

Priorities for the Plan

The long-term NHS plan and beyond:
Views from leaders in charities and voice organisations.

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Introduction

Jeremy Taylor, CEO of National Voices

Now the NHS has turned 70, and with the Government preparing a long-term plan for the service in England, a broad range of leaders in charities and voice organisations have come together to offer our views on what should happen next. In particular we are addressing HM Government, leaders of national NHS bodies and all those whose decisions shape the NHS and affect health, wellbeing and care.

We welcome the announcement of significant additional funding for the NHS and the intention to work together with staff and patients to develop the plan. This document highlights priorities that leaders within our sector wants to see reflected in the content of the plan and in the way it is developed. These priorities are rooted in the work we do with and on behalf of patients, people who use services, carers, and in communities.

This collection of chapters is not comprehensive and it is not definitive. Indeed such a thing is probably neither possible nor desirable. Rather, those who make decisions about the NHS must engage with the people it serves, in all their diversity, to ensure those decisions are sound and as far as possible co-produced. This collection should thus be seen as the start of a conversation, not the final word.

What is good?

The NHS has a special place in British life. In its 70th birthday year, three aspects in particular are worthy of celebration:

- The founding NHS principles – comprehensive healthcare, to all who need it, free at the point of use, and not dependent on financial means – have stood the test of time. They continue to be largely borne out in practice (though with some significant gaps), supported by the public and protected by a cross-party political consensus. After 70 years and in these turbulent times, that is a great achievement.
- The dedication, skill and compassion demonstrated day after day by hard working health and care staff.
- The many scientific, technical, medical and social advances that over the years have saved, prolonged and improved countless lives.

What is the problem?

But there is no room for complacency. Compared with many other highly developed countries, the UK spends less on health and in some important respects achieves worse outcomes.

The NHS has been slow to adapt to the requirements of a population that has been growing, ageing, diversifying, coping with an increased burden of long-term illness and disability in all age groups and in which millions of people now live with multiple long-term conditions. It has been slow to make the best use of new (and even well established) technology and at the same time often struggles to get the basics right. Despite waves of renewed focus on safety and safeguarding, following various scandals, it continues to cause avoidable harm.

At the same time, successive governments have done too little to tackle many of the underlying causes of ill-health and to mobilise a concerted cross-sector effort to improve population health and wellbeing. Poverty, inequality, unemployment, poor and unaffordable housing, social isolation, stress, discrimination and lack of hope are some of the factors that hugely damage health, and which the NHS cannot address alone. Nor has the NHS proved very effective at reaching out beyond its borders to the agencies and communities who together could provide many of the solutions.

The result is a number of enduring and well-documented deficiencies in our nation's health, and in our health and care system. To pick a few:

- **There are huge inequalities in health outcomes**, most dramatically demonstrated in the large gaps in mortality and healthy life expectancy between the richest and poorest neighbourhoods.
- **The system struggles to see and address the whole person** in the context of their life, family and community. Care is fragmented and disjointed: the fracture between health and social care is only one example of a more general failure to join up.
- **The prevailing model is a reactive, medical one** that does not cultivate people's capacity to do more for themselves and for each other. It prioritises expensive hospital based interventions over prevention, early intervention, community-based services and non-medical care and support.

- **The fine aspiration of “putting patients at the heart of the NHS” has yet to translate** into widespread meaningful action. Many find they have too little say in matters that affect their health and healthcare and no recourse when things go wrong. Some find their rights trampled on. This is also true at the collective level, where communities might be “consulted” but find decisions are taken behind closed doors and with little accountability.

These deficiencies are not felt equally through the health and care system and there are populations of people who are consistently less well served than others, for example (and this is by no means a comprehensive list):

- People with multiple and complex conditions;
- Frail older people and people at the end of life;
- Young people with complex health needs;
- People with enduring mental illness;
- People with learning disabilities;
- People with physical disabilities;
- People with some rarer conditions;
- People from some black and minority ethnic groups and people who identify as LGBT; and
- People from “inclusion health” groups such as Gypsies, Travellers, asylum seekers and homeless people.



Compared with many other highly developed countries, the UK spends less on health and in some important respects achieves worse outcomes.

What needs to happen?

Overall, the long-term for the NHS must be part of a broader and properly-funded governmental drive to improve health and wellbeing. In the absence of this broader approach, including sufficient investment in social care and public health, the extra funding for the NHS, while welcome and necessary, will not achieve the intended gains.

The plan must work towards a whole system approach for people with long-term conditions and disabilities that is geared to helping people live well and die well.

Key priorities must be to:

- Focus on the outcomes that matter to people. Reflected in what the health and care system measures and pays for, and in how professionals are trained, developed, managed, and held to account.
- Promote equality and reduce health inequalities.
- Provide a coordinated community-based offer of service and supports, properly joining up the contributions of primary care, community health, public health, housing, social care, volunteering and social action and the voluntary, community and social enterprise (VCSE) sector.

How to get there?

The good news is that much of what we call for is already reflected in existing national policy, legislation and guidance, for example the NHS Constitution, the Care Act 2014 and the NHS Five Year Forward View. Indeed, this collection in large part reflects a broader consensus about the reform priorities for health and care.

There is also much good practice to build on (a theme in the ensuing chapters), and growing interest in – and evidence to back – a range of person and community centred approaches that seek to engage and empower people and work collaboratively to improve health, wellbeing and care. These include shared decision-making, personalised care planning, ‘social prescribing’, peer support, personal health budgets, asset-based community development, experience based co-design and patient leadership.

But progress to a system that focuses on “what matters to people” has been patchy and inconsistent. National priorities keep changing; there is too much reliance on heavy-handed top down mechanisms, and not enough energy put into winning hearts and minds, learning from success and failure, and spreading good practice.

So the plan needs to set out an approach to change that learns from past experience. We would suggest that this must include:

- Less “major transformation” (which has little grounding in evidence) and more constant and concerted improvement, building on what already works.

- Less national diktat and more effort to cultivate empathetic collaborative local leadership and to support the spread of good practice.
- More focus on outcomes that matter to people.
- Partnership working with patients, carers, citizens, communities and the voluntary and community sector as an integral part of shaping, implementing and overseeing the plan.
- More focus on the training, development, welfare, engagement and empowerment of front-line staff.
- A balanced approach to research, innovation and the adoption of new technologies, which involves patients and the public, reflects their priorities, is not exclusively biomedical, and which is not pursued to the neglect of humanity, compassion, communication and getting the basics right.



Overall, the long-term plan for the NHS must be part of a broader and properly-funded governmental drive to improve health and wellbeing. In the absence of this broader approach, including sufficient investment in social care and public health, the extra funding for the NHS, while welcome and necessary, will not achieve the intended gains.



Prevention and public health

Christine Hancock on behalf of C3 Collaborating for Health

What is the problem?

Chronic disease – particularly cardiovascular disease, cancer, diabetes and chronic lung disease – is the leading cause of death, illness and disability in the UK.¹ **Almost half of NHS costs are from diseases related to physical inactivity, smoking and poor diet (including harmful alcohol use),² yet up to 80 per cent of premature deaths from chronic disease could be prevented by tackling these three factors.³**

Most deaths from chronic disease will be preceded by years of ill health, placing a social and economic burden on people, their families and the NHS. Each year, the UK spends about 20 times as much on treating ill health as it does on preventing it, even though prevention is 20 times more cost-effective on a lifetime basis.⁴

Health care only accounts for around 10 per cent of a population's health, with the rest being shaped by how and where we live, work and play.⁵ Health – and health care – is about more than just changing people's behaviour. It is inextricably linked with the environments we live in: our neighbourhoods and workplaces; the food sold in local shops; and what health professionals model as healthy behaviour.

Depending on where you live in the UK, your life expectancy can vary by as much as 16 years.⁶ From 1965 to 2008, 1.2 million more people died before the age of 75 in North England than in South England, which researchers attributed to 'persistent inequality' between the two regions.⁷

Evidence shows health professionals lack knowledge about prevention and often have the least healthy lifestyles. The first prevalence study of its kind – commissioned by the C3-led Healthy Weight Initiative for Nurses – found one in four nurses in England are obese.⁸

What needs to happen?

