recognise that many (although not all) people express a preference to die at home (Gomes *et al* 2013).

Figure 1 Percentage of registered deaths (all ages) in England by location (2004 and 2016)

Source: Public Health England 2017
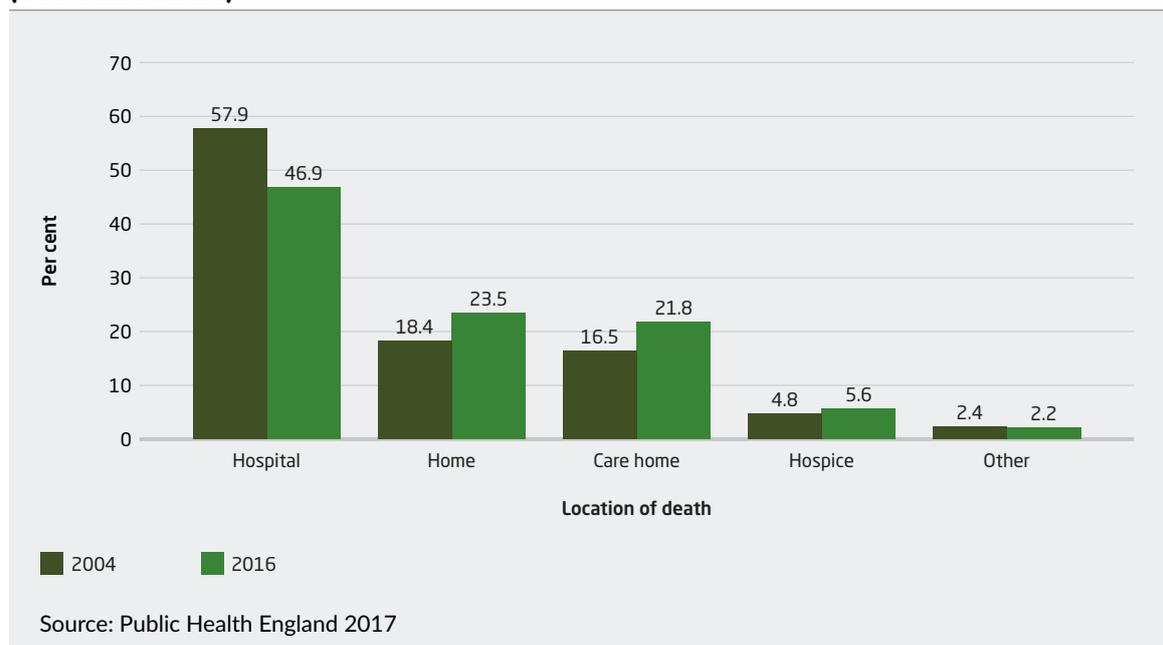
Health care support for people at the end of life spans a number of different services, including palliative care teams, district nursing and hospice care. As a higher percentage of people now die at home, families and informal carers are increasingly important stakeholders. In many areas, Marie Curie nurses and community hospice teams are available to provide overnight support to enable people to die at home.

There is good evidence that early access to palliative care can support quality of life, act as a preventive intervention, and reduce unplanned and emergency hospital admissions. The Gold Standards Framework seeks to support GPs and staff in acute hospitals to: identify patients nearing the end of life; assess their needs; plan their care (informed by the person's wishes); and co-ordinate the delivery of that care (Shaw *et al* 2010). Similarly, the development of the Daffodil Standards for GPs, by the Royal College of General Practitioners (RCGP) and Marie Curie, provides an evidence-based approach to support quality improvement in end-of-life care. They include early identification of patients, service co-ordination, and support for family

and carers (Royal College of General Practitioners 2019). Both sets of standards support priorities for end-of-life care in the Quality and Outcomes Framework, the main incentive scheme for GPs (Free *et al* 2006).

Hospice care

Hospices play a key role in end-of-life care in the UK. Traditionally, people only received hospice care in the last few weeks of their lives. However, this is changing as hospices start to engage people early in the community, where they are providing a greater proportion of palliative care.

Cicely Saunders (1918–2005) is often credited with pioneering the modern hospice approach focused on controlling pain, managing symptoms, and caring for patients' physical and non-physical needs. There are more than 200 hospices in the UK today (approximately 50 specialise in caring for children and young people with life-limiting conditions). Adult hospices are mostly run as independent charitable entities, although a few originated in NHS trusts and are still run as charitable arms of these trusts. Marie Curie and Sue Ryder each run a group of hospices.

In 2016/17, hospices in the UK maintained around 2,760 inpatient beds and provided inpatient care to around 51,000 people (Hospice UK 2017b). However, with hospices increasingly providing care to people in their own homes or through patients visiting the hospice for consultations, inpatients represented only around a quarter (24.1 per cent) of all adults accessing direct support from hospices in 2016/17 (ibid.).

The changing nature of end-of-life care

Around one in four deaths are thought to be unexpected; the rest could potentially benefit from proactive care at the end-of-life (Association for Palliative Medicine of Great Britain and Ireland *et al* 2012). However, there are longstanding challenges in meeting this need effectively. People with life-limiting conditions other than cancer (eg, circulatory disease and cognitive problems like dementia) are less likely to access care even when they would benefit (Dixon *et al* 2015). People from lower socio-economic groups (Buck *et al* 2018) and vulnerable groups such as people who are homeless (Hudson *et al* 2016) are similarly less likely to access palliative care. Geographical variation remains an issue, as does co-ordination of the numerous professionals involved in supporting patients and their families near death.

Over recent decades, the government and national NHS bodies have recognised the need to improve end-of-life care and tried to mobilise national policy in response. In 2008, the Department of Health published a strategy for improving end-of-life care for adults focused on improving the identification of people nearing death, increasing communication with them about their needs and wishes, and improving the co-ordination of care (Department of Health 2008). Most recently, in England, the Department of Health and Social Care responded to a consultation on choice at the end of life with a wider commitment to high-quality, personalised care (Department of Health 2016).

Specialist care for long-term conditions

As with end-of-life care, long-term health conditions are an increasingly important challenge for health and care in the UK. Thanks to medical progress, health conditions which in the past might have been fatal (such as some forms of cancer) are today conditions people can live with for many years (Naylor *et al* 2012).

