

# BY THE PEOPLE, WITH THE PEOPLE

HOW THE NHS CAN WORK WITH US TO MAKE US PARTNERS IN OUR OWN HEALTH

Charlotte Augst and Paul Corrigan November 2023

### Acknowledgements

We enjoyed collaborating on this report and bringing together our experience of working in government, the health and care system and the community sector. Early discussions included Dr Katherine Pereira – we are grateful for her contribution. Our thanks also go to all the people leading the good work described in this report who agreed to talk to us, despite their busy lives. You are the vanguard of a better future for people and the health system, and we are grateful for your leadership.

### About the authors

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# FOREWORD: KIM LEADBEATER MP

We need a radical rethink about how we promote health and wellbeing in this country. After years of fragmentation and short-termism, we must bring together all sectors of society and all departments of government to adopt a holistic perspective. While the NHS will rightly focus most of its efforts on treating illness, it also has a responsibility – as do we all – to further health creation by taking practical steps to promote good health and fitness, helping to keep people well, both physically and mentally, for as long as possible.

Crucially, most of what determines success or failure in this endeavour takes place outside hospitals and GP surgeries. It happens where people live: in their houses, schools, and workplaces, and through their relationships and communities.

That was the central argument of my Fabian Society report, <u>Healthy Britain</u>, published earlier this year. The response has been fantastic, with huge support in the wellbeing and fitness sector where I used to work, as well as from patient organisations, the voluntary sector, businesses, academics and political leaders at all levels. There is widespread agreement that we need to get serious about health creation in all our communities.

This is not an argument for a smaller NHS. The next government will need to invest in health and the care sector, not least in its depleted and demoralised workforce. What we need – as Charlotte Augst and Paul Corrigan argue powerfully in this pamphlet – are new ways for health professionals to work in partnership with people and communities to improve the health and wellbeing of everybody. As the authors say, health and care services must get alongside people, and focus on what helps them to manage their own health better.

This report follows up my own by asking some important questions: how does the NHS need to change, once we understand that it is far from the only actor shaping our health? How can the NHS work in conjunction with people who use health and care services, and support those who face discrimination or deprivation to play a fuller role in their own health?

I am delighted to have played a part in stimulating this debate, and it's very gratifying to see these ideas being realised in so many practical, imaginative proposals in this report.

Kim Leadbeater is the Labour MP for Batley and Spen.

# INTRODUCTION

Given the current state of services, many people find it hard to be optimistic about health and care in England<sup>1</sup>. Arguably, things have never been so bad. Dangerously long waits to be helped in an emergency, eight million people waiting to see a specialist, record low satisfaction with primary care, inadequate social care for many thousands, excess mortality, growing health inequality. The list of problems is long, and solutions seem distant.

Policy documents and national plans have, for decades, sketched out a more sustainable system for the future, to be realised by delivering more preventative interventions, 'getting upstream', joining up silos, and working better with people and communities. Such ideas are featured in the Five Year Forward View, the NHS Long Term Plan, the Future of Hospitals Plan, the Wanless review, and 'My health, my care, my choice', to name but a few.

The 2019 Long Term Plan, for example, provided clear direction:

1.2. The long-standing aim has been to prevent as much illness as possible. Then illness which cannot be prevented should wherever possible be treated in the community and in primary care. If care is required at hospital, its goal is treatment without having to stay as an inpatient wherever possible. And when people no longer need to be in a hospital bed, they should then receive good health and social care support from home.

But central government and its commissioning arm, NHS England, did not provide the resources to run preventative services, keep activity in primary care and move people through hospital quickly.

In fact, when you look at the data, we are going backwards. Investment and services are increasingly concentrated in hospitals, the share of primary care funding and staff is decreasing, community services are decimated, and the public health grant is shrinking. Resources have not followed the policy direction set out in plans. We have seen the hospital-based medical model grow, with predictable pressures building up in emergency and outpatient services. We are now stuck in a cycle of firefighting, in ever decreasing circles of acuity, facing crises, many of which are preventable.

Our intention in this pamphlet is not to restate the case for change in the health and care system. We believe that there is already consensus on where we need to get to. Instead, we are interested in what has scuppered progress on this widely shared agenda. We want to explore how we can break the logjam on change.

The NHS is often characterised as one of the last nationalised industries. Given that it is wholly funded by taxes and accountable to parliament, people would be forgiven for imagining that Whitehall could just tell everyone to change the way they work.

However, this approach to making change has been tried and tested to destruction. It is not enough. Whitehall is a long way from your GP surgery or outpatient clinic. Instructing a million doctors and patients every day that they have to interact with each other differently just doesn't work.

But change is not impossible.

It has become common for commentators to emphasise the difficulty of making change happen in complex systems, and there are few more complex than health and care. But too often this emphasis on complexity creates a smokescreen for inertia: because everything has to change, we don't know where to start.

However, drawing on our professional experience of making change happen despite this complexity, we argue that not only do we know enough to make a start, but also that we can already see the green shoots of change in multiple places. *If everything is connected to everything, then there are many places where you can start to make the change happen.* 

We contend that one key reason that change stalls is that NHS policymakers tend to leave the crucial interactions between health professionals and the people who use services beyond the policy focus. These crucial interactions remain in a black box while we try to change everything around them – the governance, regulation, payments, incentives and reporting structures shift, but nothing changes for people who work in services or who use them.

We believe that if we want to change outcomes, changing these everyday interactions is key. We need to recognise the reality that our health depends to a far larger extent on things that happen outside the consulting room – on the families and communities in which we live, our housing, our work and finances, whether or not we face prejudice and discrimination – than things that happen in it. We believe that if we take this reality seriously our healthcare system will look different: it will get alongside people, tackling obstacles to health with them, and focusing on what helps them to manage their health better. We know we are not alone in believing this. There have long been calls for a shift away from the medical model, towards creating health with people, recognising the impact of wider determinants. A 'health in all policies' approach will be vital if we want our health service to be sustainable. Most recently, we were heartened by Kim Leadbeater's call to build a health service rather than an illness service in her <u>pamphlet for the Fabians</u>, Healthy Britain.

Such a shift would have implications for every aspect of care, but this pamphlet focuses on two parts of it. First, how can the NHS work with people to keep them healthy? Second, how can the NHS strengthen the contribution people themselves can make to their health and healthcare once they have acquired an illness or an impairment?

The NHS refers to the process through which people contribute to their own healthcare as 'supported self-management'. This term captures only part of what we want to discuss – because the focus on 'self' doesn't give enough weight to the role of community. When you attend a 'life after stroke' group or go walking with people who attend the same GP surgery as you, you are not only building your own health; rather, you are collectively, in partnership with those who organise the service, building the health of the wider community. What we are interested in is helping people and communities manage and develop their health together, with the NHS as a partner, supporter and champion of this vital work.

To succeed, we will need to embed a belief in the power of people and communities at every level of the health system:

- People need to be treated as experts in their own health and care as they interact with the health system, defining the outcomes which their treatment should achieve and feeding in to how it is assessed.
- People who use care need to sit at the table, with the full range of organisations who might support them, to design and commission care pathways that meet their needs.
- NHS bodies need to work in partnership with community organisations which help people to stay well. These relationships need to build and sustain those communities, rather than extracting capacity from them.
- Commissioners and service designers need to have mechanisms for understanding what goes on in their communities and what people need and want from their health service, and should be held accountable for delivering services in accordance with these wants and needs.