The good news is that there is a huge amount that can be done to address the risk factors and prevent or delay chronic disease, and the subsequent need for expensive treatment. Three changes to improve people's health are particularly important in prevention: increasing physical activity; improving diet (including avoiding harmful alcohol use); and stopping smoking.

Health professionals are well placed to give the trusted, accurate advice needed to prevent and treat chronic diseases. NHS England has already recognised the importance of a healthy NHS workforce, both for their 1.5 million employees and as an exemplar to improve the health of the population. **By working with health professionals to incorporate healthy lifestyles into their own lives, the NHS can ensure they become credible advocates for their patients, families and communities.**

- Staff health and wellbeing should be integrated as core components of service planning, contracts and tenders so that all NHS staff – including those who are employed by third-party contractors – have access to high-quality occupational-health services, evidence-based health-promotion initiatives (such as smoking-cessation support and healthy-eating options), and fair terms and conditions.
- Other parts of the health system – such as GP surgeries, dentists, optometrists and pharmacies – must not be overlooked. They should be involved in efforts to improve the health of their staff and the people they support.

- All staff working in the health and care system should be supported to lead healthy lifestyles at work. This includes (but is not limited to): protected time to take breaks to eat; access to drinking water; healthy, available and accessible food in canteens and vending machines; and dedicated space to store, heat and eat lunch (which is not a room where staff change or where drugs are stored).

Because of inequalities, it is imperative that primary prevention efforts incorporate co-produced community action. Ultimately, incentives need to be in place to make it easier for communities to live healthy, active lives.

- Professionals must engage with communities, especially the most vulnerable, and involve them with the planning and implementation of prevention efforts.
- The built environments surrounding communities must be systematically assessed for the assets and barriers that make it easier or harder to live healthy lives. Community members, guided by public health expertise, should design the health interventions that will be most effective and valuable for their communities.
- Planning authorities, whose history is rooted in public health, should be organised alongside local public health authorities to ensure the health impacts of planning and development decisions are understood and acted upon.⁹

Where is this already being done well?

Eleven demonstrator sites, supported by NHS England, have been working on a range of actions to deliver ‘a core offer’ of what NHS organisations should do to improve the health and wellbeing of their workforce. This programme provides learning for the wider NHS to build upon.

Generating community action in prevention is already taking place in parts of the country. C3’s CHESST[™] (Community Health Engagement Survey Solutions) offers an evidence-based approach that shifts decision-making to local communities by engaging them as ‘citizen scientists’ in an investigation about their health and the built environment.¹⁰ Recently completed projects in disadvantaged areas of London and Halifax have engaged up to one-third of the local population in health and community

action, strengthened partnerships between local organisations, and led to new and extended health and wellbeing interventions. These interventions include: healthier options in local shops and restaurants; classes on cooking, wellbeing, and gardening; dance sessions; healthy picnic lunches for school children during the summer break; sports, dance and activity sessions; and improved community resilience, confidence, and social cohesion through more developed networks.

What is one priority action that needs to be taken ‘now’?

Too many policies suggest that, with education, people will change their unhealthy behaviour, yet the people most at risk live and work in tough environments. The NHS has to take a lead in addressing inequalities. It must invest in community action that sees community members, particularly the most vulnerable, designing and implementing neighbourhood health interventions that make the healthy option the easy option, for all. And the NHS must ensure that incentives – nationally and locally and across all public bodies – are aligned to tackle the underlying causes of poor health once and for all.



Almost half of NHS costs are from diseases related to physical inactivity, smoking and poor diet (including harmful alcohol use).

The
Richmond
Group
of Charities

People living with (multiple) long-term conditions

Charlotte Augst and Liam O'Toole on behalf of the Richmond Group of Charities

What is the problem?

In the public's imagination, the NHS is a service that is there for you when things go wrong, 'in an emergency' – hence the iconic status of your local A&E. But the reality of NHS use is different. The majority of users have continuing health issues that can be managed but not 'cured', and much of the required care can actually be planned for, including the fact a crisis may occasionally occur.

Increasing numbers of people are now living with more than one continuing health condition. An estimated 2.9 million people in England now have three or more long-term conditions, the majority of whom are under 65.¹¹ Almost two-thirds of adults with asthma¹² and four-fifths of adults with osteoarthritis have at least one other long-term condition;¹³ half of stroke survivors have four or more;¹⁴ and almost one in six people with cardiovascular disease have five or more.¹⁵ Seven in ten cancer patients have at least one additional long-term condition and two-thirds of

cancer patients say their care is not properly coordinated.¹⁶ Unsurprisingly, care for people with more than one health issue is more expensive, particularly where mental and physical health problems occur together.

To state the obvious, health and care services are not optimally aligned to support these core users, with dire consequences for people experiencing poor outcomes, as well as for the system itself.

What needs to happen?

People with many health conditions present the most urgent case for changing how we think about medicine. We need to move away from an exclusive focus on body parts, biomarkers and pathology in long-term conditions care. **We need to adopt a perspective that more explicitly addresses the impacts medical conditions have on people, and responds more meaningfully to what people value for their lives: purpose, connection and agency.**

This requires changes across all areas of health and care design and delivery:

- We need to measure and consider incentivising outcomes that matter for people with multiple long-term conditions. This will likely need to focus on the impacts of conditions rather than only clinical activities or biomarkers – such as pain, fatigue, mobility, breathlessness, but also issues such as work, housing or loneliness.
- Coordinated care needs to become the foundation through which any of these outcomes can be achieved. We need to invest in care coordination roles and digital tools, but also need to make coordination a clinical responsibility.
- This requires moving away from thinking that is based on linear pathways and towards team based care, with the person and their family or carers in the middle and professionals from different parts of the system (GP, pharmacy, specialist consultant, care coordinator) providing support and sharing information.
- None of this will work if we don't get data to flow. We need a shared care record the whole team sees and can work with, including the patient and their carer/s.

- Medical education needs to change – we need specialists, but we also need people who understand interdependencies, multimorbidity and systems to deliver long-term conditions care needs to become a core part of all medical training, as does a deeper understanding of social determinants of health and health behaviours.
- Particularly the interface between physical and mental ill health needs to become a normal and central part of all clinical practice – see pages 28 and 29.
- NICE guidance needs to recognise clusters of comorbidities and what this means for good clinical practice. As a minimum, an annual review of any one condition must take account of the fact the person is normally managing more than one.

Where is this already being done well?

The One Croydon Alliance brings together the local authority, the NHS and Age UK Croydon in a collaborative model of care that demonstrates much improved quality of life and considerable savings for the NHS through better, more coordinated support for older people living with multiple long-term conditions. The model is based on two strands of work – an integrated reablement and rehabilitation service upon discharge from hospital, and an equivalent service that aims to prevent hospitalisation for people who have been identified as ‘at risk’ through weekly interdisciplinary team meetings (‘huddles’) that are supported by an Age UK coordinator. These two approaches have demonstrated a return of £2.67 and £1.44 respectively for every £1 invested.¹⁷

After its first successful year, the Alliance has now been extended to a ten-year programme that also aims to reach younger adults. At its core is a meaningful relationship between a ‘link worker’ and the person who has some health-related complexity going on in their lives. This relationship is based on conversations that identify what the person wants to achieve and how medical, but also practical, social and emotional support can be brought to bear on these goals.



Robert from Croydon said:



I relied on medication for a number of long-term conditions and needed visits from carers three times a day. Thanks to [my link worker and team] supporting me, I can move around more and cook my own meals... I’m even getting up and down the stairs a few times a day and have been working with my doctor so I’m well enough to start driving again. And I’ve not been back in hospital since! I’m so much more confident now.”

What priority action needs to be taken ‘now’?

The changes people with long-term conditions (and their organisations) have been calling for years will only be achieved if the conversation between the health professional and the patient changes. This person-centred conversation must aim to identify what matters to the person and how clinical care, but also good emotional and practical support (such as ‘social prescribing’), can be brought to bear in order to mitigate the impact that illness has on their ability to live a good life.

