# 10 Year Health Plan working group: 'I am treated in a fair and inclusive way, irrespective of who I am'

# Co-chairs' report

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# **Contents**

1.	Introduction	2
2.	10-year vision for the workstream	7
3.	Key principles underscoring the vision	11
4.	Policy proposals	13

## 1. Introduction

What would it take for the following 'I Statement' to be true for all people (patients, their family, carers and wider communities) living in England in 2035?

'I am treated in a fair and inclusive way, irrespective of who I am'

This is the question we were set, with strict instruction to be bold and to go beyond conventional policy thinking. We know our recommendations are big - particularly on funding flows, workforce and accountability - and implementation will be challenging. But if we don't go big on equity, the government will fail in its promises to voters to fix the NHS, and to build a healthy and wealthy nation.

Our key recommendations cover:

- 1. Being more honest about current performance in relation to health equity.
- 2. Driving culture change by measuring what matters to patients and communities.
- 3. Fundamentally rewiring the funding flows to address the inverse care law.
- 4. Putting our staff where our most in need patients live their lives.
- 5. Stronger accountability in return for greater liberation for local teams and services.
- 6. Doubling down on the Core20Plus5 approach.
- 7. Outlining how the NHS can help maximise people's agency.

## To build an equitable NHS we need to start by facing the facts:

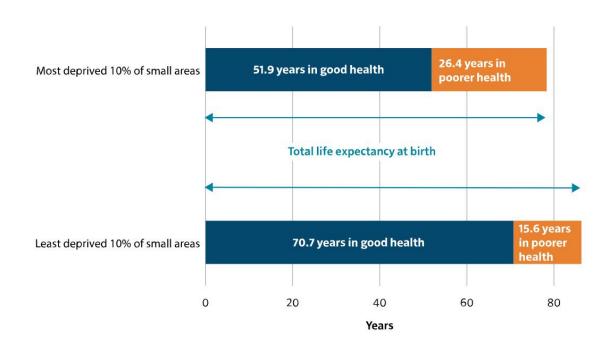
First and foremost, the NHS at all levels must acknowledge that the way it delivers care is not fair and inclusive at the moment.

Some people dismiss this idea. They argue we have a free-at-the-point-of-use system that offers 'equality' by treating people based on clinical need and in chronological order. Yet every day, deep financial inequalities and systemic racism, as well as stigma faced by inclusion health groups (people who are socially excluded, who typically experience multiple overlapping risk factors for poor health, such as poverty, violence and complex trauma), the LGBTQ+ community, and people living with physical or learning disabilities, means many people face huge barriers to getting the care they need to achieve the same outcomes as people who are not minorities. In the NHS, these groups are often referred to as the Core20Plus5 communities.

Others argue that current disparities are driven by wider social determinants, such as housing, transport, welfare and so on, which are outside of the NHS's control. While this is true, it is becoming increasingly unrealistic to isolate purely medical matters from their social context.

For any doubters, the facts speak for themselves. Access to and experiences of NHS services, and the outcomes people achieve (figure 1), are a long way from being equitable, with the latest figures all trending in the wrong direction (National Institute for Health Research, NIHR, Evidence, 2023). An urgent focus on 'equity' is the only way to achieve the key manifesto pledge around halving the gap in healthy life expectancy.

Figure 1: inequality in life expectancy and healthy life expectancy at birth for females in the most and least deprived areas in England, 2018 to 2020



Source: Chief Medical Officer's annual report 2023: health in an ageing society

Figure 1 is a bar chart showing that, on average, females in the most deprived areas spend 51.9 years in good health and 26.4 years in poorer health, whereas females in the least deprived areas spend 70.7 years in good health and 15.6 years in poorer health and live around 8 years longer overall.