• Ministers need to manage the health system with the people who use it and in line with their wishes.

In the next section, we will explore in more detail the kinds of changes we believe the NHS needs to make to become a better partner to people and communities in their health. We will showcase examples of the kinds of approaches that innovators – whether communities, voluntary, community and social enterprise (VCSE) organisations, clinicians or managers – have already established, and ask how we can make these models mainstream.

# WHAT NEEDS TO CHANGE?

If we want to change the content of the 1.5m consultations that take place every 24 hours in the NHS, then we need to start the process of change locally, at the national level, and in clinical practice simultaneously.

Our agenda is difficult to progress because it goes against the grain of how many people think about medicine and health, how we organise services, and how we regulate, commission and incentivise organisations. Yet, in the words of William Gibson: "The future is already here – it's just not evenly distributed." The change we seek is radical, but it is a radicalism that already exists within the current system. Our task is not to start anew – but to develop and scale ways of working which already exist.

However, the reality is that for these examples to be the norm, a lot will have to change. It won't happen unless the next decade is relentlessly focused on spreading these ways of working.

The good news is that, in 2023, many people are already talking about the need for a change in the model of care that the NHS delivers. At Labour's 2022 conference, Wes Streeting outlined the party's commitment to "a 10-year plan with the NHS to shift the focus of healthcare out of the hospital and into the community". What, then, are the levers that will bring this about?

We know that the upper management of the NHS cannot, by itself, drive the change needed to create new ways of working on the ground. Simply writing a wish list for change has not and will not bring it about. Instead, we need a different approach to the fundamentals of healthcare delivery, including changes to the biomedical model itself; where power resides in medical practice; how funding flows; and so on. It is time to take seriously our rhetoric on change and act accordingly.

In the following sections, we explore the changes we want to see, illustrated using examples from those who are blazing the trail of change.

#### Choice, control and agency

To pursue this model of change, we need to address the question of agency. Too often, the health system disempowers both the people who work in it and the people who use it. There is not enough interest in, or support for, the agency of staff and people at the point of care. Instead, the health system is characterised by the relative powerlessness of people, communities and their organisations in affecting change.

We want more people to get the support they want in ways that work for them – giving them choice and control over what happens to them. We want to recognise people as experts in their own lives and offer mechanisms in which they can share decision-making power at every level, from the individual patient interaction with a clinician to the setting of national priorities.

In other parts of our economy, customer choice is the mechanism through which customers express their preferences, and through which providers learn to respond. Innovations move from early pilots to universal offers because customers demand it. They stop buying an old service in preference for a new service, and providers respond or go bust. These realities keep leaders in service provider organisations on the lookout for new ways of working. But these mechanisms can't work in NHS because services users are not buyers, and rarely have all the information they need to genuinely compare services.

Choice has been part of the NHS infrastructure since 2002. It helped drive down waiting lists because people could choose a provider who offered shorter waits, and providers were incentivised to attract more patients. However, it meant hospitals ended up competing rather than collaborating for better health, and created incentives towards activity, rather than (for example) preventative work.

This version of choice is also rather limited in terms of its ability to *shape* services. It may enable me to choose one hospital over another where the wait is longer, but it does not enable me to choose a surgical team that works progressively rather than one stuck in the past, who may only realise one week before my surgery that my blood pressure or weight is too high to go ahead. Accordingly, attempts to leverage improvements and culture change through strengthening patient choice have been limited.

Meaningful choice and control would mean empowering people and communities to choose support that helps them to be healthy – regardless of where it comes from, how it is delivered or who provides it. But realising this vision will require new mechanisms through which people can explore and express their preferences, and through which providers can respond. We contend that this is best achieved by moving to a situation in which patients are explicitly treated as experts in their own care, with shared decision-making power. This means not only ensuring that their voices are heard in individual consultations – with meaningful metrics to ensure this happens – but also that they are part of the processes of developing, designing and delivering health services.

The NHS has developed many mechanisms for engagement, but ultimately still finds it hard to hear what people want and need, and what it needs to do to respond to these priorities. Too often the involvement of people in service or commissioning decisions is tokenistic and more concerned with ticking a box than actually shifting the dial. Very rarely do providers, commissioners and regulators hear how opportunities to create health and wellbeing through a service were actually realised – or missed.

By contrast, the models we showcase in this report were built in partnership with communities by sharing power and listening carefully to what people say they need. They succeed because people (individually and collectively) play a much bigger role in the building blocks of their care and healthcare. The VCSE sector is often the enabler of this shift – helping to orient systems towards the goals and outcomes that people value and drawing on a wider range of tools than the traditional medical model allows (such as advocacy, peer support or volunteering).

The shift we want to see therefore entails a much stronger role for patients themselves in setting the direction of the health system, but also for the voluntary and community sector. To democratise the NHS, we need much more community involvement in the delivery and design of health and care policy and practice, and to make that happen we need to work with the experts in community engagement and empowerment – the VCSE sector. In the next section we explore what this might look like.

### Case study: Involving patients who have surgery in improving their own health (better perioperative care)

Unsurprisingly, most of the case studies we include concern primary care. It is here that the importance of the involvement of patients and the public in their own care and health is most obvious. People need to avoid loneliness as much as smoking, but loneliness is not something a doctor can prescribe for; only by getting out and meeting people, and in general leading a purposeful life, can people look after this aspect of their health. Clinical staff can, of course, recommend such changes, but the best outcomes will only be achieved if people are supported to engage, and trust a service to work in partnership with them.

At first glance, patient involvement in more specialist aspects of health care may seem less intuitively credible. For example, given the specialist nature of surgery, it might appear that a patient could not contribute much to surgical success. But, in reality, the choices people make outside theatre already have a huge impact on outcomes. Recognising this agency and working with patients ultimately brings better results.

Professor Scarlett McNally, deputy director of the Centre of Perioperative Care, explains: "I realised after 20 years as a surgeon that how well I do things is only a small part of how an operation turns out. The complication rate of surgery can be halved if people are supported to prepare for surgery, if they exercise, stop smoking and eat well. We need the team to work with people, as a team, across the whole pathway. I've been involved in karate competitions and, there as here, it is clear that you need everyone to make all the steps better. Getting ready for surgery should be like preparing for a marathon."

There is <u>evidence from the UK and internationally</u> that this patient involvement can help to:

- increase how prepared people feel for surgery and what they understand they need to do before, during and after their treatment
- · improve people's satisfaction with their care and what outcomes they report
- increase the possibility of operating as a day case which is far more efficient and reduces cancellations due to lack of beds
- reduce the use of intensive care and the number of bed days inpatients need
- reduce complications after surgery, meaning that people may feel well sooner and be able to resume their day-to-day life and employment quicker.