Health professionals and their professional bodies should be challenged and supported to develop the knowledge, skills and confidence to have these conversations. This requires a whole system approach to setting up infrastructure in order to enable better, more holistic conversations with people about their needs, care and ambitions.



Integrating care

Don Redding on behalf of National Voices

What is the problem?

The NHS provides great care, and sometimes it provides poor care. The great care, for which people love the NHS and its staff, is usually provided by single individuals or teams working in a particular service. The poor care happens when someone needs care from a number of teams or services, and they don't work together.

Care and treatment have evolved, over decades, in different 'silos'. Each has its own governance, management, legal duties, performance targets and measures. They try to adapt to work together, but all too often they fail. This is a major issue because the people with most health needs are using multiple services over time:

- The NHS spends 70 per cent of its resources on people with long-term conditions.¹⁸
- Millions of them have several conditions, often a mix of both mental and physical illness see pages 10 and 11.¹⁹
- People make most use of services when near the end of life – when quality of care is defined by its coordination, but professionals don't always provide it.

There is now a growing awareness of the 'burden of treatment' that patients bear when they are required to get tests, treatments and monitoring from many services in parallel.²⁰ The risks of 'polypharmacy' (when someone is taking too many

drugs prescribed in different places) are well known.²¹ And stress and anxiety are caused to people and their carers by having to do their own care coordination in a fragmented system that they don't understand.

This poor care is unfair, unethical, potentially unsafe, and can make illness and the experience of death worse.

What needs to happen?

What people want is person-centred care. **When care services treat them as a whole person, educate them, empower them to make decisions, support them to define their own priorities, and then bring together what they need (clinically, socially and emotionally), people are relieved of this burden of coordination.**

Poor care – siloed, fragmented, based on the needs of the system – needs to be eliminated, by integrating care. But in order to do that, the right goals for integration need to be understood, accepted and adopted across the various systems and bodies that manage care.

In 2013 it looked like we were getting closer. All the national bodies signed up to a shared commitment,²² facilitated by Think Local Act Personal and National Voices. This redefined 'integration' from the individual perspective as 'person-centred coordinated care'. This was summarised as:

*"I can plan my care with people who understand me and my carer(s), allow me control, and bring together services to achieve the outcomes that are important to me."*²³

But in the subsequent five years, and as the House of Commons Health and Social Care Committee has reported,²⁴ we have taken one step forwards and two steps back.

'Integration pioneers' and new model 'vanguards' developed some exciting and effective small-scale schemes. But these were again judged, not by their benefits to people, but their impact on the system: on reducing hospital use, rather than achieving people's outcomes.

The select committee's advice on what needs to be done was clear.

Make a new integrated care plan, but don't get lost in structural tinkering. Focus on the person at the centre; judge progress by the outcomes for people; and ask Parliament for new legislation, where it is crucial to deliver those things.

Where is this already being done well?

The Fylde Coast²⁵ was a leading 'vanguard' developing a more coordinated offer to people over 60 with multiple health conditions. Its 'extensivist' model, copied elsewhere, brought together clinical and non-clinical staff in a multidisciplinary team around the person: including both GPs (generalists) and consultants (specialists), a care coordinator, and a wellbeing worker. Social care could also be triggered.

This model means the person has the opportunity to make a cross-service care plan, followed through with support to pursue their own personal goals using a single point of contact – the wellbeing worker – with whom they regularly meet.

What priority action needs to be taken 'now'?

The loss of clear goals and momentum for 'integration' since 2013, combined with the limited impact of previous experiments, has shown one thing above all. So long as separate performance requirements and perverse funding incentives remain in place, system-centred reform will always trump a person-centred approach.

We agree with the Care Quality Commission, which carried out in-depth investigations into joined-up care for older people in 20 local areas, and concluded that:

*"There should be a single, joint, nationally agreed framework for measuring the performance of how organisations collectively deliver improved outcomes ... [using] metrics that reflect outcomes for people."*²⁶

And the Health and Social Care Committee, which called on the key national bodies to address this:

"The Department of Health and Social Care, NHS England and NHS Improvement, should clearly define the outcomes the current moves towards integrated care are seeking to achieve for patients, from the patient's perspective, and the criteria they will use to measure."

Place-based, population-focused and person-centred care requires everybody in the health and care systems, including VCSE sector partners, to work collectively to achieve the outcomes most important to people and communities.

A short, single, simple, cross-system and consensual set of person-centred outcomes – with, as the CQC has also said, full reform of the funding that flows to achieve these – is essential to achieve great care for all the people who will need coordinated treatment and support during the next ten years.



Focus on the person at the centre; judge progress by the outcomes for people; and ask Parliament for new legislation, where it is crucial to deliver those things.

CARE & SUPPORT ALLIANCE

Sustainable social care

Caroline Abrahams on behalf of the Care and Support Alliance

What is the problem?

What happens in social care has a big impact on the NHS and vice versa. People being stuck in hospital even though they are medically fit to leave, because it has not yet proved possible to secure a social care package for them (either at home or in a care home) is a very real problem that demonstrates the interdependency of the two systems. Age UK has recently calculated that delayed discharges of older people due to a lack of social care cost the NHS a whopping £500 every minute.²⁷

One of the main reasons the relationship between health and care matters so much is because many people are in need of help from both. Our population is ageing, with the number of people aged 85+ growing faster than any other cohort. It is at this advanced age, as they approach the last part of their lives, that people are most likely to develop significant care needs. And these often coincide with living with multiple long-term conditions, including the dementia that now affects 850,000 in our society.²⁸ As a result, very old people are major users of both the NHS and of social care. Older people form such a big and increasing proportion of the NHS's patients that getting things right for them across health and care is imperative for it to thrive in the years to come.

Although the NHS still has much to do to adapt to the ageing population, the announcement of additional Government investment spurs genuine hope that good progress can be made. The position is less optimistic when it comes to social care, which starts from a far weaker position. **The poor relation to the NHS, ever since both were founded after the Second World War, social care in England has been allowed to wither away by successive governments.** Today it is chronically short of money, following years of cuts to the local authority budgets that mainly fund it. Without regular 'subs' from the NHS, and periodic bailouts from central Government, social care would now be completely bust.

Of course, social care isn't only a service needed by older people; it provides essential support for many disabled and chronically mentally and physically ill adults too, as well as their informal carers. Happily, people with disabilities are living much longer than they used to, but this is another driver of increased demand for care.

Although demand for care is rising fast, the numbers actually receiving it have gone down in the last few years, because of underfunding. Around 1.4 million older people now have some unmet need for social care,²⁹ and over half of disabled adults of working age say they do not receive the vital support they need.³⁰



Age UK has recently calculated that delayed discharges of older people due to a lack of social care cost the NHS a whopping £500 every minute.

The level of need people have to demonstrate to be eligible for state-funded social care has climbed as the services on offer have shrunk. In addition, many of the community services that used to provide low-level support to people of all ages – helping them to stave off the need for more formal care – have disappeared or been heavily scaled back. Among these are many local lunch clubs and day centres run by the VCSE sector – again the result of austerity.

The impact on people's lives of the crisis in social care is often severe, as shown by responses to a survey of 4,000 recipients of social care carried out by the Care and Support Alliance in early 2018. **As a result of a lack of care, over a quarter of respondents had been unable to maintain the basics such as washing, dressing or going to the toilet; one in five said they had gone without meals; and a quarter said they had needed hospital treatment.**³¹ Loneliness – increasingly recognised as a risk factor for ill health – is inevitably increased when social care is in short supply.

Good social care helps people of all ages to stay fit and well at home; in its absence, those in need of it are less resilient and have greater exposure to risk; for example, the risk of falling if you are an older person, or of failing to feed yourself and manage your finances if you are a younger person with severe learning disabilities or mental health problems.

There are obvious consequences for the NHS when social care fails; people are more likely to need to be admitted to hospital as an emergency and health issues are less likely to be picked up before they have taken hold.

What needs to happen?