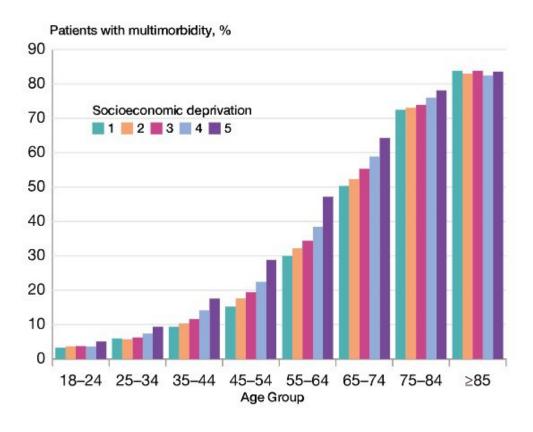
Services and clinicians must be much more curious about the context of their patients' lives and do everything in their power to help address factors that are impacting their health. Whether this is done by the NHS, or in partnership with other public services, industry or the Voluntary Community Faith and Social Enterprise (VCFSE) sector, this

support should be designed with patients to help maximise their agency in managing their own health.

At a national level, the case for focusing on the most deprived and marginalised communities, and crucially doing so where they live, has been well made. Lord Darzi (2024) said "the inverse care law seems to apply: that those in greatest need tend to have the poorest access to care" (page 67). The Health Foundation's modelling to 2040 has shown that areas of deprivation are increasingly clustered together (Raymond and others, 2024).

Addressing this isn't only a moral imperative. The Chief Medical Officer said in his 2023 report that the sustainability of the NHS lies in compressing "the period spent living with ill health by delaying disease onset" (page 4). Figure 2 shows that the biggest gains to be made here are in reducing the early onset of multimorbidity among 45 to 54 and 55 to 64-year-olds in our most deprived areas. Furthermore, an emphasis on addressing the extreme disease burdens experienced by the most marginalised communities can help reduce some of the issues around high intensity service users (British Red Cross, 2021).

Figure 2: prevalence of multimorbidity (2 or more conditions) by age and deprivation



(Index of Multiple Deprivation quintiles: 1 equals least deprived, 5 equals most deprived)

Source: Chief Medical Officer's annual report 2023: health in an ageing society

Figure 2 is a bar chart showing that the percentage of people living with multimorbidity increases with age. The rate of increase is fastest in the most socioeconomically deprived groups. For example, 47% of the most deprived 55 to 64-year-olds are living with multimorbidity, compared with only 30% of the least deprived 55 to 64-year-olds. This difference persists until the oldest age group, where around 82% of adults over 85 are living with multimorbidity regardless of socioeconomic deprivation.

Our expert working group, and our engagement with over 400 additional individuals and organisations, supports this view: that inequity is deeply embedded in the way we structure and resource services, and addressing this is the only way to create a sustainable NHS.

# The opportunity: how an equity approach will help meet the Prime Minister's milestones

Whilst creating an equitable NHS is a massive challenge, it is also an opportunity to support the government's wider agenda around growth and can help provide a common focus across two of the Prime Minister's key milestones (Starmer, 2024).

On raising living standards - the government has committed to delivering improved living standards in every part of the country by the end of the Parliament, measured through real household disposable income per person and Gross Domestic Product (GDP) per capita. This will be delivered in part by helping people be well enough to return to work and to keep working. Economic inactivity and health inequalities are deeply interconnected in a self-reinforcing cycle. Regions with high unemployment and low workforce participation often experience worse health outcomes, as economic inactivity exacerbates poverty, limits access to healthcare, and increases stress levels, all of which contribute to higher rates of chronic disease. At the same time, these health inequalities further entrench economic inactivity, as poor health reduces individuals' ability to participate in the workforce. (Marmot, 2010; Thomas, 2022).

An NHS fit for the future - a concrete promise has been made to be achieving the 18-week elective care target of 92% by 2029.

Through bold and radical reform of the NHS, focusing on improving the access, experiences and outcomes of those currently getting the poorest service, we can help hundreds of thousands of people stay in work or get back into employment after a period of ill health.

Lord Darzi's review showed that nearly 1 million working age adults from the 20% most deprived communities are currently waiting for elective care. 44% have been waiting more than 18 weeks (Darzi, 2024).

Independent analysis by the King's Fund demonstrates that you are twice as likely to wait over a year if you live in one of the poorest areas in the country (Jefferies, 2023).

Research conducted by Healthwatch England found long waits had a greater impact on people living on low incomes - more adversely affecting their ability to manage pain, to care for loved ones, and to work (HealthWatch, 2022).

There are currently an estimated 600,000 people on long-term sick leave who want to get back to work (Office for National Statistics, 2024).