As McNally says: "All the evidence we've amassed at the Centre for Perioperative Care shows that the results are even better than we guessed. What improves results for patients and makes them feel empowered, also saves money for the NHS and increases staff morale. The 'waiting list' should be a 'preparation list'. Even better, many patients can also maintain any behaviour changes to improve their future health." "The seven things that help prepare for surgery are almost the same as the things that improve health more generally and reduce health inequalities. The time before an operation is a 'teachable moment'. It is almost never too late for 'prevention'. With so many people on waiting lists, this is a huge opportunity to improve health for those who need it most. They are: smoking cessation, physical activity, better nutrition, alcohol moderation, a medication or senior review, good psychological preparation and mental health support, and practical preparation (after care, transport etc)."

### Partnership with communities

We need a new partnership with communities, with a far stronger role for voluntary, community and social enterprise (VCSE) sector organisations in designing and delivering health services.

Supporting people to stay well is the bread and butter of the VCSE sector. Yet too often these organisations doing valuable, health creating work are lurching from short-term grants to over-complicated funding streams that commit them to system outputs rather than community ambition. This holds back the power of the communities. VCSE organisations are often cheap, but they are not free, so need sustainable funding.

#### Case study: Learning from the Covid Community Champions

Collaborating effectively with communities is central to achieving good health outcomes and equity. Given the NHS is so proud of its principle of equal access for all, free at the point of delivery, you might think it would have spent 75 years straining every sinew to reach out and learn from the various communities in England. But, in reality, it has fallen short.

The Covid-19 pandemic acted as a powerful argument for change. There were two main aspects to that argument. First, as the pandemic hit, it quickly became clear that more deprived, and also Black and minority ethnic communities, had higher death rates from coronavirus. Second, these communities benefited less from the lifesaving potential of an effective Covid-19 vaccine. In other words, our universal health service was not succeeding in equally protecting the lives of everyone in England, although some NHS organisations and councils responded more

effectively to these discrepancies than others, by focusing on building trust and working through existing community relationships.

The most high-profile response to these challenges came from the bottom up. In London, thousands of people signed up to be Community Champions, Covid-19 Champions and Covid-19 Vaccine Champions. Through these programmes they shared information about Covid-19 with people in their communities and supported people to access Covid-19 vaccines. This groundswell spread across the country, with the Department for Levelling Up, Communities and Housing providing over £50m funding to more than 60 places in England to implement vaccine champions programmes.

The Covid Champions programmes that emerged were not totally new. They drew on significant work that had come before in the UK and elsewhere – including, for example, how news spread during the aftermath of Hurricane Katrina. However, they were different. The Covid-19 pandemic demanded that organisations delivered real, two-way, engagement. Information had to get to people but people also had to be heard by councils and the NHS. The need to use WhatsApp (which had not been used by councils and the NHS previously), Zoom and other technology was in part imposed by the pandemic, but also reflected the realities of how communities communicate today. The adoption of these methods demonstrated the willingness of institutions to take risks and try new things in unprecedented times.

The Champions programmes not only had a significant impact on the response to the pandemic, but helped transform the way that councils, the NHS and others engage with and listen to communities.

In London, health leaders from the NHS, the Office for Health Improvement and Disparities / UK Health Security Agency (previously Public Health England), the Greater London Authority, the Association of Directors of Public Health in London, and London Councils funded a programme from March 2021 to maximise the impact of champions. The programme achieved three things:

- It enabled places to learn from each other and coordinators to feel supported and enabled by each other.
- It established direct connection between health system leaders in London and local partners – for example, to shape the door-todoor testing programme. The dialogue that the champions had with their communities went two ways, and public services learnt

to be more effective in reaching different communities by learning from what those communities told them.

• It brought London's Regional Health partners together to collaborate on specific communities and challenges, such as the needs of homeless people, or those who live nomadic lives.

The programme was led by the champions coordinator from the London Borough of Newham, Anne Pordes Bowers, who said: "Champions programmes were invaluable to all of us in local places as we worked at unprecedented pace to get information to people that they would trust and would respond to. This information was about how to stay safe, how to stay within the rules and what would keep them and their families healthy. We had the public health knowledge, the resources to create simple visuals and infographics and the staff to share these with communities in ways that worked for them."

"Champions had the connections, trust and relationships with communities that we would – and will – never have. Together we were a powerful partnership, making sure that more people knew how to be safe – and trusted that information – than either of us could have done alone. It wasn't easy or always smooth and simple. [But] it was worth it."

The VCSE sector is already part of local health systems – delivering vital support through peer support groups, helplines, social groups, benefits advice, exercise classes, coaching, befriending services and more. However, these vital contributions to health are not always recognised, and even less often properly rewarded. This needs to change. The VCSE sector must be a full partner to NHS services at every level – whether in Neighbourhood Teams in primary care (as recommended in the 2022 Fuller stocktake report), sitting on Integrated Care or Partnership Boards as full remunerated members, delivering services and setting priorities at national level.

Many patient organisations are already very vocal about what they would like to see happen. Large, professionalised national organisations with research, improvement and policy teams can put on the record what good service looks like and how we get there. But smaller organisations, with less capacity to shape research and practice, also have crucial perspectives on what it is like to live with a rarer condition, or to come up against inequality in health. We need this insight and ambition at the heart of policymaking, commissioning, planning and delivery. For example, in July 2023, Age UK published its annual State of Health and Care report, which provides detailed analysis of the challenges facing older people and clear-sighted recommendations for how the system needs to change to better meet their needs. They are by no means unique in offering a wealth of insight and expertise into which health leaders need to tap. Diabetes UK has developed an <u>award-winning self-management tool</u> that more than 100,000 people have used to improve their lives after a diabetes diagnosis. Macmillan Cancer Support runs an online community where people living with cancer provide each other with mutual support and information. Like so many other charities, the Stroke Association runs a helpline and peer support groups, including for carers. It also supports people with rare issues, such as childhood stroke. Rethink Mental Illness successfully redesigned the entire mental health support system in Somerset, in partnership with other mental health charities, council services and the NHS, ensuring that people are well supported at home, and that they have a say in how services are actually designed and run.

At the much smaller end of the spectrum, the Charity <u>Shine Cancer Support</u> runs innovative support programmes for young people who are diagnosed with cancer, including residential trips and networking events to help people adjust to their new realities. The health charity for people with experience of homelessness, <u>Groundswell</u>, offers a novel peer advocacybased model of support for people affected by homelessness to access health services and to create better health and wellbeing for themselves. The Caribbean and African Health Network a weekly <u>Health Hour</u>, where Black health professionals reach out to wider communities affected by discrimination and inequality, ensuring they have access to the best information and advice for their own health.

These are just a handful of examples. This immense insight, expertise, reach and energy needs to be built into the formal health and care system, with a recognised role and remit to shape the design and delivery of services around the needs and wishes of local populations.

Neglecting this passion and resource is a waste that the NHS simply cannot afford.

#### Outcomes that matter

We need a different way of setting outcomes and collecting data across the NHS.

The innovations described in this report focus on improving lives, not on clocking up interventions. However, too often NHS data collection, and

even more so social care, simply counts whether something has happened. We need to report and analyse whether interventions have worked to improve lives rather than simply whether they have happened.