The Department of Health has estimated that around 15 million people in England are living with one or more long-term conditions (mental and physical) (Department of Health 2012). Recent work has suggested that the number may be higher still (Stafford *et al* 2018). Looking ahead, the number of people living with several conditions is likely to rise; older people are more likely to have long-term health conditions, and the number of people aged 65 and over in England is projected to grow by nearly half (48.6 per cent) between 2015 and 2035 (Kingston *et al* 2018).

Recognition of these trends has partly driven recent efforts to provide more integrated care (discussed further *below*). In practice, national NHS bodies have preferred condition-specific or population-specific strategies. This has resulted in some conditions or populations (eg, cancer and mental health) receiving greater attention, while others receive less recognition if at all in national policy. However, the recent publication of a plan for Universal Personalised Care is an attempt to implement a comprehensive model of care for people living with long-term conditions (NHS England 2019b).

For some diseases, the clinical outcomes delivered for patients have vastly improved in recent years. However, in a practical sense, the NHS's model of care for some long-term conditions has remained resistant to change, with expertise still located in hospitals and organised in clinical silos. Patients may also undertake additional therapy in community or hospital settings to help

manage their symptoms, with co-ordination of that care often undertaken by the GP.

This model of provision has several well-rehearsed limitations. Organised around the professional specialisms, it can be inconvenient for patients; it can lead to lengthy waiting times; information exchange between GPs and specialists can be slow and prone to administrative error; and it hardly suits the growing number of people living with several conditions. An increasing range of specialist nurses have been developed for individual areas of care or conditions, but with the supply of specialist nurses struggling to keep pace with demand, there are large inequities in the delivery of care. For example, the most recent cancer workforce survey (Macmillan Cancer Support 2018) found that there were between 48 and 251 newly diagnosed patients per specialist cancer nurse (depending on the type of cancer), while Parkinson's nurses can have a caseload of between 800 and 1,000 people, with patients in some areas of the country having no access to a specialist nurse.

In some areas, this model of provision has changed, such that staff deliver care in new ways (Robertson *et al* 2014); but change is far from systemic. In cancer care, for example, multidisciplinary working is now the norm, but face-to-face hospital-based condition management remains preponderant. And while there is an ambition to move more care into community settings, developments in medical treatments for some conditions (such as disease-modifying therapies in multiple sclerosis (MS)) are resulting in an emphasis on the provision of care in hospitals.

National policy

The sectors in which the National Garden Scheme's beneficiaries work have been affected by a range of cross-cutting national policy initiatives over the years.

Community services, for example, have seen a plethora of initiatives over the past 20 years to promote care closer to home. Among other things, these have introduced 'one-stop' primary care centres, increased the use of contracting out, and promoted the involvement of the voluntary sector. Today, the sector is still managing the consequences of the Transforming Community Services programme, which saw services removed from primary care trusts and dispersed (arguably in a rather ad hoc manner) among a range of providers (Spilsbury and Pender 2015).

Yet despite much policy activity, the prevailing view is that community services have yet to realise their full potential. On the positive side, patients' average length of stay in hospital has fallen over several decades, and some parts of the country have developed innovative approaches to community-oriented services. However, there is yet to be a systemic shift to community-based models of care (Edwards 2014).

Part of the explanation for this can be found in NHS Improvement's work to boost operational efficiency among providers. Its work has highlighted substantial variation in how services are organised in the community sector and limited robust data showing what works (NHS Improvement 2018a). While there is now work under way to improve national data, this lack of clarity over best practice presents a continuing challenge.

The Health and Social Care Act 2012 arguably made it more difficult to deliver changes in care for certain long-term conditions, by sharing responsibility for commissioning these services between a number of organisations, as CCGs took on most community and hospital services, public health functions became the purview of local authorities, and specialised services were handed to NHS England. Consequently, for some long-term conditions (eg, cancer and some neurological conditions), various services that patients interact with as they progress through treatment are commissioned by different organisations (Independent Cancer Taskforce 2015, pp 63–65; Croft *et al* 2016).

Notwithstanding these challenges, national leaders today are unequivocal in making the case for a more community-oriented health and care system. The *NHS five year forward view* aimed to boost out-of-hospital care (NHS England *et al* 2014) and a number of new care models were pioneered to support this. In particular, primary and acute care systems and multispecialty community providers were focused on bringing different professionals together to find new ways of meeting patients' needs that are less reliant on hospital care. Early evidence from vanguard sites suggests they can improve the patient experience and moderate growth in demand for emergency care (National Audit Office 2018).

Today, the work of the new care models is being built on by integrated care systems (ICSs). These sites are taking on additional responsibility for planning and commissioning care for their populations. The ICSs have wide-ranging agendas, but building capacity in community care and forging closer links between those services and primary care and mental health professionals is a common theme (Charles *et al* 2018b).

The latest strategic document for the NHS in England, the *NHS long term plan*, makes further pledges to reorient the health service towards community provision. General practices will join together to form primary care networks with a role in population health management. Community services will be organised along the footprints of primary care networks to support the development of 'fully integrated community-based health care'. A radical overhaul of outpatient services is planned, using technology to cut redundant face-to-face consultations (NHS England 2019a).

To conclude, the sectors in which the National Garden Scheme beneficiaries operate – community services, end-of-life care, and care for long-term conditions – have seen a good deal of change in recent years, with even more change likely in the coming years. While challenges remain, the overall direction of travel – towards integrated, community-oriented provision that meets people's multi-faceted needs – is ripe with opportunity for these beneficiary organisations. The wider health and care system is embracing ways of working in which they are steeped.

4   Investing in the future of care

The Queen's Nursing Institute

The Queen's Nursing Institute (QNI) works to support high-quality nursing in the community. Established in 1887, it is the oldest professional organisation for nursing in the UK.

The Queen's Nursing Institute and The National Garden Scheme

With its origins in the history of The Queen's Nursing Institute (QNI), the National Garden Scheme continues to have a strong relationship with QNI and is its largest funder, contributing just under half of its annual income. This funding supports an increasing number of Queen's Nurses, and most recently has included leadership development for those working at an executive level.