The 'Get Britain Working' White Paper is a start - redirecting modest resources to communities most in need (GOV.UK, 2024). But to prevent tens of thousands more from falling out of the workforce, and to support those who can't work to still live fulfilling and independent lives, we need elective care recovery to be inclusive, with a strong equity focus.

To do this we need to fundamentally rewire the way the NHS thinks, creating a system that rewards services that take the time to understand the social factors affecting their communities and individual patients, designs services with these in mind, and seeks to give every citizen more meaningful power and control over their treatment. We need to go further on NHS England's strategic priority to restore NHS services.

#### The cost of inequity

Inequalities in health outcomes often lead to increased long-term sickness, preventing individuals from participating in the workforce. These inequalities are closely linked to socio-economic factors.

In 2024 over 2.7 million working-age individuals in the UK were economically inactive due to long-term sickness, marking an increase of over 500,000 since the onset of the COVID-19 pandemic (ONS, 2024)

Research by the Health Foundation has shown what will happen if we don't tackle inequity (Raymond and others, 2024):

On current trends, inequities in health will persist over the next 2 decades: people in the 10% most deprived areas can expect to be diagnosed with major illness a decade earlier.

Inequalities in working-age ill-health is also projected to continue. 80% of the increasing number of working-age people living with major illness between 2019 and 2040 (from 3 million to 3.7 million) will be concentrated in more deprived areas (deciles 1 to 5).

# 2. 10-year vision for the workstream

The Secretary of State's key challenge to our working group was to develop a bold new vision for the NHS, underpinned by a set of guiding principles, that will lead us to a more equitable future for all citizens.

Working with the experts on our group, people with lived experience and widespread representation from across the NHS and the VCFSE sector, we have followed an iterative coproduction process to create the following vision:

By 2035, we will have high quality, joined up care for all with excellent access, experience and outcomes, in partnership with patients and the public, a liberated workforce and our success judged by how we narrow the health equity gap between people and communities.

## The journey to this vision

At the heart of this vision is the recognition that the NHS must prioritise those who face the greatest barriers in accessing care. From the beginning, discussions with the working group highlighted themes such as accountability, liberation and equitable funding which guided the early drafts of the vision. The group also recognised the critical difference between fairness, equality and equity, emphasising that achieving true health equity means giving the most support to those with the greatest need. The first draft of the vision stated:

Pursue health equity, by creating a welcoming and safe healthcare system, where patient voice is valued, and system leaders are liberated to act and held to account for delivering an inclusive healthcare service for all.

The vision evolved because:

- feedback highlighted the need to expand beyond leaders to reflect the shared responsibility of staff patients and communities to drive meaningful change
- the vision needed to shift towards empowering patients and communities, ensuring they have the tools and resources to take control of their health
- greater importance was placed on practical measurable goals that prioritise those most in need while ensuring the entire healthcare system works effectively for everyone

The second draft stated:

What we will see in 2035 - the best healthcare access, experience and outcomes for all; empowering patients, liberating the workforce, joining up care and judging our success by how we provide for those most in need.

Further refinement was needed because:

- it was felt that best healthcare should be linked more to the language around workstream 2 in terms of delivering high-quality and effective care
- judging success based on the outcomes for those most in need was also felt to be too vague and could be misinterpreted as purely medical needs and wouldn't necessarily drive equitable improvement

#### Case study - liberating the workforce

Maggie's staff are overwhelmingly from the NHS - they trained as nurses, psychologists and radiographers and worked in NHS cancer care for many years. But at Maggie's, they are given greater control over how they work and plan services, with delivering good patient experience seen as their north star. This allows them to build different relationships with their patients and provide truly patient led services.

In Manchester, for example, staff observed that Muslim patients sometimes struggled to ask for support because they didn't necessarily trust the NHS. Language and cultural barriers were identified as a particular driver of this. Working in partnership with the Christie, Maggie's Manchester set up and supported a 'Brothers Group' and a 'Sisters Group' where Muslim men and women can talk with their peers about the physical and psychological impact cancer is having on their lives. A recent study by York University of three Maggie's centres, where they are providing psychological, pre-cancer treatment and exercise support, showed they were saving their local hospital trust £432,000 per year and helping to reduce the need for over 2,000 NHS Talking Therapy appointments and 2000 oncology appointment hours (Martin, Nettleton and Buse, 2019).