The funding gap in social care is generally agreed to be about £2.5 billion; that's the amount now needed in terms of new investment just to prevent things from getting worse.³² In reality, much more is required to restore social care to being a decent service on which the public can rely. The Government is committed to publishing proposals by the end of 2018 for placing social care on a sustainable financial footing for the future, but the date has already been put back twice and, in any event, these proposals will look to the medium and longer term. Important as it is to redesign social care and how it is funded for future years, there is a pressing need to get a lot more money into front line services in the shorter term. **If the NHS is to have any chance of making the most of its additional funding, then there must be a generous three-year settlement for social care at the Budget later this year.**

Chronic underfunding is the underlying strategic problem social care faces, but regrettably, over time this has spawned other challenges too. One is a desperately unstable market, with significant numbers of providers quitting the business. Another is an enormous workforce shortage, recently estimated at 90,000 vacancies each day. A third, consequent on the other two, is poor or inconsistent quality, often as a result of there being too few well trained staff available, in care homes and home care. A fourth is the millions of informal carers, mostly family members, buckling under the strain – they need a lot more help and support, and to be involved in decisions.

What priority action needs to be taken 'now'?

If there is one crucial step that must be taken in the short term – in addition to the multi-billion pound, three year injection of state funds into front line care services already called for – it must be to start to grip the workforce crisis with a lot more ambition and determination than we have seen to date.

We are in desperate need of a truly integrated, long-term approach across health and care to workforce planning.

We have to end the situation in which care is merely a feeder for the health workforce. This means making a start now to create new, integrated roles, and narrow the gap in terms of pay and conditions. The NHS and care need each other and millions of vulnerable people of all ages need both of them; as 'people services', above all else, strengthening the workforce must be a core focus.



Relations and partnership with the VCSE sector

Alex Fox, as Independent Chair of the Joint VCSE Review and on behalf of Shared Lives Plus

What is the problem?

Voluntary, community and social enterprise organisations are key to establishing a more community-based health, care and public health system that will help people live well, longer, and at home, rather than spending long periods within health and care services. They are particularly vital to groups and communities that experience health inequalities and are currently less well reached and supported.

Many VCSE organisations build more supportive and active communities that tackle some of the social reasons for high levels of ill health. Some VCSE organisations support people in crisis or who have complex needs. Across this range of preventative and crisis services, great VCSE organisations think and act ‘whole-person’, building personal, long-term relationships with people.

These changes are crucial to integrating the NHS with social care, housing and other services that currently dip into people’s lives separately, causing people with long-term conditions stress and confusion, which in turn limits the effectiveness of those services in creating health, wellbeing and resilience.

The VCSE sector’s work benefits health and healthcare, but it has never been sufficiently valued by the NHS, which often mistakenly believes that work happens for ‘free’.

What needs to happen?

The Joint VCSE Review, following a wide consultation, set out two shifts that would reset the relationship between NHS, VCSE and communities themselves.

Firstly, co-designing health and care systems with citizens and communities, through the NHS and community-rooted organisations reaching and engaging citizens from all parts of local communities. This is crucial to delivering care that people feel is personalised to their needs, and maximises their capacity to look after themselves and each other. **The NHS needs new voices in the room to redesign itself, including from communities that feel under-reached by big statutory bureaucracies.** When public services do not listen to the people who use them, or they ignore some groups, then they do not live up to the NHS’s founding goal of providing more equal access to health and healthcare.

Where co-design happens, citizens ask for more of what the VCSE sector has to offer, which leads to the second shift: a bigger, strategically-resourced role for those VCSE services that demonstrate they can provide support that thinks and acts whole-person, whole-family and whole-community. **The growing number of people with one or more long-term condition, for instance, want support from people who have the time to build a relationship with them, and who can be there for the long haul.** VCSE organisations, whether delivering health and care directly, or working alongside other public services, are often able to take that long-term approach.



The NHS needs new voices in the room to redesign itself, including from communities that feel under-reached by big statutory bureaucracies.

This new partnership between statutory and voluntary organisations would mean them sharing their resources more equally: VCSE organisations would have more say in how local money was spent, while public services would benefit from community expertise, and increased volunteering.

It would also mean sharing responsibility and power more equally. So, when the NHS shares its resources with VCSE organisations, it is right that those organisations are challenged to deliver and demonstrate their outcomes, providing those challenges are proportional to the amount of money at stake.

Currently, VCSE organisations describe a constant battle between their missions set by their communities, and the need to chase funding priorities set elsewhere. To get the most out of every kind of organisation, all organisations involved in creating health and tackling illness must share the same clinical and wider wellbeing goals, set together with local people.

What priority action needs to be taken 'now'?

Actions to make these changes happen have been identified and further refined by the Joint VCSE Review oversight group and the Health and Wellbeing Alliance.

They include:

- Ensuring that VCSE organisations of all sizes have easy access to the tools they need to demonstrate their impact on health and wellbeing for the full range of groups and communities with whom they work, as well as how those impacts relate to clinical outcomes, efficiencies and savings.
- Integrated Care Systems utilising the co-production tools already produced by Think Local, Act Personal, plus NHS England and the Coalition for Collaborative Care working with the VCSE sector to co-design their services with poorly served groups and communities.
- Resourcing groups led by people who use services and self-advocacy groups to play a meaningful role in service co-design, with a greater role for citizen scrutiny of health and care commissioning and its success in tackling inequalities.
- Developing and expanding local infrastructure initiatives such as 'social prescribing' that can bridge the gap between the local community's organisations and NHS or council commissioners. Using 'simplest by default' funding for smaller organisations and specialist programmes to develop the smallest and most innovative enterprises.
- Making the use of existing Social Value Act powers routine across council and NHS commissioning, in order to embed volunteering, peer support and social action into public service delivery.

It is unthinkable that we will see a sustainable, community-based NHS in ten years' time without the new plan setting out a much more prominent role for the community sector in both the design and delivery of health and care services. This cannot be left to 'local leadership' alone: there is a need to invest in it; mandate it; measure and demand its outcomes; and challenge poor performance.

The NHS and its social care partners often talk about the VCSE sector as being important. The long-term plan is the NHS's opportunity to demonstrate that value through making ambitious, tangible changes in the relationships it has nationally and expects locally with our sector, backed up by commensurate investment.



Accountability for getting it right, and for when it goes wrong

Rachel Power on behalf of The Patients Association

What is the problem?

It can be fashionable to describe the NHS as a 'monolith'. As soon as you have to navigate it as a patient, it becomes clear that the truth is different. Rather, the NHS is an alphabet soup of organisations, processes and entitlements. Many people approach our helpline for basic information about where to turn next in the system, and how to access services, and even one's own medical records.

It is telling that in the week of the NHS's 70th anniversary, both the Care Quality Commission (CQC)³³ and the National Audit Office³⁴ issued reports setting out how interfaces between different NHS organisations, and between the NHS and social care, can often leave patients unsure of who will be caring for them, or who should be, or even if anyone will at all. This is a particularly acute and critical failing when the major challenge for the service is a growing number of older people with complex combinations of long-term conditions. Sometimes, of course, it all joins up – but if you find it doesn't, then figuring out where to go to fix the problems, let alone how to hold anyone to account, is mind-bogglingly hard for any regular patient.

This problem with accountability and navigability gets much worse once something goes wrong. People frequently turn to our helpline about: how to make complaints, how to report poor care for vulnerable patients, what to do about an unsatisfactory outcome, and how to take an issue through the Parliamentary and Health Service Ombudsman (PHSO).