The QNI works at a strategic level to improve the context in which community nursing is organised and delivered, by influencing policy development. It also gathers data and evidence to inform decision-making, particularly around workforce planning and education. It supports the professional development of community nurses through a range of activities, including:

- a national network of Queen's Nurses with access to continuing professional development

- the Community Nurse Executive Network, which provides support and opportunities to share learning for nurses with executive responsibility for the delivery of community nursing services

- an annual scheme for the professional support and development of nurse-led projects that offer innovative approaches to improving patient care in the community

- support for the professional development of nurses working in the community through the production of national practice standards, education and the publication of learning resources and materials

- educational grants to enhance nurses' clinical knowledge

- financial assistance for working and retired community nurses in times of financial need or life crisis

- linking up working and retired nurses for regular telephone contact.

The focus of Queen's Nurses is on best patient care, putting the patient at the centre of care, innovation in practice, learning and sharing, and leadership. The Queen's Nurse programme supports community nurses to develop their professional skills, knowledge and competence through opportunities for continuing professional development. The programme is open to individual nurses who have demonstrated a high level of commitment to patient care and nursing practice. Nurses, health visitors and midwives with five years' experience of working in the community are eligible to apply. Nurse managers, general practice nurses, specialists and educators are also eligible. In 2017, there were a total of 1,106 active Queen's Nurses.

The Queen's Nurse programme has been running since 2007 and recognises excellence in community nursing. However, in recent years, The QNI identified a need to support the movement of community nurses beyond the award of the Queen's Nurse title by developing their leadership skills. This has resulted in the establishment of a dedicated leadership development role and the launch of two leadership development courses: the Queen's Nurse Leadership Programme, which focuses on the development of individuals and their capacity to lead others; and the Executive Nurse Leadership programme, which aims to develop the leadership skills of community nurses in strategic roles to make an effective contribution to system leadership, while also addressing their current under-representation in leadership roles.

Case study: developing executive leaders of the future

The QNI Executive Nurse Leadership programme was established in 2017 and has run two cohorts to date. The programme is open to Queen's Nurses who are working at an executive or assistant director level in a community setting, be that in an NHS provider organisation, general practice, commissioning role, or in the independent and voluntary and community sectors.

The programme is delivered in partnership with The Leadership Trust, an independent provider of leadership training, which is unique in delivering experiential leadership development at an executive level. In contrast with traditional didactic approaches, participants are subjected to a series of practical tasks and experiences with increasing levels of complexity and

challenge. Each combines practical leadership skills and communication theory and seeks to create an emotional impact to support learning. This is followed by a process of direct and honest feedback, which highlights the behaviours that individuals employ under pressure and their impact and influence on others. The course is delivered through a series of residential sessions over a five-month period and is led by a programme director from The Leadership Trust, supported by a group of coach facilitators.

There are a number of different leadership development courses available to health professionals and nurses. However, part of the impetus for establishing a dedicated programme for community nurses was that few available courses reflected the unique nature of community nursing, which requires nurses to work extensively with others across the system, and advocate for an individual's care. There was also recognition that compared with acute hospitals, community settings often had less clear pathways for the career progression of nurses.

A common feature of those who have participated in the course is the experience of being in an executive role, but not having the confidence in their skills, or feeling insufficiently effective to influence change. This could lead to individuals feeling disempowered and, in a few cases, considering leaving leadership roles. Having completed the course, what is distinctive among participants is not only their sense of empowerment, but their commitment to putting their experiential learning into practice by trying new ways of working to influence, actively seeking and providing feedback, and developing the practice and leadership capacity of other nurses.

The latter is an important component that The QNI is keen to build on. Participants in the Executive Nurse Leadership programme shared their experience of developing greater resilience and a broader knowledge of the strategic roles that community nurses occupy, and have continued to support each other, share practice and consider how they can collectively influence change. They have also committed to providing mentorship to participants in The Queen's Nurse Leadership programme. As budget-holders, it is hoped that they in turn will be able to support the development of other nurses, creating a pipeline of community nurses able to take on leadership roles within organisations and the emerging structures of integrated care.

Macmillan Cancer Support

Since its founding in 1911, Macmillan has focused on providing support to people living with cancer across the UK. Today there are approximately 360,000 cancer cases diagnosed in the UK each year (Cancer Research UK n.d.), more than half of which are cases of breast cancer, prostate cancer, lung cancer or bowel cancer. There are thought to be around 2.5 million people in the UK living with cancer.

Macmillan Cancer Support and the National Garden Scheme

The National Garden Scheme is Macmillan's most longstanding and largest funder, having made annual donations since 1984, which now total over £17 million. For the past 35 years the National Garden Scheme has donated £500,000 a year (currently the joint-largest donation it makes to any single beneficiary).

As Macmillan's scale has grown, its activities have diversified. Today, its work includes the following activities:

- funding cancer services and staff within the NHS and working to influence and support service development

- providing information to cancer patients (via a website, telephone line, information booklets and local information centres)

- providing financial support to people living with cancer (through grants and advice on how to utilise the social security system)

- campaigning to influence national policy and raise awareness about issues that matter to cancer patients (for example, through influencing national cancer strategies).

Over the past 40 years or so, Macmillan has developed a model of partnership working with the health service. The model of funding cancer specialist nurses to work in the NHS involves Macmillan providing funding to cover the costs of a post for a set period of time (generally two or three years) and the partner NHS organisation (commissioner, provider or health board) committing to meet that cost subsequently. These posts are then known as 'Macmillan' posts on an ongoing basis.

In the past, clinical nurse specialists were the focus of Macmillan's funding for workforce development. However, over the past 20 years, multidisciplinary team working has become central to how the NHS treats people with cancer. These teams typically include clinical nurse specialists, diagnosticians, other allied health professionals and administrative staff (Gray *et al* 2017). Improvements in diagnosis and treatment of cancer have contributed to huge progress in improving outcomes such that around half of people diagnosed with cancer in the UK today will live another 10 years – approximately double the survival rate achieved 40 years ago. This has led Macmillan to invest in developing a range of 'Macmillan professionals' to support the holistic needs of people living with cancer and to develop an approach to partnership working with the NHS that enables Macmillan to help shape and influence the care that people with cancer receive.

Case study: building strategic partnerships to influence access to care and quality of care

In 2018, Barts Health NHS Trust celebrated the 25-year anniversary of its association with Macmillan (Barts Health NHS Trust 2018). Barts is one of the largest providers of cancer care in London, treating approximately 3,500 people for cancer each year.