Starting from the outcomes that matter to people brings a different perspective to what success and value means in the health system. For example, in 2013, as the NHS was developing plans for better integrated care, partly in response to the fragmentation inflicted by the Lansley reforms, it worked with National Voices (the coalition of over 200 health and care charities) to develop a <u>patient-led perspective of what integrated care</u> <u>should look and feel like.</u> This took the form of a series of 'I statements'

Perhaps the most iconic of these was the simple expectation: "I have to tell my story only once." This is not an unreasonable thing for people to expect. If you live with an ongoing problem, or a set of interrelated ongoing problems (such as obesity, sore knees, high blood pressure, and care responsibilities for your learning-disabled son), it is frustrating, demeaning, and importantly destroys trust, if every encounter with a health and care service unfolds as if it were your first one.

Yet the system currently neglects the power of relationships in health creation. It simply is not designed to deliver this basic ambition, which in practice would rely on a lot of things working differently: from joined-up care records, to multi-disciplinary team working, and shared decisionmaking.

There are examples, as we have shown, of services that do things differently – that prioritise relationships and continuity, and allow people who need to rebuild their lives or health to do so with reliable support. Focusing on patient-defined outcomes enables this approach.

Of course, there are already some examples of user-led outcomes being used to inform NHS practice. Patient reported outcome measures (PROMs) already exist in some parts of medicine, and help to ensure that what matters to people is measured – for example whether joint surgery has actually improved someone's ability to walk.

Some services help people define their own outcomes, for example by using tools such as the <u>outcomes stars</u>. These enable service users to set out what they are trying to achieve and to have a conversation about what they can do themselves, and what support they may need to do this. Tools like these are often used in health coaching. Shifting to a focus on whether health interventions have met the individual's needs rather than corporately defined objectives would likely lead to significantly different approaches, accelerating the wider shifts we need to see.

Reorientating our system to be measured against outcomes relevant to people – such as the 'I statements' – would help remind those commissioning and providing services of what they are meant to deliver, and draw attention to the ways in which the system currently is not aligned to achieve those outcomes.

#### Case study: Peak Health Coaching

We spoke to Ollie Hart about his work to mainstream better selfmanagement support in primary care, and what his experience of working with people to coproduce services has taught him about what really matters to people who live with long-term conditions.

Until around six years ago, Ollie exclusively worked as a GP in what he describes as a 'no-nonsense' GP surgery. He tried to embed better self-management support for people with diabetes and other chronic conditions, but he realised that the GP contract, quality outcomes framework and money flows prevented such support from ever becoming mainstream.

When the position became vacant, he moved into the role of clinical director for his local primary care network (PCN). He felt that pooling resources across a number of GP surgeries and using the extra national funding to create roles that supported self-management, such as social prescribers, health coaches and care coordinators, offered a real opportunity for more progressive practice.

There are now four teams of staff supporting people in new ways: a social prescribing team (supporting people with practical, financial and emotional issues), a medical team (working with people whose needs are more complex and need more careful care coordination), a pharmacy team (dealing with chronic condition management, deprescribing and polypharmacy) and a mental health team – this team, in particular, is now branching into new issues and ways of working: substance misuse, peer support, a hub that coproduces support solutions and so on. He is hopeful that the integrated neighbourhood teams, bringing together primary, community and social care and the voluntary sector can further embed this approach.

However, he's also concerned that medical leadership is reaching its limits. Ollie told us: "If you put a group of GPs in charge of a PCN, they will always privilege the medical model. And particularly as larger sums of money became available, GPs often couldn't see the point of expanding the non-medical, preventative offer."

In his view the national policy focus on immediate access for everyone has also meant that general practice can retreat into an 'acute' model (see people quickly for episodic care), rather than a population health model, which requires building of relationships and ongoing work with people around behaviour change and self-management.

He now only does one day in general practice, which he uses to run innovative group sessions for people living with type 2 diabetes, coproducing what kind of support they want. And it turns out that people want a 'life enhancing' service that focuses on their energy, their sleep and what they can do to make themselves feel better. Some of them have also joined a group that talks in more detail about managing type 2 and even putting it into remission. What both groups have in common is that people support each other with trying to build a better life for themselves.

Ollie is now mainly focused on his company, Peak Health Coaching, which takes training for primary care staff on health coaching into teams across the whole of the UK. It has worked with hundreds of practices and PCNs and has trained 350 health coaches, as well as supporting 500 health professionals to adopt a more coaching 'style' when they work with people with chronic conditions, particularly pain, diabetes and other metabolic health issues, and mental health.

He is energised by how his organisation is now supporting both individuals with their skills and teams and organisations with the changes they need to make to really see through a self-management focus: "It's no good the health coach working with a person in pain on self-management, and a GP then suddenly throwing more pills at the issue again. Everybody needs to believe in and support this new way of working."

He believes that health coaching could make a massive contribution to workforce pressures and growing disease burdens: "It takes four days to properly train a health coach. They don't need to know lots of medical things, they just need to have compassion and curiosity for people and the situations they find themselves in. Their core skill is to help people identify a reason for trying to improve their health and wellbeing, and then walk alongside them until people feel more confident and hopeful."

"If I was a minister for health, or a team preparing for government, I would ensure that the GP contract incentivises good supported selfmanagement and population health, not just lots of transactions. And I would also back coaching training and apprenticeships. So much of the day-to-day support for people with chronic conditions could be provided by them. And it would allow highly and expensively trained clinicians to focus on the issues that require more clinical oversight."

### Funding better outcomes

People who use health services are rarely interested in how money flows to the doctor, the nurse or the pharmacy. What matters to people is the outcome of their interactions. However, at present our funding arrangements are orientated to reward activities, rather than human outcomes. They do little to address fragmented systems, or to incentivise upstream, preventative action.

Over the next few years, the public purse will be tight. There will not be enormous new sums of money going into the NHS. But there will be investment – the NHS will grow. Indeed, according to the current government's own plans, the size of the NHS workforce will grow to 2.2 million staff by 2037, from the 1.5 million we have today. If we are going to meet people's priorities, then we need to make sure that those extra staff work providing those services that create the most health and that people actually want.

Looking at NHS funding streams, it becomes apparent that most of them are connected to inputs – a hospital or GP doing a thing. This is understandable, as inputs are easy to measure: it is far harder to measure the extent to which someone has done something about having high blood pressure, than simply that it had been found to be high. But if we are serious about listening to what people want, we will care a lot less about inputs and a lot more about outcomes. People want to feel well, they want their pain to stop, they want to stop smoking, they want to not be lonely.

Ultimately, we need to move to a system that rewards the achievement of outcomes for people rather than activities. But we can already do a lot to address this dysfunction of the funding landscape, channelling more funding into prevention focused, health creating interventions, rather than into more hospital activity.

This would start with making sure that the kinds of approaches exemplified by our case studies become part of the mainstream of NHS practice – funded as a part of the mainstream. Yet this is not guaranteed. Ways to Wellness, for example, was one of the early NHS social prescribing services and had to fund itself from outside of the NHS using private finance (see box, page 20). While funding for link workers has been included in the primary care GP contract, that contract ends this year. It is important that this funding continues, and that further funding is earmarked for the support services and activities people are linked into, not just the linking.