But as we have seen too often, there is more going on here than merely a bureaucratic tangle. **Probably the least attractive characteristic of the NHS, sadly, is that when patients are harmed it has an enormous cultural predisposition towards secrecy, defensiveness and blame.**

We saw it in Mid Staffordshire, when the NHS completely lost sight of patients' experiences, often good professionals were driven to neglect any sense of compassionate care, and the hospital, *"put corporate self interest and cost control ahead of patients and their safety."*³⁵ We saw it at Gosport War Memorial Hospital: patients' concerns were ignored over decades; there was a, *"disregard for human life"*; and the hospital and other institutions who investigated it, *"all failed to act in ways that would have better protected patients and relatives, whose interests some subordinated to the reputation of the hospital and the professions involved."*³⁶

Official inquiries into these and other incidents, which reached the conclusions quoted above, have successfully shed light on the problem. Sir Robert Francis's Freedom to Speak Up review has outlined how staff can feel afraid to speak out because of, *"fear of the repercussions that speaking up would have for an individual and for their career; and the futility of raising a concern because nothing would be done about it."*³⁷

The CQC's 2016 review of how the NHS deals with patient deaths found that families, *"are not always treated with kindness, respect and honesty,"* and sometimes, *"family and carer involvement is tokenistic and the views of families and carers are not given the same weight as [those] of clinical staff."*³⁸

What needs to happen?

Happily, the direction of travel now seems positive in many ways. In terms of enabling patients to understand and navigate the system, the shift to integrated systems for delivering and funding services must surely provide a substantial improvement – although the acid test must be patients' experiences, not merely the creation of the institutions.

In the realm of safety and transparency, there has been a flurry of welcome measures: the Healthcare Safety Investigation Branch (to become the Health Service Safety Investigations Body) has a remit to investigate the systemic dimensions of failings, and spread learning; the CQC's methods and remit continue to be expanded and developed; a much-needed change programme is underway at PHSO; and the Duty of Candour and Freedom to Speak Up Guardians are now in place. All of these initiatives hold promise, but are yet to prove themselves. Given how long it takes to achieve cultural change at scale, they must be given adequate time and resources, and be evaluated as they go.

Elsewhere, however, obvious and sensible paths are not being taken. In response to rapidly rising litigation costs facing the NHS, the Government proposes simply to cap the costs available to injured patients. Inevitably this will exclude many from justice.

A step-change in complaints handling is needed instead: there must be real local resolution, where patients and their families are involved in planning the resolution meeting, and patients and staff are prepared and supported to attend. Mediation is currently under-used, and the NHS takes far too long to admit errors. Addressing these problems is the only way to address rising litigation costs at root.

What priority action needs to be taken 'now'?

Several essential actions already appear to be in the pipeline: the proposed new structures for the NHS should enhance accountability; threats to patient safety from over-stretched services should be mitigated at least in part by the new funding settlement; and the new safety initiatives need to be backed fully and allowed to make a difference.

However, structural and cultural change is still needed to deal with the systemic behaviours that lead the NHS to get it wrong on safety and transparency. As the pattern of the NHS's services is shifted from a focus on acute care to a focus on primary care and the community, this will have to be accompanied by a shift in where it focuses its targets and performance management. Any new targets must be carefully judged to ensure they do not incentivise perverse behaviours or a culture of bullying, and NHS Improvement's role, in this context, needs to be more about driving improvement than about performance management.

Leadership must be geared to ensuring patients have a high quality experience of care, and that when things go wrong the NHS takes patients' feedback seriously and is as open and transparent as possible. Performance management, transparency and responsiveness when things go wrong must be tackled and improved together, as a connected piece. The outcome must be an NHS that wants to hear the voices of patients and families.



Probably the least attractive characteristic of the NHS, sadly, is that when patients are harmed it has an enormous cultural predisposition towards secrecy, defensiveness and blame.



Promoting equality and reducing health inequalities

Jabeer Butt and Samir Jeraj on behalf of the Race Equality Foundation

What is the problem?

Chadrack, a four-year-old with learning disabilities and autism, was found with his arms round his dead mother Esther in October 2017 in their Hackney flat. According to the coroner, Chadrack had passed away about 12 days after his mother. He was unable to call for help. Esther, a lone parent, had epilepsy and appears to have passed away suddenly. According to the Multi-Agency Case Review, her GP had referred Esther to neurology.³⁹ Although she had tried the telephone booking service, she had been unable to secure an appointment because of her limited English. Whilst the school Chadrack attended had engaged with his mother, they were unaware that she had epilepsy and did not investigate his absence until 5th October, three days later – when staff unsuccessfully attempted to enter their building. Esther and Chadrack were eventually found on 17th October when the police broke into their flat after being alerted by Esther's cousin.

How much we can conclude from this case about the impact of inequality may be open to debate. However, evidence of poorer life expectancy of people with learning disabilities is clear, with them dying more than 14 years younger than the general population. Poorer access to health services for migrants, lone parents and those with English as a second language is also well documented. Hackney is the 11th most deprived area in the country, with the particular areas that Esther and Chadrack lived in ranked as in the most deprived fifth of areas in the country.⁴⁰ **What no one can debate is that the failure to promote equality and reduce health inequalities has real and material impact.**

The legislative framework in England already has many of the components to promote equality and address health inequalities in place. The application of the Public Sector Equality Duty to health services, with specific duties for CCGs to agree and publish equality objectives, has been in place since 2013. Alongside this, the duties introduced by the Health and Social Care Act 2012 include requiring the Secretary of State to annually report on progress in addressing health inequalities. Importantly, the NHS has not lost sight of its original focus on inequality – for example embedding the Workforce Race Equality Standard into the standard contract, and requiring NHS organisations to start recording sexual orientation.

Repeatedly, however, the health care system has fallen short. The evidence from Winterbourne View showed systematic maltreatment of people with learning disabilities. Caribbean men continue to be over-represented in secure mental health settings, with poorer access to community mental health services. And the biggest employer in England appears to be still struggling to deliver equality: female doctors are still not progressing or being paid as much as their male counterparts, whilst disabled workers across the NHS and workers of black and minority ethnic origin continue to experience comparatively poorer rates of promotion and pay.

What needs to happen?

We need wide action to address the social determinants of health, as has been the call since the publication of the Acheson report and Marmot review. Nevertheless, the NHS also has a duty to promote equality and reduce health inequalities.

Primary care in areas of multiple deprivation must be a priority. There were 8,207 GPs working in areas containing the most deprived 20 per cent of the population in England in 2008, but by 2017 that had fallen to 7,696 compared to a small increase within wealthier areas.⁴¹ Health Foundation research indicates this is likely to worsen,⁴² and worryingly, the Care Quality Commission has rated a higher proportion of GP practices as 'Inadequate' and 'Requires improvement' in urban areas.⁴³ At the end of last year, 62 GPs in Tower Hamlets wrote to Jeremy Hunt to raise the issue that they had seen an increase in population of around 12 per cent while the funding to their CCG only covered two-thirds of that increase – equating to a cut of £12.5 million compared to five years earlier.⁴⁴

The case for change in mental health services is made in pages 28 and 29, but the experiences of black and minority ethnic people in mental health crisis care underline the need for better access and quality of services at an early stage. Black and minority ethnic people continue to be at greatest risk of being detained in the mental health system.⁴⁵ This persistent inequality in use of detention was explicitly recognised by the Prime Minister in launching the Independent Review of the Mental Health Act.⁴⁶ Both young South Asian women and black women are more likely to self-harm at a young age than white women and less likely to attend A&E with repeat episodes of self-harm.⁴⁷

Improving Access to Psychological Therapies (IAPT) services have been tasked with reaching 25 per cent of people with depression and anxiety by 2020. They had an early focus on black and minority

ethnic communities, with services encouraged to develop and implement good practice, for example Birmingham's Healthy Minds, which ran a scheme focused on South Asian women.⁴⁸ However, there continue to be challenges, with black and minority ethnic people less likely to be offered talking therapies, waiting times that can be several months,⁴⁹ and outcomes still unequal. Moreover, the black and minority ethnic led voluntary sector, which was rated best in the review of Crisis Care, is facing existential challenges, with several specialist and many generalist organisations collapsing in the past decade.

Again, there is recognition of the need for wide action to address the social determinants of health. **Nonetheless, the long-term plan for the NHS must promote equality of access and address health inequalities to positively change the experience of black and minority ethnic communities as a whole, and Caribbean men and South Asian women in particular.**

What priority action needs to be taken 'now'?

The introduction of a formula (in 2014/15) for the allocation of funding for primary care and CCGs that attempts to improve access to services and reduce health inequalities has been welcome. However, as NHS England has recognised, the lack of comprehensive data on unmet need across England has led to a pragmatic approach to adjusting the weighting of the formulae, which continues to be revised.