A key aspect of the partnership has been the development of a substantial Macmillan workforce at the trust. Today, there are around 150 Macmillan posts at Barts, most of which have been funded by Macmillan at some point in the past. Most of these are Macmillan nurses, who account for approximately half of all clinical nurse specialists working in Barts' cancer services. New roles are agreed in collaboration with Macmillan as part of the partnership. Barts develops a business case as to why a new role is needed, outlining the rationale and envisaged benefits. This is used as the basis for discussion with the local Macmillan service team whose knowledge of the organisation allows them to reach a decision on how further investment will contribute to improving patient care.

Clinical nurse specialists remain vital to providing high-quality cancer care. However, through targeting opportunities for investment in other roles such as allied health professionals, Macmillan has supported the development of a wider range of Macmillan professionals at Barts, including occupational therapists, speech and language therapists, and physiotherapists. Like Macmillan nurses, these roles are funded with an agreement that they will continue to be part of Barts' approach to cancer care once the initial investment ends. Alongside this, the partnership has enabled Barts to pilot a

range of roles, including care navigators and support workers, to identify their value and potential impact on patient care.

Macmillan provides initial oversight of the roles it funds to ensure that they are delivering the envisaged impact. In addition, a link is retained with the staff in Macmillan posts in the form of a skill development offer. Macmillan makes resources available to staff in those posts, and they are offered access to continuing professional development. Macmillan convenes communities of practice across London to enable staff to learn from each other and share challenges and areas of best practice.

The opportunity and challenge offered by the partnership has facilitated Barts to develop care that goes beyond traditional cancer treatment modalities. An example of this is that Barts has provided dedicated space for Macmillan Information centres at its four hospitals providing cancer care. Staffed by a combination of Macmillan information professionals and volunteers, these offer a range of information and support in a non-clinical setting to people receiving cancer treatment and their families.

The strategic approach of the Barts and Macmillan partnership is a reflection of the longevity of the relationship and the value it delivers for both parties. A member of the Macmillan team sits on the trust's cancer board and together they are involved in ongoing conversations about how to improve services. Recently, Macmillan has made some focused investments in management capacity at the trust to support service improvements. For example, Barts appointed a Macmillan director of cancer nursing and palliative care, and a time-limited Macmillan lead for patient experience and engagement to focus on improving patients' experience and maximising use of patient insights to improve services.

The partnership provides an example of how Macmillan's role extends beyond funding clinical posts. While funding such posts will remain crucial, today it is only part of their offer. Through long-term partnerships, Macmillan is supporting a new service offer and shaping the make-up of the cancer workforce by developing and rolling out new roles that focus on meeting people's wider needs when living with cancer. Alongside they are investing in the skills of people filling those roles and supporting colleagues to learn from each other. Finally, they are acting as an agent of improvement and strategic challenge within providers of cancer services.

Marie Curie

Marie Curie is the leading charity for people living with a terminal illness. The charity helps people and their families make the most of the time they have together by delivering expert hands-on care and emotional support, enabling family members to care for each other, supporting them through a difficult time and preventing people from going into hospital. Marie Curie employs more than 2,700 nurses, doctors and other health care professionals. With nine hospices around the UK, it is the largest provider of end-of-life care outside the NHS.

Marie Curie and the National Garden Scheme

The National Garden Scheme has supported Marie Curie with annual donations since 1996. It has raised more than £9 million during that time and is the single largest funder of Marie Curie's work. Funding provided by the National Garden Scheme helps to fund core services, as well as sponsoring a bursary fund for clinical staff.

Marie Curie provides a range of services, including the following.

- Nursing services: there are currently 2,167 nurses and health care assistants working in people's homes in local communities across the UK providing specialist care for people living with terminal illness and supporting their families (Marie Curie 2018).

- Nine hospices across the UK: these provide inpatient and outpatient care and offer a range of services such as specialist palliative care, symptom management, active rehabilitation, emotional and spiritual care, garden and art therapy, bereavement support, and advice.

- Helper and companion volunteer befriending service: this pairs specially trained volunteers with someone living with a terminal illness in their community to provide companionship and emotional support.

- Information and support service: this provides practical information through the website and telephone support line, and peer-to-peer support through an online community.

Marie Curie has also established a bursary fund to support Marie Curie nurses and other clinical staff at the charity to undertake post-registration qualifications or specialist training in palliative and end-of-life care. The scheme aims to raise levels of knowledge and expertise among clinical staff and ultimately provide those living with terminal illnesses and their families with the highest possible standards of care and support.

Traditionally, Marie Curie nurses have been known for providing overnight care in the last two weeks of a person's life. However, the shifting landscape in end-of-life care is recognising the importance of advanced care planning and a need to support primary care. This sits alongside the aim to move from providing reactive care to more proactive care. To achieve this, Marie Curie is developing its role to become involved in a person's end-of-life care earlier and for a longer period of time. It is also playing a more active role in co-ordinating that care by managing the whole end-of-life pathway in collaboration with other providers, so that individuals and their families have a better experience.

Case study: a co-ordinated and responsive approach to end-of-life care

Northamptonshire's Rapid Response Service was set up in 2010 to provide timely and responsive support for people in the last eight weeks of their life who have expressed a wish to die at home or in a setting of their choice in the community (such as a hospice or residential home). The service aims to support people to receive care in the right place, and to remain at home with support for the person and their family.

At the heart of the service is a 24/7 call centre that co-ordinates the care it provides. People registered with the service and their families have immediate access – the call-handler takes their name and a note of the problem and they are then contacted by a nurse within 20 minutes. The service has found that people like it because they do not have to go through a whole triage process, there is someone on the end of the phone who is going to answer the call, who knows what they are talking about and has the skills to make decisions.

The Rapid Response Community Team provides unscheduled visits and support, which is delivered alongside the care provided by a person's designated key worker (typically a GP, district nurse or palliative care nurse). The team comprises six nurses and four health care assistants, with one or two nurses on duty at any one time. The team is able to provide support over the phone, or a home visit if necessary. Most home visits by nurses are

related to symptom management. Health care assistants support this by providing planned, scheduled care such as undertaking practical tasks like picking up a prescription when the family is unable to do so, taking it to the pharmacy and taking the medication back to the person's home.