In response, clinicians might argue that paying them for outcomes is not fair. They can only control the input – the medical activity – and the output needs the involvement of the person, their family, their community. We have no desire to argue otherwise; indeed, *this is the lesson at the heart of our pamphlet*. Yet clinicians will have a key role to play in building a new system that builds support around a person, including clinicians, coaches, carers, and community workers. A surgeon may not personally help the person in front of them to exercise more in the month before their operation, but they need to be part of a system which does so. If a GP, health coach or link worker does not succeed in helping the patient to get out more and exercise, then everyone's effort is wasted – it does not make sense to pay someone simply for telling the patient to do something they either can't or won't do.

We therefore need to change the funding model to one that recognises the importance that patient and community involvement brings to successful health care. We need to incentivise clinicians and their support staff to work with people and communities to achieve the changes that matter to them.

The challenge is not just that the system pays for inputs rather than outcomes, but also that it pays in such a way as to fragment what should be a single patient pathway. For example, a person with diabetes may receive care from many different parts of the NHS and social care: there will probably be costs to primary care, community care, a hospital and social care. Each of these services is financed differently, meaning that if a primary care provider succeeds in reducing the demand for hospital care, it has no way of obtaining the resources saved in the hospital to help pay for the additional primary care. There is no flow of finances which will pay for prevention. Helping the public to improve their own health – as embodied by the Growing Health Together programme, discussed later – takes more than one input.

Improving the health of patients before and after operations will involve clinical and support staff from inside and outside the hospital working together to help the patient improve their own fitness. Yet because the NHS pays for different aspects of care in different ways, it is unclear who is responsible for the overall pathway – often, nobody is.

A health coach, who helps a patient to live a healthier life, is paid for by primary care services as an additional member of staff for a GP practice. If they carry out their work well, they will succeed in helping people be much heathier for many more years of their life, which in turn will help to wean the NHS off its over-reliance on hospital care, particularly unplanned care. However, because the funding of hospitals is totally different from the funding of the health coach, the hospital will at present pay nothing towards the cost of the coach, and the GP surgery will not benefit from the savings it helps generate. This is one of the main reasons why prevention within the NHS is so very poorly resourced and why we are not moving fast enough with shifting activity upstream.

The promise made in the move to integrated care systems was that they would address this unhelpful fragmentation of funding streams, and bring providers together in partnerships to achieve outcomes together. This is the right ambition, but to be meaningful we need to see a much more significant shift towards outcomes defined by patients, and we need to ensure that all health-creating partners – whether they are in primary care, the VCSE sector, social care, or acute settings – can share in the rewards of achieving them. The Hewitt Review recently recommended that a small proportion of each ICS's spending should be ringfenced for prevention-focused work. This would, of course, be a start, but the very modest ringfenced amount proposed also demonstrates how far we have to go. If we consider smoking cessation a drain on resources rather than an investment that repays its cost over and over, we have gone seriously wrong somewhere with how we account for health spending. We need a more radical assault on funding orthodoxies to really achieve the shift we need.

In April 2023, we saw the beginnings of a movement to challenge these fragmented financial flows. The Hewitt Review <sup>2</sup> recommended that ICSs be allowed to develop new financial flows to finance prevention out of the savings that could be made from resulting decrease in demand for hospital treatment. The problem at the moment is that most savings from prevention will be realised in a part of the health system other than the part where investment takes place. For example, as with some of our case studies, investing more in primary and social care could keep frail elderly people out of hospital. But the savings are realised in the hospital, whilst the costs occur elsewhere.

As a response to the Hewitt recommendation, the NHS Confederation has, with several ICBs, set up a working party to develop such financial flows. The hope is that they will be ready for ICB implementation in the financial year 2024/5.

#### Case study: Ways to Wellness

Ways to Wellness was launched in April 2015 in the west of Newcastle. Here, deprivation is higher than average in England, life expectancy is lower, and people with long term health conditions experience high rates of unplanned hospital admission.

The service supports people aged 40 to 74 years with specific long-term conditions, many of whom have multiple complex medical, practical and social needs. Ways to Wellness has two overarching aims:

- to improve the health and wellbeing of people living with long term conditions in the west of Newcastle; and
- to do so by reducing costly and low value interventions.

Like many other social prescribing services (now mainstreamed into primary care in many areas) the service rests on the relationship between the social prescribing link worker and the client. What makes Ways to Wellness different from other social prescribing models is its funding. Its contracting and funding approach was pioneering as the world's first health service to use social impact bond (SIB) investment paired with a fully outcome-based seven-year NHS contract.

The value of the relationships the model builds reveals itself in the work people undertake together with their link worker: exploring priorities and assets, understanding motivation, learning about health and long-term conditions, goal setting, action planning and building healthier habits. The programme uses a targeted approach to eligibility criteria to reach the people most likely to experience inequalities related to the social determinants of health.

Chris Drinkwater, chair of Ways to Wellness, said: "Link workers work with clients to overcome barriers. Clients remain with the service for an average of 18 months, which allows time for them to achieve multiple and progressive goals across a wide range of areas that link to wellbeing. This longer-term service also enables sustained behaviour changes and resilience building."

Link workers encourage clients to identify personally meaningful goals, working towards achieving them through an agreed action plan. The most prevalent category of goals, increasing activity levels, reflects a frequent aspiration of clients to improve their physical health and fitness. It also often reflects clients' desire to increase their social connections by getting more involved in groups or activities that get them out of the house more often. Link workers also signpost clients to community services and groups that are aligned to their goals, supporting clients to access and engage if needed.

Ways to Wellness contract payments from the CCGs are 100 per cent based on outcomes – specifically, improvements in patient-reported wellbeing and reductions in secondary care costs. Ways to Wellness link workers use Triangle Consulting's <u>Well-being Star</u><sup>TM</sup> to assess clients' self-reported wellbeing across eight domains of wellbeing, completing assessments after around six months. In 2020/21, the secondary care cost per patient for the Ways to Wellness cohort was 27 per cent lower than for the comparative cohort.

The funding arrangements for Ways to Wellness are complex. Bridges Fund (now Bridge Ventures) management initially committed £1.65m in the form of a social investment bond, of which £1.11m was ultimately used to pay for the service, with the remaining £500,000 left unspent. These funds were fully at risk with no guaranteed repayment of capital or secured rate of return for the investors. Instead, repayment of capital and return on investment was based only on hitting agreed outcomes. Ways to Wellness began to repay the capital in year four as planned, with the final amount being paid in year six.

The programme rests on a cross-sector collaborative partnership across multiple organisations, with Ways to Wellness positioned centrally as a "special purpose vehicle" holding key contracts with all partners: public sector commissioners, local voluntary sector delivery organisations and a specialist social investor. It is expected to reach approximately 9000 patients over seven years and provide social prescribing for up to 3000 patients at any one time.

Such collaboration is no mean feat. As Chris told us: "Bringing together cross-sector partners with differing perspectives, cultures and priorities creates an opportunity for everyone to learn from one another and draw on each other's strengths. However, this is paired with an inherent tension that emerges from organisational and sectoral differences in culture, perspective and preference. Managing this tension can create challenges".