#### Statement on the basics

The vision represents the ideal world we will live in in 10 years' time. However, both the public engagement exercise and our own wider conversations with equalities groups highlighted a need for us to be realistic about the challenge in front of us and concentrate on getting the basics right. We have therefore proposed a baseline of where the NHS should be on delivering equity by the end of the plan in order to comply with the Equality Act and the NHS Constitution (Equality Act 2010; Department of Health and Social Care, DHSC, 2023).

#### **Equality Act 2010**

The NHS will be consistently meeting the public sector duty to remove or reduce disadvantages for people with protected characteristics. Specific examples include adhering to the commitments set out under the accessible information standard.

#### **NHS Constitution**

The NHS provides a comprehensive service, available to all. It is available to all irrespective of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status.

#### How the vision applies to the 3 shifts

As the discussions evolved, the group explored how the 3 shifts could make this vision a reality. These shifts were considered not just as isolated concepts, but as lenses through which the thinking on the vision and principles were refined and tested.

#### Hospital to community

The group reflected how this shift has the potential to redefine the relationship between healthcare systems and the communities they serve.

Recognising the need for healthcare systems, including hospitals, to be embedded within communities to provide access, culturally sensitive care in trusted, familiar settings. Hospitals must play an active role in the prevention agenda and be seen as part of the community fabric, helping to mitigate the risk of destabilising the acute sector due to significant funding shifts into community care.

Emphasis on co-designing services with communities to ensure they meet specific local need, build trust and reflect the community.

Recognising the importance of creating systems where patients feel their voices are heard, valued and central to shaping their own care.

Resources (how funding and workforce are spread throughout the system) must be aimed towards underserved communities if this shift is to narrow existing health inequalities.

#### Sickness to prevention

Discussions highlighted the growing recognition of the need to move from a reactive to a preventative model, that promotes long-term health and wellbeing.

Targeted prevention efforts are prioritised to address the needs of the most vulnerable in society. There is evidence that universally applied interventions which do not also target specific communities or account for their "particular needs, assets, and barriers to health" are less effective in reducing health inequalities and may even widen them (Davey and others, 2022).

For prevention to be effective, interventions such as NHS health checks and cancer screening programmes must be changed to reflect differences in the occurrence of diseases and conditions across diverse populations. For example, the earlier onset of Type II diabetes in South Asian communities and the higher risk of prostate cancer in Black men (Diabetes UK, 2022; Lillard and others, 2022; Prostate Cancer UK, 2023)

We need an increased focus on preventative services for babies, children and young people to ensure we are giving the next generation the best possible start in life and equipping them with the skills to self-manage.

Measuring success in prevention requires a focus on outcomes that matter most to patients, emphasising overall wellbeing and meaningful improvements in daily life. This should move beyond relying on quality adjusted life years, which may not fully capture the broader and long-term impacts of preventative care. Equity is a central consideration in ensuring preventative care benefits everyone, particularly those most at risk.

#### Analogue to digital

The shift from analogue to digital healthcare has sparked discussions about how technology can create opportunities to improve care but also risks excluding certain populations.

Digital transformation requires flexible approaches tailored to the diverse needs of patients, avoiding one-size-fits-all solutions that might sideline those with low digital literacy or limited access to technology.

Ensuring equity in digital healthcare involves bridging the digital divide through appropriate resource sharing, providing education and support to patients, and ensuring that services are accessible in both digital and non-digital formats.

Patients should be offered choices about how they engage with services - whether digitally or in person - to empower them and ensure care is inclusive and equitable.

Adopting the principles and practices set out in NHS England's Digital Inclusion Framework will be crucial in mitigating against digital exclusion (NHS England, 2023a).

These discussions informed the development of the 8 core principles, which reflect a commitment to creating a healthcare system that is inclusive, responsive, and designed in partnership with the communities it serves.