The aim is to get to the person's home within an hour; however, calls are prioritised and if the team is unlikely to be able to visit within four hours, the call centre will contact the district nurses and out-of-hours service to see if they are able to attend more quickly. The service has found that patients and their families like knowing who is coming, and when. The service will contact them to provide an estimated time of arrival and update them when that person is on their way. This provides a sense of security, even if it may be a couple of hours before the nurse arrives.

The service receives approximately half of its referrals from the community and half from hospitals. As a means of identifying people early, it has a nurse in each general hospital in Northamptonshire, who specialises in end-of-life care discharge. People are referred from across the hospital and nurses meet with them to do a complete assessment and meet with the patient and their family to talk about options for care out of hospital. The team sets up a care package, assesses equipment needs, and undertakes a range of practical tasks required for discharge (such as making sure the person has the appropriate medication to go home). They also complete the documentation to ensure that once home, community staff can administer the medication required. Everything is set up to minimise, as far as possible, a crisis occurring within the home that cannot be managed there. The service reports that 70 per cent of patients go home, and between 90 per cent and 95 per cent of those are not readmitted to hospital before they die.

The specialist discharge nurses in each hospital have a close relationship with the hospital training and education team and the palliative care team, helping to identify wards where referrals for end-of-life care have fallen, or inappropriate referrals, and providing joint training to support early referral for end-of-life care.

A final component of the Rapid Response Service is a subcontract with Age UK to provide 550 hours of planned, scheduled patient care a week. Community health professionals and the hospital discharge nurses can contact the co-ordination centre when a care package is required for support. If there is capacity, Age UK can start the care package immediately, completing the first home assessment when they get to the patient they are providing care for.

This has been particularly important in facilitating rapid discharge from hospital. Without this, and if Age UK has insufficient capacity, the key worker is required to complete a fast-track continuing healthcare application, which can mean a delay of up to two days before the appropriate care can be put in place. Similarly, when someone dies in the community, the care provided by Age UK can be immediately transferred to someone else whose care needs are increasing.

The health care assistants employed by Age UK are specialised in providing end-of-life care. Their training programme is provided by the Rapid Response Service and through the service they have access to a trained nurse, at all times, to get advice.

By working with the district nursing service and other providers, focusing on what the person and their family want and delivering care that is responsive to the needs of people at the end of life, the Rapid Response Service is helping to support the person and their families to feel in control at the end of life.

Hospice UK

Hospice UK is the national charity for hospice and palliative care. Its membership includes 210 hospices.

Hospice UK and the National Garden Scheme

The National Garden Scheme is the largest funder of Hospice UK's work, donating £500,000 in 2018 and a total of more than £5.5 million since 1996. Its funding has been vital in supporting projects such as the Commission into the Future of Hospice Care (Hospice UK 2013), providing bursaries to hospice staff to attend training and courses, and supporting the National Care Support Team, providing hospices with access to advice, support and expertise.

Hospice UK champions and supports the work of hospices through a range of activities, including the following.

- Policy and advocacy: Hospice UK promotes the value and contribution of hospice care with national and local decision-makers and works with hospices and other organisations to influence and shape the policy environment.

- Clinical and care support: the charity provides a range of support and resources to promote clinical excellence to ensure high-quality hospice care. This includes a clinical benchmarking programme, communities of practice, and quality improvement programmes for people admitted to hospital in an emergency.

- Education and training: they provide a range of topical courses and conferences and other learning events for those working in or with hospices. They also support hospices to deliver their own programmes of education and training.

- Grants programme: they manage a number of grant programmes. These include funding for hospices to undertake specific capital projects, develop new or existing services for the people they care for and their families, and increase their expertise in the work they do.

- Fundraising support: the charity supports members with their income-generating activities through sharing knowledge and good practice.

Hospice UK seeks to operate at a strategic level, supporting clinical executive leads to enable them to provide excellent clinical care, but also being the voice of hospices in the communities they serve. As a consequence, the charity is well placed to identify emerging issues that influence the effectiveness and sustainability of the hospice sector. This has led to innovative work to explore the future of hospice care and, most recently, the appointment of a head of learning and workforce, in light of the considerable workforce challenges facing the sector.

Case study: building virtual communities of practice to share knowledge and expertise between specialist and generalist settings

Project ECHO, developed in the United States, is a not-for-profit movement that aims to improve care by creating virtual communities of practice for learning and support. At the heart of the ECHO model is its hub-and-spoke knowledge-sharing networks, led by clinical specialist teams (the hubs) who use videoconferencing to conduct virtual meetings with multiple health care providers who often reside in the community (the spokes). ECHO aims to improve clinical decision-making and better support isolated practitioners by sharing learning and best practice. Participating providers acquire new skills that allow them to treat patients they would otherwise have referred elsewhere. Patients with complex chronic conditions get high-quality care, where they live, from providers and in settings they know.

Hospice UK's journey with Project ECHO began with Northern Ireland Hospice, where efforts to regularly convene the 33 specialist palliative care nurses caring for people in the community to provide teaching and support had proved challenging given the time commitment once travel was factored in. Northern Ireland Hospice decided to trial Project ECHO for six months. The evaluation showed high levels of satisfaction among the nurses involved, who reported benefit from the education sessions and welcomed the support. As a result, the Northern Ireland government provided funding to expand the networks beyond palliative care, and Hospice UK secured funding to develop further networks across UK hospices.

Since 2018, Hospice UK has supported the development 20 hubs and more than 50 networks. One of those hubs is St Christopher's Hospice, which provides palliative care across four London boroughs covering a population of more than 1.6 million people. Prior to Project ECHO, St Christopher's ran a Care Home Project Team supporting practice development among the nursing homes across the four boroughs. When the team was decommissioned, St Christopher's decided to embrace ECHO to maintain the relationships it had

built with nursing homes and support staff in providing high-quality care in the community.

A key feature of the ECHO network is that it is facilitated by a trained, dedicated facilitator and supported by a dedicated IT technician and an administrator. Individuals running ECHO have to attend a three-day immersion training course, as well as specific training for each of the roles. At St Christopher's, the ECHO team comprises a clinical nurse specialist (0.8 full-time equivalent (FTE)), IT support (0.6 FTE) and administrative support (0.6 FTE). These roles are important: together, they identify people with relevant expertise to present at meetings, support the care homes with setting up and using the IT, and ensure that all the materials are available for use by network members.