The new investment in the NHS must build upon the existing formula and learning, which will require filling some of the data gaps. It will also mean reviewing whether the current 'pragmatic' weighting is sufficient to be transformative in addressing health inequalities such as the unacceptable level of cervical cancer screening offered to women with learning disabilities. The long-term plan must also ensure areas of multiple deprivation are adequately funded so that access to primary care services can be equitably transformed.



'The workforce': People and relationships

Jocelyn Cornwell on behalf of The Point of Care Foundation

What is the problem?

There are not enough of the right people with the right training and experience to meet the needs of patients. This is the immediate problem staring the NHS in the face. The critical lack of bodies on the ground has focused senior decision-makers' attention on 'the workforce'. But to solve the problems, we need to stop talking about 'the workforce', and start talking about people and relationships. And we need to focus on the deep-seated systemic issues within the health system that underlie workforce problems.

In primary care and in community settings, the shortage of qualified personnel is desperate. Over half of GP practices report at least one vacancy,⁵⁰ and between 2009–14, district nursing posts halved.⁵¹ In hospitals, consultant numbers have risen, but there are rota gaps in all specialities because the number of newly qualified doctors choosing to go straight into NHS posts is falling – from 72 per cent in 2011 to 50 per cent in 2016.⁵² In nursing, 36,000 posts are vacant and leavers are not

being replaced quickly enough.⁵³ The number of student nurses has fallen since the Government removed bursaries, and the number of new joiners from Europe has fallen from 9,389 in 2015/16 to 805 in 2017/18.⁵⁴

It is impossible to overstate the impact of these shortages on the staff who remain in post or have recently joined the service, and who have to help or work around temporary staff, plug gaps and spread themselves more thinly. They come under increasing pressure, which in turn causes stress and make the work less satisfying. Surprisingly perhaps, sickness absence has declined in the last few years – while it is very highly managed, presenteeism (people reporting to work when they do not feel well) has reached an all-time high of 65 per cent.⁵⁵ **The everyday experience of too many employees is one of feeling that although their work with patients is worth doing, the organisational environment makes the work difficult or impossible.**

Some of the people under the most intense pressure are the middle managers – the department and directorate managers, many of whom are clinicians in management roles who sit below the level of executives, with numerous, often first time managers reporting to them. These are the people who have to reconcile conflicting and sometimes incompatible demands. They are operationally responsible for everything that happens to staff and patients, but have very little power over resources and decisions.

Recent annual NHS staff surveys show that staff engagement and relationships between staff and their immediate managers are satisfactory and improving, but they also tell us that NHS organisations discriminate against black and minority ethnic staff and tolerate levels of bullying and harassment by managers and co-workers that would not be tolerated by good employers. In 2017, 38 per cent of staff reported feeling unwell due to work related stress.⁵⁶

What needs to happen?

At national level, **senior policy makers need to stop talking about 'the workforce' as if it is some kind of abstract and renewable natural resource, and start talking about people – with lives of their own, who have choice and who need to be attracted, rewarded and supported** as they do the difficult work of caring for patients within a difficult and uncertain environment.

Employers need to make practical provision to promote the physical and mental health of employees, provide opportunities (such as the Schwartz Rounds) for them to reflect together on their work with patients, and reduce the administration and bureaucracy that weighs people down and gets in the way of delivering good care.

At local level, NHS employers must make sure the people who work for them feel supported, listened to and valued by their managers and colleagues. Staff must be able to seek help when they need it, without being labelled as 'weak', and be able to develop their career and themselves.

Finally, staff wellbeing and experience needs to be incorporated into the narrative about change and transformation. **We cannot change services in the ways described elsewhere within this collection, without investing in helping the people who provide the services to change.** This will require investment in training, coaching and on-going support. To give just one example: doctors today have had no formal training in patients' experience of illness, patients' experience of services, how to share decisions about treatment with patients or how to help patients manage symptoms. If we want staff to have compassionate, more equal relationships with patients, and to provide leadership and work effectively in multi-disciplinary teams, then we need to offer new and different types of training and supervision at scale.

What priority action needs to be taken 'now'?

NHS England is the lead organisation responsible for providing safe, high quality services and should not delegate responsibility for 'the workforce' to other bodies. It needs to set the pace and create a bold and inspiring ambition for the NHS to become the place where people of all ages in the UK want to work, and it needs to lead practical actions that will achieve it.

Nationally, more can be done to recognise the intense pressures on people who work for the NHS and how hard they are working to maintain standards for patients. The NHS is brilliantly positioned to exploit its position as Britain's most loved institution and actively and openly celebrate the fact that, in an era when work for many is soulless and unsatisfying, the work of caring for people and helping them to live healthier and fulfilling lives has meaning and purpose.

Local NHS organisations should cultivate a reputation for listening to and caring about their staff. For trusts that have yet to make staff engagement a board level priority, the recommendation is to make it one. All trusts should have board level strategies for staff engagement that are supported by an operational plan, a two-way communications plan co-created with staff, a governance plan, and a plan for investment in organisational development and training. Within these, trusts need to recognise and respond to the needs of middle managers – the people with most influence over how other employees feel at work – including through investment in multi-disciplinary leadership training and on-going developmental support.

There is much to do, but we must start by remembering that staff and services are synonymous. Without engaged and motivated staff it is simply impossible to provide high quality treatment and care, let alone accelerate improvements.



Senior policy makers need to stop talking about 'the workforce' as if it is some kind of abstract and renewable natural resource, and start talking about people.



Respecting and supporting carers

Laura Bennett on behalf of Carers Trust, Emily Holzhausen on behalf of Carers UK

What is the problem?

Carers are children and adults who care, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support. Carers are also patients – a group with their own particular health needs – who the NHS needs to treat and support. Carers are important partners in care: they are the people who will spot when someone is relapsing, or who can share valuable information about treatment that worked in the past.

Carers face significant health inequalities, with their health and wellbeing highly impacted by their caring role: 61 per cent of carers said their physical health had gotten worse because of their caring role, and 70 per cent have experienced mental ill health.⁵⁷ Carers are more likely to have long-term health conditions: 61 per cent, compared to 52 per cent of people not in a caring role, and are more likely than those not in a caring role to report problems with depression, pain, and mobility.⁵⁸

Research shows 67 per cent of older carers say being a carer has an adverse effect on their own health, 57 per cent of older carers had cancelled or postponed their own health appointment because of their caring role, and 81 per cent of older carers felt lonely and isolated.⁵⁹ Where carers have to give up employment or aren't able to reach their potential in education, this also impacts on their wellbeing and income.

Despite this, carers are still too often overlooked. They didn't receive a single mention in the Prime Minister's speech on the future of the NHS on 18 June 2018.

What needs to happen?

There should be a duty on the NHS to identify carers. Policies that identify carers should be a requirement for all NHS services.

As described on pages 12 and 13, a major improvement in care coordination between health and social services is needed so that carers do not become burdened navigating the health and care systems on behalf of those they care for.

NHS staff need to make sure they are supporting carers to stay as healthy as possible. This means not just identifying carers, but supporting carers with their health, and referring carers to local support and services.

The NHS needs to work more closely with local carers services, which are well placed to help, as part of the wider local VCSE sector.

As explored on pages 14 and 15, the continued impact of the delay in finding a long-term sustainable social care funding solution has a major impact on carers. They are having to do more caring because health and social care aren't working for the people they care for, as well as not getting their own social care support. Whatever changes the NHS makes will struggle to make an impact without social care improvements.

Carers' needs must be seen as a public health issue: this group face difficulty in attending screening appointments, getting enough exercise and making healthy food choices. Carers also experience loneliness, another public health issue that is gaining increasing recognition.

Where is this already being done well?