The focus of Ways to Wellness on outcomes, and the measurement, monitoring and achievement of impact, is an essential part of this approach, as is working with VCSE partners. The added longer-term advantage is that the NHS services in Ways to Wellness had to learn how to make real savings in order to pay back the original bond. This initial success has allowed the Ways to Wellness to broaden out from this original targeted approach. It now includes link workers for maternal mental health, children with complex neurodisabilities and people waiting for hip and knee replacements.

#### Focus on inequalities

In April 2023, we saw the beginnings of a movement to challenge these fragmented financial flows. The Hewitt Review <sup>3</sup> recommended that ICSs be allowed to develop new financial flows to finance prevention out of the savings that could be made from resulting decrease in demand for hospital treatment. The problem at the moment is that most savings from prevention will be realised in a part of the health system other than the part where investment takes place. For example, as with some of our case studies, investing more in primary and social care could keep frail elderly people out of hospital. But the savings are realised in the hospital, whilst the costs occur elsewhere.

We believe everyone wants to live well, to be connected to others and to be engaged in purposeful activity, but at present, people's ability and confidence to contribute to their own and their community's health creation is not equal. The NHS aims to provide equal access for all, but our wide health inequities demonstrate that it is not providing equal access to the tools and assets we need to live well and build healthy lives.

People's innate desire for a better life can be tapped into, but doing so will look different for different people, recognising their different needs, levels of trust in institutions, circumstances and experiences of inequity, discrimination and stigma.

If we are serious about addressing inequalities we need to make sure that the impact of our interventions on inequity is considered at every juncture, whether that's in the individual interaction between a patient and GP – offering longer consultations, or continuity of care for someone who is facing multiple disadvantage – or in how we design and deliver services – working with organisations already in trusted relationships with marginalised communities and seeking out voices that are not at the table.

Addressing health inequities will require a new humility across health and care services, which need to recognise that they are not always best placed or sufficiently trusted to provide support. During the Covid-19 pandemic, the NHS (somewhat late in the day) recognised the need to work with and through community organisations to support its vaccine rollout. These lessons need to be applied day to day in the health system, which should approach community organisations with humility and seek genuine partnership, not just to deliver support but to design services and pathways and set priorities.

The models of care we describe here have the potential to make a big difference to unequal outcomes, but they won't be realised without a specific focus on addressing the inverse care law in everything we do.

#### Case study: home dialysis

Too often, conversations about self-management come up against fears that they are a front for reductions in services, to professional roles or to available support. But 'supported' self-management is not about 'sink or swim' approach to health, where only the most capable and wellresourced get what they need. Instead, these approaches wrap a range of care and support around an individual to enable and bolster their own capabilities, and to make it easier for them to do the things that they can and want to do to maintain their health.

We caught up with the work Kidney Care UK have been doing on home dialysis. In home dialysis, a patient living with kidney failure connects to a dialysis machine in their own home, often every day, rather than travelling to a dialysis unit at a local hospital several times per week.

Once they have received the appropriate training, many people with this serious and often life-limiting condition prefer this way of managing their illness. It means they get to spend more time with their family or friends, it saves on frequently difficult and expensive trips to hospital, and it means they are not exposed to infections while there.

It is also estimated that <u>home dialysis saves the NHS £10,000 per patient</u> <u>per year</u> compared to traditional hospital-based treatment. So on the face of it, it is the perfect case study for enhanced self-management.

But dialysis is energy-intensive, and it also cools down your blood, which means you have to do it in a properly heated room. As a result, rising energy costs have meant that many people cannot afford to sufficiently heat their homes or run the dialysis machines for many hours per week.

This is why NHS England, recognising the potential for exacerbating inequalities, not only mandated that all kidney failure services must offer the choice of home dialysis to people, but also that they must reimburse the energy costs this generates for patients and their families.

However, <u>Kidney Care UK have found</u> that this guidance is applied in very patchy ways and most people do not have all their costs covered, with many receiving no help at all. This causes huge anxiety, and leads to people's physical and mental health deteriorating, with some stuck in bed all day to stay warm, and some not able to conduct home dialysis because they cannot heat their rooms to the required 19C. All of which suggests that the centrality of addressing inequality and ensuring equitable access to the tools to live well is not being factored into decision-making in every area. Fiona Loud from Kidney Care UK explains: "We are dismayed that this successful and popular move towards more self-management of kidney failure is getting stuck because some trusts don't follow guidance and don't acknowledge that, while home dialysis is really good value for money, it isn't free. It creates significant costs for patients and their families. It is a moral and practical necessity to support them with these costs."

This example vividly illustrates that health services cannot firewall their interactions with people from the wider circumstances of their lives. The failure to consider their patients' economic circumstances, and to take action to address them alongside providing medical interventions, not only risks widening health inequalities, but also increasing the long-term cost to the public purse.

If we want to make progress on self-management and people-centred approaches to healthcare, we need to dismantle the short-termism of much NHS thinking, and also tackle the inability of the system to meaningfully 'follow the money', to make effective use of their resources. We need to acknowledge that if people are required to play a bigger part in managing their health, their homes become places of healthcare. This means we need to be much more curious about their living situations, their accommodation, and their ability to pay bills.

#### Beyond the medical model

Finally, and maybe most fundamentally, if we want to spread the good models described in our case studies, we need to understand and dismantle one of the main reasons we have been so slow in adopting more holistic, person-centred approaches: the hegemony of biomedical thinking in healthcare.

It is obviously very important that the nurses and doctors in the NHS are able to provide the very best, most up-to-date medical interventions. Clinical effectiveness matters enormously to any successful health service and to nearly every one of those 1.5m consultations a day. Professionals need to understand the science underpinning medical interventions, and they need to apply it correctly.

However, most clinical interventions also need social, practical and cultural inputs to make them work effectively. A surgeon with great medical skills will operate more successfully on a patient that has been exercising for the month before the operation. The patient will be fitter, better able to survive the surgery and better able to recover because of their fitness. A GP can

better look after an older person's physical or mental health if the person gets out more and is less lonely.

In our view, the hegemony of the medical model also underpins the relatively low status of 'care giving' compared to the heroic 'curing illness', and therefore can at least partly explain why huge and important parts of health and care practice, such as the work of care assistants, informal or family carers, or even areas such as community nursing, don't get the attention they deserve.

Many of the innovations we describe recognise the limits of medicine and the power of non-medical support. This needs to be the norm.

#### Health and social care

The relationship between health and social care is crucial. Social care goes far beyond the provision of personal care – as our friends from Social Care Futures highlight, it is about ensuring that we can all live in the place we call home, with the people and things that we love, in communities where we look out for one another, doing the things that matter to us. Social care workers help people take part in the lives of their communities as well as providing personal care.

Many people who use social care also have health conditions – yet even these people tend to spend much more time with their social care workers than with NHS staff. This means that social care staff often have much more opportunity to help people with their health and their health care than NHS staff do. Consequently, a better integrated social and health care service would almost inevitably increase the help with health that most people would receive.

But social care services in England are in a bad way, and have been for some time. Low pay and a lack of career progression mean there are many vacancies, and the lack of resources going into the care service mean that there are hundreds of thousands of people who need social care but do not receive it.