To date, St Christopher's has launched four networks – three with nursing homes in different boroughs, and a fourth with residential homes. Networks comprise between 9 and 16 care homes, and St Christopher's aims to eventually be able to offer Project ECHO across all of the 110 care homes in its area. For each network, hub and spoke members have an initial meeting to collectively agree a curriculum, times, dates, evaluation, and responsibility for presenting, teaching and sharing cases at each meeting. The care homes (spokes) set the agenda, identifying areas and issues they would like further training on or support with. Sessions range from a focus on education to practical support; topics identified range from recognising pain in dementia, and hydration, to working with challenging families, and expectations.

Each ECHO session lasts 70–120 minutes, focuses on a particular issue and follows a specific format. This includes 20–30 minutes' teaching from a topic expert followed by one or two case presentations from individual spokes, followed by network discussion. The teaching session aims to share best practice and reduce variation in practice, while the case presentations use real-life cases to facilitate discussion and learning that goes beyond textbook examples. Rather than information flowing in one direction, community providers learn from specialists, they learn from each other, and specialists learn from community providers.

All sessions are filmed and edited and, along with additional materials, form a private online library that grows with each session. Participants are required to provide their consent as part of this process and receive a certificate of attendance for each session. The Project ECHO team also submits data to a

central iECHO database, which supports hubs to complete an evaluation of how their project is transforming service delivery.

Project ECHO has enabled St Christopher's to maintain the relationships it had built with the care homes, but an additional benefit is that it has allowed them to increase their reach. ECHO reduces the amount of time staff are required to spend attending external training sessions in person, and lessens the pressure to backfill time. In addition, night staff, who are rarely able to attend training, are able to access the online library of sessions to keep up to date with their training. For St Christopher's, ECHO provides an opportunity to see what goes on in care homes, and by identifying topic experts from local organisations to build relationships and an understanding of care homes.

The ultimate aim of Project ECHO is to change service delivery models so that improved decision-making leads to better and more timely patient care. The St Christopher's team are particularly keen to engage managers, deputy managers and senior staff in care homes as they are best able to influence and implement changes in practice.

Hospice UK sees Project ECHO as a key enabler of its overall five-year strategy to open up hospice care, helping hospices build relationships with and instil confidence in other health care services to care for people at the end-of-life. Through this it aims to increase capacity for hospice quality care to be delivered in any setting and maximise their impact by engaging with more communities who often miss out on accessing palliative care input when they need it most. To support this, Hospice UK has invested in developing three 'super-hubs' able to deliver Project ECHO training. It is also embarking on a programme of evaluation to identify changes to practice that emerge from the networks, and which could be spread more widely across their membership.

Parkinson's UK

Parkinson's UK was founded in 1969 with a focus on providing information and support to people living with Parkinson's disease and their families. There are estimated to be around 145,000 people in the UK with Parkinson's (Parkinson's UK 2017). Parkinson's is a chronic, progressive neurological condition that affects movement but is also associated with a range of other physical and psychological symptoms. Patients experience different combinations of symptoms, and symptoms fluctuate over time.

Parkinson's UK and the National Garden Scheme

The National Garden Scheme has been supporting Parkinson's UK since 2012 with a cumulative donation so far of more than £1 million. In 2018, it donated £185,000.

Today, the work of Parkinson's UK focuses on:

- providing leadership and funding to accelerate research towards better treatments and a cure

- offering information and support to people with Parkinson's and their families through the charity's website, a helpline, local advisers, local groups and an online community

- influencing policy and the delivery of public services for people with Parkinson's through both regional and national activity.

As part of its work to influence services, Parkinson's UK promotes access to specialist Parkinson's nurses. It deploys a similar funding model to that of other charities: making a financial commitment to a post for an agreed period (usually two years), with the partner organisation (provider, commissioner or health board) committing to continue that funding thereafter.

In recent years, Parkinson's UK has sought to identify new ways to support people living with Parkinson's and improve services. This work has drawn on national and international examples, including networks of professionals collaborating to support people with Parkinson's developed in the Netherlands (*see* http://www.parkinsonnet.info/); and an approach from the United States to recognise departments that are providing excellence in the delivery of care for people with Parkinson's disease. Parkinson's UK also recognised the importance of clinicians working collaboratively with people with Parkinson's

disease and their carers. This led to the development, in 2015, of the Parkinson's Excellence Network – a method of driving quality improvement and sharing best practice across services providing care for people with Parkinson's.

Case study: creating a collaborative network of health professionals and people with long-term conditions to drive quality improvement

The Parkinson's Excellence Network is a national initiative that brings together health care professionals working in Parkinson's services and patients living with Parkinson's to improve services across the UK. The network aims to:

- strengthen the voice of people affected by Parkinson's

- support quality improvement

- build a network of experts in Parkinson's care (not just nurses)

- enable collaboration for change, share good practice and reduce variation.

The network is organised into 22 regional groups across the UK, and a number of thematic groups (focused on specific areas such as education and under-served groups) that operate nationally. Regional groups meet regularly to share information on the activities of the national network, discuss examples of good practice, understand their local services better, identify areas for improvement, and initiate projects to improve practice. They are open to participation by health care professionals of all backgrounds who work with people with Parkinson's, and by people living with Parkinson's. Alongside their formal proceedings, regional groups help to connect participants to a more informal network of support and shared experience.

To complement the work of regional and thematic groups, the network undertakes national activities that groups can take part in. These include:

- convening an annual conference and awards ceremony for staff working in Parkinson's services (who can be nominated by people living with Parkinson's)

- making resources available online covering a range of topics relevant to staff of different groups (eg, guidance on medications management and guidelines on how to manage Parkinson's patients when they are in hospital)

- providing training and education opportunities for staff (online modules and face-to-face seminars).

Parkinson's UK provides an infrastructure to support the network. This includes a team of around 20 people within the charity who manage programmes focused on: (1) service improvement; (2) workforce and education; (3) communications and professional engagement; and (4) involvement and inclusion. The regional groups can also work with Parkinson's UK's local development teams whose role is to influence local health and care services. In 2017, Parkinson's UK recruited a national clinical leadership team for the network with representation from neurology, geriatrics, nursing and physical therapy. These are clinical leaders who can act as advocates for the network at a national level, tap into their respective professional networks, and bring a frontline perspective to the leadership of the network.