Following the Five Year Forward View, NHS England has provided, through its Commitment to Carers programme, a carers' commissioning toolkit, and a memorandum of understanding to help the NHS and local authorities cooperate and meet their duties under the Care Act.⁶⁰

Involving local carers services, as part of the wider VCSE sector, has shown examples of innovation with positive results:

- Bristol Carers Support Centre has a carers' app. With appropriate consent, the app allows GPs to directly pass on carers' details to Bristol Carers Support Centre, leading to a 40 per cent increase in referrals. This helps increase identification and get carers timely support, whether this is low-level prevention type support, or more intensive casework.
- Trafford Carers Centre has also developed an app, which brings health information (prescribed medication, vaccinations, GP record, GP appointments, repeat prescriptions, blood test results) together in one place. This supports carers around managing their own health, and – with the consent of the person they care for – helps carers support, or manage, the health of the person they care for.
- Leeds Health and Wellbeing Boards have made a commitment to carers. Support for carers is part of the local performance dashboard, and carers are written into the Joint Health and Wellbeing Strategy. A joint post sits across the local authority and CCGs, and they work closely in partnership with Carers Leeds. All Leeds GP practices can refer carers to Carers Leeds by completing a 'Yellow Card Referral'. As part of the process, GP practices are encouraged to use the Yellow Card as a prompt to record a patient as a carer on their practice database, ensuring that carers can be identified when contacting their practice and offered appointment times and services that fit with their caring role, including carer health checks and access to flu vaccinations. Carers Leeds also offers Carer Awareness Training for staff in primary care.
- The RCNi (a subsidiary of the Royal College of Nursing) Award 'Commitment to Carers' nominees and winner show excellent examples of the NHS making carers their business.⁶¹

What priority action needs to be taken 'now'?

The NHS should ensure all eligible carers are offered a flu vaccination, and ask everyone attending an NHS health check if they are a carer. This gives primary care staff the opportunity to make contact with carers, offer advice on issues for the NHS like being a healthy weight and stopping smoking, check their blood pressure, promote appropriate screening for their own health (such as cervical smear or bowel screening), and proactively refer carers for other NHS support like psychological therapies (IAPT). This would see the NHS offering carers something for their own health, enabling them to feel supported as partners in their own care as well as that of the person they care for.



The NHS should ensure all eligible carers are offered a flu vaccination, and ask everyone attending an NHS health check if they are a carer.

VOLUNTEERING MATTERS

Volunteering and social action

Duncan Tree on behalf of Volunteering Matters

What is the problem?

'Volunteering' is time given freely for the benefit of others. It takes many forms and may take place through organisations (formal) or with friends and neighbours (informal). Within health and care, it can happen in any service, including GP surgeries, hospitals and community centres.

'Social action' is time freely spent with others to tackle local challenges, negotiate with public services, and improve conditions that benefit all. It is often carried out through community groups – some of which are long-standing, and some of which come together for the cause in question. Social action can be aimed at maintaining or improving the health of people and their communities.

Volunteering and social action are regarded by the NHS and its partners as broadly positive and helpful, **with almost 3 million people volunteering in health and social care services in England.**⁶² Yet our public debate, our commissioning and our operational management are often out of kilter with the reality of volunteering's importance, let alone its greater potential.

There are well-documented reasons why volunteering and social action are yet to be mainstreamed:

- Volunteering has a less positive reputation among certain groups, notably among many men, some younger people and some ethnic groups. These groups are significantly under-represented in formal volunteering, including health and social care volunteering.
- There are particular issues for disabled people. These include 'access issues' and the impact of the stigma still sometimes associated with disability.
- Potential volunteers and social activists have other important commitments, including work, caring responsibilities or study.
- Some volunteering opportunities lack flexibility or do not provide sufficient financial help for unemployed or low-income volunteers.



Almost 3 million people volunteer in health and social care services in England.

What needs to happen?

Volunteering and social action – already integral to the NHS today – should be instrumental in shaping how health services work tomorrow. **Across local government as well as the NHS, there is increasing interest in approaches that seek to work with and build upon the assets of our communities. Many of these approaches depend on volunteers and social activists – as 'health champions', advocates, information givers, representatives, peer supporters, patient leaders, community organisers and concerned, empowered citizens.** They could be transformative in shifting behaviour and building relationships that support our individual and collective health and wellbeing.

We face fundamental challenges in terms of skills, culture and organisational rigidity. We need to take action to:

- Promote the public understanding of volunteering and social action.
- Improve genuine access to volunteering opportunities for all in society.
- Offer more tailored, person-centred opportunities, so that we engage people in activities they really care about.
- Become better at measuring and understanding the impact of volunteering and social action on health and care; and learn and then build upon what we find.

What does this require in practice?

- Key NHS and social care personalisation and integration programmes should be required to clearly set out how volunteering and social action are part and parcel of their delivery through individual citizens' involvement in, for example, 'social prescribing', personal health budgets and health champion initiatives.
- **Strategic investments should be made in local organisations, such as Centres for Voluntary Service and Volunteer Centres, that promote and support volunteering in their communities;** as well as at local volunteering and social action initiatives carried out by other charities, voluntary sector organisations and Community Interest Companies.

- There needs to be support for national and local 'demonstrator' work on promoting and broadening volunteer participation, particularly with regard to improving the inclusion and experience of those who are currently benefiting least from volunteering.

Where is this already being done well?

There are many examples from across the country of exemplary schemes that promote volunteering and social action. One is Volunteering Matters' Futures Project, based in Norfolk, which recruits and trains volunteer mentors to support young volunteers with disabilities into the right volunteering opportunity for them. The mentors also support mentees to acquire the skills and resilience they may then need to stick with that opportunity, so making a meaningful and personally fulfilling contribution to society. To achieve this, the project works closely with young people, their families, schools and other support networks and organisations. It provides an opportunity for young people with disabilities to maximise their skills and future employability; enables them to make friends and expand their networks; and helps ease many of them through the difficult transition from adolescence to adulthood.

There are of course also many well-established schemes in our hospitals, health and community centres, libraries and GP surgeries – each of which makes a contribution to the mental and physical health of people using services, to the wellbeing of the volunteers, and to the wider public health and resilience of the whole community.

What priority action needs to be taken 'now'?

The health system cannot achieve its goals without the support of volunteers and social activists. The "new NHS," as outlined in the Five Year Forward View, and coming to life through national programmes including New Care Models and Integrated Personal Commissioning, must be built on a bedrock of empowered citizens – each of whom has a personal stake in their health and care services. **Patient activation and active citizenship need to be thought of as two sides of the same coin.** These programmes now need to be at the forefront of shifting volunteering and social action from margin to mainstream.

Centre for
Mental Health



The NHS and mental health

Andy Bell, Centre for Mental Health

What is the problem?

In 2012, the Health and Social Care Act included a new requirement for the NHS to have equal regard for both mental and physical health at every level of the system. The idea of ‘parity of esteem’ followed a significant rise in public and political attention to mental health issues, as well as a growing awareness that the NHS had favoured physical health care to such an extent that it was both failing to meet millions of people’s basic needs and wasting money as a result.

Support for our mental health accounts for about 12 per cent of all NHS spending. Yet mental health problems account for about twice that proportion of the ‘burden of disease’ in society.⁶³ And the NHS spends as much again, if not more, on the consequences of not treating mental health difficulties – particularly among people with long-term conditions.

The King’s Fund and Centre for Mental Health⁶⁴ noted that some 4.6 million people in England have both a long-term physical condition and a diagnosable mental health difficulty at the same time. Without effective help for their mental health, the result

is significantly poorer physical health, earlier death and an extra cost to the NHS of around £10 billion.

Inequalities between mental and physical health are prevalent across the NHS. People living with a serious long-term mental health condition face a life expectancy that is 15–20 years shorter than average as a result of poorer physical health (and health care).⁶⁵ And up and down the country many more people living with ‘unexplained medical symptoms’ are sent from GP surgeries to outpatient departments without any support for their mental health.⁶⁶

Historic under-investment in mental health services, particularly for children and young people, is only now being addressed at the national level. Both the Five Year Forward View for Mental Health and the Future in Mind strategy will help to narrow the gap, but only if nationally-mandated investment is matched by local commitment to sustain and build on their improvements.

What needs to happen?