As such, in order to develop a wider set of holistic approaches to healthcare, we must ensure that social care is on a sound footing. Earlier in 2023, the Fabians published Support Guaranteed – a Roadmap to a Social Care Service. The need for very speedy work was underlined:

"The most urgent priority will be to develop a "rescue plan" for both adult social care and the NHS. This should mainly focus on recruitment and retention and therefore pay. We suggest that an initial minimum wage for the sector is in place by 1 April 2025 (subject to an election being held by autumn 2024). Other extra spending at this time should focus on service continuity and ensuring both adult social care and the NHS are able to provide an acceptable minimum level of service."

People who need support with their health or their daily lives know that both the NHS and social care need to be on sound footing for things to work. Social care reform therefore needs to be a crucial part of any conversation about non-medical work on health care.

This is an important conversation that we need to have with each other and with medical professionals. Some areas of clinical practice are further ahead: most psychiatrists and geriatricians recognise that their patient's social activity or financial situation will have an important impact on the efficacy of their medicine. Many GPs recognise that people need to be able to access debt advice or parenting support, not just medicine, when they struggle with ill health. Occupational therapists are often great at asking their patients: "What do you want to be able to do again? And what can we do to help you achieve this?", and health coaching and peer support work are firmly based on the insight that people need more than medicine to thrive, physically and mentally.

Yet all too often, people feel disempowered by their interactions with the health system. And, while the NHS may cherrypick from the offers available from the wider community sector, this is done on the basis of procurement rather than partnership, and the wisdom of those already expert in designing and delivering support which addresses the wider determinants of health is left out of the conversation about how to create health in communities.

Years of training and medical expertise give clinicians legitimate power in clinical consultations, but in reality, the ultimate outcome of their interventions is rarely in their control. The patient cooks her own meals, and chooses when and if she eats; she does or does not leave the house; she may or may not take up a vaccine, or stick to a treatment regime the doctor has carefully handed to her. Crucially, she also knows what gets in the way of her doing 'the right thing': her stressful, insecure job, her unhealthy relationship with her partner, her debt. Given the importance of these parts of health and healthcare, clinicians need to recognise that the balance of knowledge – so powerfully in their favour on medicine – swings just as powerfully against them when it comes to health creation. The patient and community, and the pressures shaping their lives, often have more power than the clinician.

Sharing power with people and communities to help them create better health and wellbeing for themselves is the only way the NHS can survive and thrive.

Therefore – and this is the core of our argument – both the clinicians and the patient need to be ready to engage in a conversation that recognises who has power over what, and what needs to happen to fully realise the health-creating potential of the clinical interaction. Both patient and clinician need to grasp that they need to play an active role in delivering a meaningful outcome. Where patients are up against the many obstacles in their way to achieving better health, such as stigma, poverty, racism, or low literacy, they need support to tackle them.

This will be a significant change and will need each clinical specialism to rethink their practice. Such efforts must be supported by work at local and national levels that mirror the power sharing approach – treating people and communities as experts and working with them to set priorities, to design and deliver mechanisms for meeting those priorities, and choosing measures of success.

#### Case study: Growing Health Together

Over the decades, there have been a number of GP practices that have moved beyond the medical model of healthcare and recognised how much the social and economic conditions and cultural lives of their patients contributed to the ill-health that they saw in their consulting rooms. Many GPs have recognised that if they simply deal with ill-health and not the building blocks of health, they are too far downstream to have the impact that they need. But until recently, the structure and organisation of GP practices as small individual businesses made it difficult to spread this different way of working.

In very recent years, the creation of primary care networks (PCNs) at the neighbourhood level and integrated care systems (ICSs) at the area level have provided the opportunity for GPs to work more cohesively. In east Surrey, this shift has led to innovative ways of working, with GPs and their partners recognising that they needed to tend to the building blocks of health rather than just medicine – to bring just as much focus to housing, social connection, cultural expression, and trust.

GPs in east Surrey had been part of an action learning set, which tried to address how people's lives and health connected and the sources of, and barriers to, health and wellbeing in their local areas. Out of that work they created the Growing Health Together programme, which invites people who live and work in the area to come together to strengthen the conditions that allow health to improve.

From the outside, Surrey might seem like a wealthy part of the world, but a closer inspection reveals different realities. For example, the proximity of Gatwick airport means parts of east Surrey have higher than average numbers of refugees, with different health needs and challenges.

Growing Health Together has three priorities:

- Health: supporting social, physical and mental health for people of all ages and backgrounds as we emerge from Covid-19.
- Equity: making access to health-giving opportunities such as physical activity fairer and more equal.
- Sustainability: reducing waste and supporting a healthy environment, and recognising that doing so is critical to human health.

The close partnership between primary care, council, schools, cultural institutions, and crucially, communities and their organisations has helped create initiatives in five PCNs, as varied as nature-based health interventions, creative art projects, group-based breast-feeding support, inclusive exercise classes, Friday night activities for young people and cultural events for African communities. Importantly, people themselves identify priorities for change, and the assets and connections they can bring to the challenge.

Progress was aided by supportive leadership at a system and PCN level and the presence of a large and proactive GP federation which wanted to spread this good practice.

Dr Gillian Orrow, one of the GPs leading this work, said: "When I began discussing these ideas with colleagues in 2019, I imagined they [would] remain on the fringe of accepted practice. After all, while common sense, they initially seemed too radical to challenge the status quo. The Covid-19 pandemic changed everything, and four years later, I could not be prouder to be working alongside so many community members and colleagues from all levels of the NHS and other statutory and nonstatutory organisations to proactively and collaboratively grow health from the ground up in our embedded neighbourhood model."

"Growing Health Together has held engagement events with community members and frontline professionals across east Surrey, identifying the sources of and barriers to health and wellbeing in local communities, with a particular focus on groups experiencing health inequalities."

# MORE GOOD THINGS: THE CHALLENGE OF SPREAD

The examples in this report show that 'green shoots' of the future are already present in the practice of health and care today. However, as we also discussed, there are formidable obstacles in the way of adopting this better practice more widely. These obstacles are rooted in how health and care are currently organised: the medical model, funding streams and inappropriate outcome measures.

In the next section, we set out a series of recommendations which we think will address these fundamental issues, but we want to emphasise one more crucial enabler of progress: if we want to accelerate spread (and we urgently need to) we also need to work with, through, and on relationships.

The layering of different relationships within our healthcare system is extensive. A GP, for example, is a member of a Royal College, of a local medical committee, of a practice, of a PCN, of a system, of a national GP contract – and so on. And the conversation about relationships in health and care often progresses along similar lines to that which we discussed earlier around complexity: because it's *all about relationships*, that's the only place we should focus. This is not our argument.