According to interviewees, the relatively small community of Parkinson's health care professionals means that most frontline staff working in Parkinson's services are aware of the network and the regional group in their area. Participation in the network by specialist staff (such as Parkinson's nurse specialists) is good but the network sought to go beyond this to incorporate other clinical groups, and now includes therapists and neurologists. People living with Parkinson's play a varied role in the network but increasingly they are taking up key roles such as chairing and co-chairing regional workstreams. The network aims to further strengthen their role in the future.

The network's agenda is informed by participants' expertise, but also by the Parkinson's Audit – a national audit of services providing Parkinson's care (around 700 services have participated). It gives a snapshot of key service quality indicators – for example, whether services are organised in multidisciplinary clinics, the extent of access to specialist nurses, and medicines management. The audit is conducted every other year, enabling services to benchmark their provision against other parts of the country. It includes a module of patient reported experience questions that are completed by patients and their carers. By asking some questions repeatedly over time, the audit gives an insight into how services are changing. It thereby informs the network's activities by identifying priority areas for improvement and serves as a resource to influence national policy.

MS Society

The MS Society was founded in the early 1950s to offer support to people diagnosed with multiple sclerosis (MS). There are thought to be around 100,000 people with MS in the UK (MS Society 2018a), with around 5,000 new cases diagnosed each year. MS is a long-term neurological condition with a wide range of symptoms, including problems with vision, arm or leg movement, sensation or balance. Unlike some other neurological conditions, onset of MS can occur relatively early in life.

MS Society and the National Garden Scheme

The MS Society was a guest charity of the National Garden Scheme between 2016 and 2018. Over that period, the National Garden Scheme's cumulative contribution to the MS Society amounts to nearly £400,000.

Guest charities are identified through recommendations from National Garden Scheme's volunteers. While an element of nursing is desirable, trustees are open to supporting charities with a broader agenda, where they are able to demonstrate value to local communities. Guest charities are usually supported for two or three years.

Today, as in the past, the MS Society funds biomedical and health services research into MS treatment and care. More recently, it has developed its information offer to people living with MS, mainly through its website and a telephone helpline. The charity campaigns nationally to influence public policy (in particular health care and social security policies) and to raise public awareness about MS. In 2017, the MS Society had an annual income of around £29 million (MS Society 2018b).

Throughout the charity's history, convening groups to support people living with MS has been a core activity. Over time, the scale of these activities has expanded, such that today, the MS Society supports around 270 volunteer-run groups across the UK. These groups vary in their approach, tailoring their offer to members' priorities, but most tend to offer social activities, exercise classes, information and support.

Case study: from specialist services to community groups, developing integrated approaches to providing support

Care for people living with MS is evolving, due to changes in national policy and to recent technical developments in drug treatments. While these developments are shaping how patients' health care is organised and delivered, patients' experience of living with MS continues to be strongly influenced by the non-medical support and advice they are able to access to help them live an independent, full life.

One example of how the MS Society's volunteer-led groups contribute to this more holistic support can be seen at The Walton Centre NHS Foundation Trust, the NHS's only specialist neurological, neurosurgery and spinal care trust, based in Liverpool. The Walton Centre recently participated in NHS England's New Care Models programme with a view to developing a sustainable model for an integrated neurology service (Harrison *et al* 2018). This included a number of discrete projects to change how patients interact with services – for example, a nurse advice line so patients can access advice on managing their condition, and an integrated neurology nurse specialist service that consults with patients with MS, Parkinson's and epilepsy in community settings.

Alongside this ongoing work to provide a more user-oriented and cost-effective model of care, the trust maintains a relationship with the MS Society volunteer-led support groups in the Merseyside and Cheshire area to make it easy for patients to access support when they think it could help them. Volunteers from local MS Society groups organise a Friday morning information clinic at the centre. This involves volunteers being present on site at a desk with literature to speak with people who have recently been diagnosed (at the instigation of the patient). The volunteers are able to listen to people's concerns and suggest useful places to seek out information or support. Staff at The Walton Centre are also able to signpost people to a number of volunteer-led groups in the community.

There are eight MS Society volunteer-led groups in the Merseyside and Cheshire area. Each group has a co-ordinating team that must include a group co-ordinator and a finance volunteer, and at least one other volunteer role (eg, activities organiser, administration volunteer or support volunteer).

The Vale Royal and West Cheshire group has around 400 members who pay an annual membership. Members receive a regular newsletter updating them about upcoming events and raising awareness of issues that may affect them.

The group also puts on social events such as coffee mornings and day trips, and regular exercise classes like yoga and tai chi (individual classes are subsidised by the MS Society, with attendees making a contribution to the cost). The group is also able to offer home visits for people who are newly diagnosed, and those who may be struggling or isolated and may benefit from additional support.

The group holds a regular information afternoon for members, with invited speakers, such as a neurology nurse specialist from The Walton Centre. The group also has a minibus, which in addition to providing transport for group trips, enables them to take members to attend appointments at The Walton Centre or other services if they have no means of transport and are unable to take public transport.

Participants value the groups for different reasons. MS results in both physical and psychological challenges, and while support in managing the symptoms is important, the groups can provide a sense of purpose and social support for those who have had to give up jobs and make significant adjustments to their lives as a result of the disease.

Each volunteer-led group is established by people in the local area and can be formed to meet the needs of a group of local people. Groups are bound by the MS Society's code of conduct, policies and rules, and are required to keep the charity informed of their activities. Groups handling money are also required to adhere to certain operational requirements (eg, managing finances appropriately and raising sufficient funds to cover their costs). To help with this, the MS Society makes support available to local groups. There is a network of local officers or managers who are MS Society employees and who provide practical advice to groups (eg, on managing their finances, dealing with problems, and updating them on information from the national centre). Alongside this, the charity employs a network of external affairs managers to act as a conduit between public services and volunteer-led groups in each area.

5 Concluding reflections

For more than a decade, The King's Fund has argued that decision-makers in health and social care need to think differently about how we meet current and future challenges in providing high-quality care (Ham *et al* 2011). Among those challenges is being able to respond to the changing patterns and burden of disease, such as an ageing population and the growing prevalence of multimorbidity.

The government's commitment to increase NHS funding over five years, up to £20.5 billion by 2023/24 in real terms, was widely welcomed; but tough choices remain, despite consensus on the need to invest to improve how we provide health and care. While social care and public health remain core to achieving this improvement, it remains to be seen if they will receive the necessary support in the future spending review.