A long-term plan for the NHS is an opportunity to bring about the level of change that will be necessary to rebalance health and care towards greater ‘parity’. Essential to achieving this, is to shift the balance of investment towards mental health: for example by offering many more people with long-term physical conditions access to effective emotional and psychological support. But as described on pages 22 and 23, it also depends on making changes to the NHS workforce: ensuring that all health and care staff have a better understanding of mental health and the ability to cross the divide with physical health.

It will also require further changes to the way mental health support is offered throughout our lives. We know that our chances of having good or poor mental health are influenced from pregnancy and at every stage of our lives by the environment we live in. Preventing mental health difficulties and offering effective help when people first seek it are essential for both a sustainable NHS and a fairer society. We therefore need to invest at scale in supporting young families to nurture their mental health, in promoting good mental health in schools, and in reaching out to young people who face the biggest risks of lifelong mental ill health unless they receive the right

support early on.⁶⁷ And in adult life, we know that poverty, poor housing, loneliness, unemployment and physical health problems are all risk factors for mental ill health and its consequences. Yet it doesn't need to be this way.

Where is this already being done well?

Across the country, NHS commissioners and providers are working with partners in local government and the VCSE sector to bring about change. Many are creating new perinatal services to support women experiencing poor mental health during pregnancy and in the months that follow. And as more and more acute hospitals have liaison mental health teams in place, some psychiatric units are now setting up liaison physician services and providing regular health checks and fitness facilities.

A growing number of primary and secondary schools are seeking ways of supporting their students' mental health, working with organisations like Place2be. There are projects that seek to support marginalised young people's mental health in new ways, such as Up My Street in Birmingham⁶⁸ and the work of MAC-UK in London.⁶⁹

In adult mental health services, more trusts are now adopting Individual Placement and Support approaches to supported employment, as well as recognising the need to provide help with housing and finances. Some local areas, including Sheffield and Bradford, have taken concerted action to ensure people needing hospital care are not sent far from home, without having to increase their supply of beds. We are also seeing important new developments in primary care to offer better support to people with a wide range of mental (and physical) health needs – such as City and Hackney's Psychotherapy and Consultation Service, the LIFT service in Swindon and PRISM in Cambridgeshire.

What priority action needs to be taken 'now'?

The challenge for the next decade is to take all of these advances to a nationwide scale, and in doing so bring about shifts in investment to address inequalities, achieve a greater focus on earlier intervention, and create services that are designed and delivered in partnership with communities. Too often, the biggest barrier to 'doing what works' is the inability of local and national systems to invest now to save later.

In the case of mental health, investment is often needed in one sector to generate savings within another – savings that may take years or even decades to materialise in full – routinely seen as unthinkable in times of austerity.

A long-term plan is therefore an opportunity to make large-scale change happen in every part of the country. But for the NHS, this will require a preparedness to work much more closely (and generously) with local authorities, schools, housing providers and community groups – and indeed within the NHS, across its many organisations. To date, there has been little evidence of this happening beyond a few local areas. And it is the people who are most marginalised who fall into the cracks created between systems and services.

If the NHS can plan for the long term to build on the progress it has made through the Five Year Forward View for Mental Health – in a genuine partnership with others at every level – then there is a chance we can create a fairer, more sustainable and more effective health and care system for the future. There can be no greater legacy for the NHS's 70th birthday.

Support for our mental health accounts for about



of all NHS spending.



Better engagement for a better plan and better results

Imelda Redmond on behalf of Healthwatch England

What is the problem?

The relationship the public has with health and care services is central to our national life. How well we are involved in decisions about health and care, from the NHS Plan down, will determine whether any of the aspirations set out by other writers in this collection can be achieved.

Why does this matter so much? People's love for, pride in and concern about the NHS is one of the constants of modern policy and politics. IpsosMORI's research for the King's Fund this year showed that almost eight in ten of us want to maintain the NHS on its current basis and nine out of ten support its founding principles.⁷⁰ That's what has won the argument for improving NHS funding and it's why there will be a long-term NHS plan. It's also why those who fund and depend upon the NHS must be at the heart of decisions as it rolls out across the coming decade.



People's love for, pride in and concern about the NHS is one of the constants of modern policy and politics.

It's crystal clear that the plan will mean substantial change – change that will simply be impossible to deliver without people recognising it as meeting their needs, being in their interests and bearing the visible marks of what they've said. You can't sustain and transform a crucial public service without taking the public with you, or without an honest dialogue with and about the inevitable winners and losers from any change.

What needs to happen?

Now, more than ever, there's a real chance to do that. Possibly the most critical barrier to engagement in the past has been the taboo stopping leaders from admitting when things aren't working and using that to make the case for change. Trying to sell changes to something you say is already working wonderfully is like trying to push water uphill. Now, at last, the NHS doesn't have to; it's OK to acknowledge the scale of the challenge.

The Next Steps on the Five Year Forward View rightly began to talk about trade-offs and used people's views in that process. **The frank and very public discussions this year about the problems the NHS would face without – and even with – substantial extra funding have now opened up a space to develop the right approach to engagement.**

The NHS's national leaders know that and have already set out clearly in the Next Steps on the Five Year Forward View how things need to be done, by adopting the five Healthwatch engagement principles:⁷¹

1. Set out the case for change so people understand the current situation and why things may need to be done differently.
2. Involve people from the start in coming up with potential solutions.
3. Understand who in your community will be affected by your proposals and find out what they think.
4. Give people enough time to consider your plans and provide feedback.
5. Explain how you used people's feedback, the difference it made to the plans and how the impact of the changes will be monitored.

Let's focus in the next few months on ensuring what people have already said truly shapes the plan.

These principles apply just as much to the NHS plan as to local or regional work, and national leaders need to model this behaviour, pushing it through the system and rewarding local leaders for working in this way.

There's a wealth of current insight from the independent work of Healthwatch, the VCSE sector, and from national and local work in health and care services. The plan should use this to shape and describe the reasoning behind its proposals. It should invite comment from the start, so that people can help to build workable solutions. It should commit to developing a deep understanding of different communities' needs and experiences, to put flesh on the bones of recent welcome messages about focusing on health inequalities. And it should be explicit that the plan is not the last word but the start of a continuing conversation, where honest assessments of progress help people to shape decisions each time there's a fork in the road.

Healthwatch work has consistently shown that people are reasonable, realistic, flexible, thoughtful and intolerant of waste and inefficiency. Yet too often, those who should welcome people's creative input are instead paralysed by fear of hearing uncomfortable truths. Really, there's more to fear from not involving and engaging people.

All of this presents the plan's authors with real opportunities. The scale and scope of the plan needs to be ambitious, yet there's limited time to produce it. That means the wider health and care community, local government, the VCSE sector and the public all need to acknowledge that the plan unveiled in November

won't and can't be a total solution. Similarly, NHS England has announced that it will develop an NHS Assembly to bring wider voices into these key debates and decisions. If the Assembly's to come into existence once the plan is published, that means two things.

Firstly, let's use this time for proper thought about what will really take engagement forward over the next decade. The Assembly will provide a key national focus and there needs to be good engagement about its construction so ideas about how to make it genuinely representative and impactful can all be fully explored. Bolting such an important mechanism together in a post-plan rush simply wouldn't deliver.

Secondly, let's also focus in the next few months on ensuring what people have already said truly shapes the plan.

Vitaly, the plan also needs to clearly set out how a meaningful chunk of the additional resources will be invested in involvement and engagement, through the statutory route of the Healthwatch network as well as through the VCSE sector and public bodies' own activities.

We have an era-defining chance to incorporate meaningful engagement into the way health and care services think and operate and we owe it to those who fund and depend on the NHS to get it right this time. Now's the time to do it.

**Almost eight in ten of us want to maintain
the NHS on its current basis.**



**and nine out of ten support
its founding principles.**



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Priorities for the Plan

July 2018

Please contact the authors through their organisations' 'Contact Us' webpages to find out more about the issues considered within their chapters. Please direct any general queries to info@nationalvoices.org.uk, referencing 'Priorities for the Plan' within the subject header.