Rather, we want to recognise the way in which good ideas spread between places through existing relationships, and to urge a deliberateness in identifying and capitalising upon these different ways in which people, communities, health professionals, commissioners, funders and policymakers relate as we seek to make more good things happen. Looking across our case studies, we can see how different relationships and networks have been used to create change:

- The Covid Champions programme drew on existing community relationships as agents for change the trust and connectivity between people and their informal networks enabled this programme to reach people otherwise left behind.
- In the Growing Health Together example, a group of like-minded GPs built a set of relationships strong enough to shift practice across a whole area, backed up by values driven leadership at the system level.
- In Peak Health Coaching, a private business, with its ambition for growth and entrepreneurialism, created a mechanism for spreading coaching into multiple practices and helping more GPs change their approach.
- Home dialysis spread because a NICE guideline, and GIRFT guidance and funding, mandated change.
- Progressive guidance from a Royal College, backed by an NHS England programme, has helped build interest in pre-operative support.
- Ways to Wellness in Newcastle is interesting because social financiers helped to force two parts of the health system into a relationship that doesn't normally exist.

We need to be strategic about how we recognise and respond to existing relationships, and bring our understanding of these to the 'spread challenge'. If we work with the grain of existing networks, doing the right thing becomes easier, rather than harder.

# RECOMMENDATIONS

As we have set out in this report, action needs to be taken at all levels to shift the dial of mainstream NHS care towards a much stronger role for people and communities in supporting and maintaining their health and wellbeing.

In the final section of this report. we set out our recommendations for making this change happen around each individual – starting with their individual clinical encounters, moving through to collective engagement, and onto local, regional and national support and oversight.

### Shifting the individual encounter

We need structures that correct the power imbalances that often shape people's encounters with the formal health system, recognising that these can be even greater where people may face additional barriers such as low literacy. We need to make it harder to ignore the outcomes people want and experience, and easier to respond to their priorities.

We can do this by **improving the metrics we use to assess the impact of services to focus on outcomes that matter to people.** The current 'friends and family test' asks patients whether they would recommend the service they have just received from the NHS to friends and family. This data takes up time, but adds little to our understanding of whether a service has helped people become healthier.

We need to develop **new measures of the user experiences**, and the health **creating impacts** of health intervention. This could include questions like:

- Do you understand what you yourself can do now to help your health and wellbeing?
- Do you know who is in charge of your formal care?
- Do you know what to do if things get worse?

We need to make **better use of tools such as the NHS app**, both as a trusted source of support and information and to capture ongoing data about the health and wellbeing impacts of services – including where they come from outside the formal health system. Data from these tools needs to be treated

as a **resource for service improvement** and shared widely with people, communities and providers so that they can collectively use it to shape better services in future.

We also need to equip clinicians to have different conversations with their service users: identifying goals, sharing responsibility for outcomes and supporting people to overcome practical obstacles standing in the way of better health that derive from inequality, discrimination and lack of trust. Royal Colleges and universities have a critical role to play in providing appropriate training for clinicians of the future. Regulators also need to be a part of the debate, so that regulatory regimes reflect the different risks involved in sharing responsibility.

### Building a community for health

No patient should leave a consultation without being clearer about what they themselves can do to support their own health, their next steps, and back-up plans for crisis or deterioration.

For many patients this will involve tapping into a range of resources across the wider community. At a minimum, patients should **expect to be signposted to the available support from national and local charities** who may be able to support them with their condition. Again, the NHS app would be the ideal place to facilitate this integration.

Clinicians need to be meaningfully engaged as members of teams that can provide this wider holistic support. The **neighbourhood teams** envisaged in the 2022 Fuller stocktake are the right vehicle for this, bringing together support from across health, care and the VCSE sector, and working to build and sustain community capacity and assets.

Technology has played and will play an increasing role in assisting people to manage their health and health care. The NHS is proud of its principle of equal access to healthcare for all, free at the point of need. Now and into the future, that principle of equal access will depend upon the public's ability to use tools and resources that will help them manage their health and healthcare. For us to put the NHS founding principle fully into practice, **the NHS and other major institutions must work relentlessly to reduce and overcome the digital divide**.

#### Improving systems

Integrated care systems will need to commission and run services that build on community and multi-agency partnership. They will need to create money flows that incentivise upstream, preventive intervention. They need to ensure that they understand community need, inequalities and assets and build strong mechanisms to hear from service users, community groups and the formal VCSE sector as part of any decision making.

In line with the Hewitt Review, we believe that **the role of both local government and the VCSE sector needs to be strengthened in the ICS structure**. This will be vital if we are to shift money and influence out of hospitals.

Systems need to be able to draw on improved data – on outcomes rather than activity, as outlined above – to **hold themselves and their partners accountable for population health outcomes and for reducing inequalities**. They also need to ensure that money in the system flows to those who achieve the outcomes that matter to people. This will mean significant **sustainable and strategic funding for community and voluntary activity that is health-creating**.

#### Leading from the centre

National leaders need to clearly set out that a new relationship with people and communities is both a prerequisite for a sustainable and equitable health and care system and a core part of the operating model for how health and social care will be organised.

We need clarity of purpose and communication around this shift. 'Health creation', with its focus on the role of community and individual action, is the right paradigm. This lens needs to shape all national decisions: we need a **workforce plan that supports a massive shift towards community-based and non-medical roles**.

We need funding that focuses on population health outcomes, rather than transactional activity – starting with a **reversal of the decline in public health budgets**.

The **overall goal of all health policy and spending should be a longer healthy life expectancy**. This metric should be one of the organising principles of a new government, with a **cross-departmental cabinet committee in charge of progress on narrowing the healthy life expectancy gap**. So that the hegemony of the medical and professional voice is balanced at the centre, the **government should appoint a 'patient tsar' and an NHS England 'patient director' to work alongside the many clinical directors it already employs**. Patient and community voice needs to be formally included on the board of NHS England, the Care Quality Commission, and NICE.

**The Department of Health and Social Care mandate** (which is already discussed with Healthwatch, a statutory body which champions the needs of health and social care users) needs to be **based on much more sustained engagement with the patient and community perspective**, for example through an ongoing analysis of the priorities identified in every system's strategy and joint strategic needs assessment.

National professional bodies need to focus on strengthening their members' ability to engage in person- and community- centred care. **Patients, communities and their organisations** have a clear role to play in developing curricula and in delivering training to health professionals.

# CONCLUSION

For British society and economy to have a brighter future, we need healthier people. Our economy needs a bigger and healthier workforce. Our society needs more people with better mental and physical health living well together. Our NHS needs not to be overwhelmed by the decades of ill-health that too many people start to experience in their 50s.

To succeed, the whole of our society will have to think much more about creating the building blocks to health.

For the NHS to play its part, it will need to use many more of its consultations to create better health *with* patients and the public. It was in 1985 (38 years ago) that a book was published that suggested when a clinician met a patient it was a "meeting between experts"<sup>4</sup>. After nearly 40 years, we should get on with recognising how to make that joint expertise work.

### Endnotes

<sup>1</sup> Health is devolved, so regulated and commissioned differently in the four nations. We focus on England here, because it is where we work, but the same arguments apply to healthcare across the UK and probably the Western world more widely. All developed countries' health systems struggle with similar problems to an extent.

<sup>2</sup> The Hewitt Review An independent review of integrated care systems published 04/04/2023 on Gov.UK

<sup>3</sup> The Hewitt Review An independent review of integrated care systems published 04/04/2023 on Gov.UK

<sup>4</sup> Meeting between experts David Tuckett Mary Boulton Coral Olson and Antony Williams Routledge 1985