None of this can be achieved without an adequate workforce. NHS hospital, mental health and community providers report a current shortage of more than 100,000 FTE staff, with nursing facing some of the greatest challenges (NHS Improvement 2018b). Based on current trends, The King's Fund, the Health Foundation and Nuffield Trust estimate that the NHS will have a shortfall of 108,000 FTE nurses in 10 years' time (Beech *et al* 2019).

The adult social care sector is also under pressure and facing many of the same issues as the NHS. There is little doubt that part of the solution lies in increasing the numbers of staff, and in particular addressing the number of people who start nursing training. However, even with these increases, shortfalls are likely to remain, particularly in roles such as district nursing and clinical nurse specialists. Ensuring that people are able to access high-quality care will require significant workforce and service redesign to create the right teams with the right skills and support.

It is within this context that the *NHS long term plan* has set the course for the health system over the next five years and beyond. The plan outlines an agenda to provide more integrated care, boost primary and community care, improve clinical outcomes across key disease areas, make a new offer to people with long-term conditions, and harness digital technology. Furthermore, it highlights an ambition to address the interface between

primary, community and secondary care, supported by a commitment to increase funding for primary and community services by at least £4.5 billion between 2019/20 and 2023/24.

As our previous work highlights, addressing that interface requires decision-makers to redesign care based on a set of principles (Charles *et al* 2018a). This includes care which: is organised and co-ordinated around people's needs; understands people's needs in the round; makes the best use of all the community's assets to plan and deliver care; enables professionals to work together across boundaries; builds access to specialist advice and support; empowers people to take control of their own health and care; and supports and strengthens relational aspects of care. That report called on those involved to 'reimagine services' but it is our belief that the fruits of that process are already evident in the work of the National Garden Scheme's beneficiary charities. This final section of our report frames those opportunities, outlining how they may contribute to shaping the future of health and care.

Beneficiaries as drivers of change

Looking across the case studies, it is striking that the National Garden Scheme's beneficiaries have expertise relevant to some of the NHS long-term plan's key priorities because they are already delivering change in those areas. The need to find creative solutions to workforce shortages, for example, is essential in the coming years; through its work with partners, Macmillan is diversifying the cancer workforce, developing new roles and finding new ways to deliver care and support. Similarly, national leaders are keen to harness technology's potential to improve care; Hospice UK is using technology to leverage specialist clinical expertise to support quality improvement in end-of-life care in community settings. At a time when delivering operational change is high on the agenda, these are tangible contributions to improvement in areas of national priority and potentially hold learning for the wider system.

Beneficiaries' diverse approaches and the interface with the statutory system

The case studies highlight the diverse ways in which charities contribute to health and care. Considering only some of the National Garden Scheme's beneficiaries, their activities include developing leadership capability, supporting quality improvement, developing new roles within the workforce, and facilitating peer support among service users. These multifarious

approaches feed into how the beneficiaries interact with the health system: some make an offer directly to patients, some interact mostly with frontline staff, others focus on senior leaders.

This heterogeneity raises questions about how the wider voluntary sector and the statutory system can work together most effectively to drive improvement. While national leaders regularly acknowledge the role that voluntary organisations play in health and care, local systems – sustainability and transformation partnerships (STPs) or ICSs – are intended to become the key decision-makers in designing services and implementing change. As such, how these local planning forums engage with voluntary groups in the years ahead is a key question. Based on this project, a one-size-fits-all approach to these local conversations, which focuses on charities as potential providers of services or as sources of volunteers, will miss opportunities to leverage their capabilities and expertise to the fullest extent.

Ways of working and opportunities for shared learning across voluntary and community sector organisations

Responsibility for maximising the contribution of the voluntary sector does not, however, rest exclusively with the statutory sector. Through ways of working, organisations in the voluntary, community and social enterprise sector can help to foster partnerships with the statutory system that are based on strategic alignment and complementary capabilities (rather than duplication). Informed by our case studies, we offer two reflections for the wider community and voluntary sector in this respect.

First, some of the ways of working of the beneficiary organisations could potentially be emulated by organisations in other parts of health and care system. For example, Hospice UK's use of technology to bring professionals together has been used to support different types of care across a range of settings other than hospices; similarly, Parkinson's UK's approach to quality improvement could hold useful lessons for charities focused on other disease areas. Much as within the NHS itself, realising these opportunities to share within the voluntary sector will rest on a readiness to embrace innovation that originates elsewhere – alongside supporting home-grown change.

Second, looking across the six beneficiary charities, there is a recurring theme about beneficiaries taking a long-term view and understanding how they make a unique contribution. The Queen's Nursing Institute, for example, identified a gap in provision of leadership development for executive-level community nurses and developed an offer that meets that need. Marie Curie

is transitioning towards engaging and supporting people earlier in end-of-life care, informed by the needs of patients and some of the well-known service co-ordination challenges. Not all charities will have capacity to make and implement strategic choices like these, but for those that do, it could help to maximise the value they generate and facilitate different conversations with NHS leaders.

The role of the National Garden Scheme

The National Garden Scheme's funding has helped to make possible the work of the beneficiary charities explored in our case studies. While it is one among many funders in this space, its approach is notable for how it seeks to maximise impact. It develops long-term relationships with beneficiaries (over 30 years in some cases) and generally provides funding in unrestricted form. As others have highlighted (Esmée Fairbairn Foundation 2019), this form of funding can support innovation by allowing beneficiaries to test new approaches, take risks and learn. In practice, the 'durable' funding that the National Garden Scheme provides has supported the development of specific projects including Queen's Nursing Institute's Executive Nurse Leadership programme; and because their funding support is generally long-term in nature, it reduces the subsequent effort and cost those charities have to invest in income generation.

We end by reflecting on the totality of the National Garden Scheme's work. It is perhaps best known for gardens. The King's Fund has previously explored the positive contribution gardens can make to health and wellbeing (and much remains to be done to translate that evidence into practice) (Buck 2016). Without detracting from the gardens, this report has sought to elicit the other, perhaps less immediately visible aspect of the National Garden Scheme: the health and care work it enables through the funding it distributes. Looked at in the round, what stands out is that throughout the National Garden Scheme's work – both the means by which it raises money and the activities it supports – there is a mutually reinforcing focus on improving health, care and wellbeing.

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