# 3. Key principles underscoring the vision

Trust is key: all services are universally welcoming, showing exceptional cultural awareness and proactively building trust with their communities to deliver compassionate, respectful, trauma-informed and stigma-free care. To achieve this, staff teams are recruited to ensure the community is reflected in the workforce and services reach out into the community to identify the needs of those who are and aren't accessing care. Where the NHS lacks connections to communities the VCFSE sector is a helpful ally. Service commissioners and providers include anti-racism principles and practices in their service design, commission, implementation and evaluation.

Care is patient led: the traditional medical model of care is combined with a social model to create an NHS that is curious about those it is caring for. This should involve the NHS learning as much as it can to help maximise people's ability to manage their own health, putting in place health coaching and peer support to build on people's existing skills, knowledge and capacity. This will also take account of the rise in people living with multiple conditions, with the NHS focusing on treating the whole person rather than a single disease.

Funding is assigned to narrow inequities: funding is assigned to narrow inequities in access, experience and outcomes in healthcare services. The NHS addresses deeprooted inequity by actively redirecting resources to deliver services at scale and intensity to match the degree of unmet need. This concept underpins all financial decisions, and ensures investment has the biggest impact in improving healthy life expectancy in areas of deprivation, but also in services where extreme inequity is experienced such as the criminal justice system. People and communities, including children and young people, should also be involved in major commissioning decisions to ensure resources are directed towards their priorities.

Services are designed in partnership: the NHS shifts power to people and communities by actively creating opportunities to gather and discuss experiences of care, and then working with them as equal partners from the very beginning on how to fix any problems or deciding how new services should be delivered. Co-design processes should be inclusive and involve communities whose voices are rarely heard in evaluating the impact of any changes, creating a continual feedback loop. Particular emphasis must be given to working with the communities who are least represented, such as people who are socially excluded, in decision making to address traditional power imbalances and tackle stigma.

Success is judged by patients: we measure what matters most to patients and communities and use it to deliver, using a framework that drives service improvement based around real-world outcomes. For example, whether people feel their symptoms are well managed, they are supported with their mental health, they are able to work and care for loved ones. These measures of success are given equal weighting alongside clinical outcome measures, financial controls and output measures. Existing performance data is also regularly broken down by key demographics to ensure inequity in access, experience and outcomes is examined.

Digital inclusion by design, inclusive by default: digital inclusion must be an integral part of all clinical pathways, products and services. This requires designing solutions that actively address the digital divide, ensuring services are accessible to all, regardless of digital literacy, connectivity or technology access. Efforts must focus on giving individuals the skills, tools and confidence to engage with digital health solutions, while also providing non-digital alternatives (NHS England, 2023a).

Leadership and Accountability: strong accountability systems are an essential part of delivering health equity. Without strong accountability mechanisms focused on reducing health inequalities, actions on health inequalities are at risk of being ignored as other priorities with clear and demanding accountability mechanisms are focused on. Strong accountability frameworks have been shown to drive behaviour, improve quality and value for money (Allen and Boyce, 2023).

Achieving equity is a team effort: making 'health equity in all policies' a reality is a collective responsibility, requiring all parts of the healthcare system and its wider partners in social care, public health, housing, welfare, and transport to work together. The NHS commits to an equal partnership approach, sharing assets and co-producing solutions. Clear roles and responsibilities are essential to ensure co-ordinated action and progress. This is of particular importance when collaborating with the VCFSE sector, which plays a vital role in narrowing health inequalities. To support this, the VCFSE sector requires sustainable, long-term funding to remain workable and contribute meaningfully to shared outcomes. All partnerships must be built on mutual respect and inclusivity, including fair working practices and the transparent sharing of data to understand problems and assess the effectiveness of potential solutions.

## Case study - commissioning groups for VCFSE organisations

There is significant scope for commissioning groups of VSCFE organisations at a national level that could then provide additional capacity for integrated care systems (ICSs) to address some of the very real and practical barriers certain communities face in accessing care and managing their conditions. For example, in terms of managing long-term conditions (LTCs), Diabetes UK, Mind, and Asthma and Lung have proposed a partnership

which primary care could refer newly diagnosed patients to for immediate follow-up and to get people on a good path to self-management (unpublished, annexes A and B). Collectively treating these conditions costs the NHS £30 billion a year, so any efficiency savings that can be made through self-management are vital.

#### **Policy tests**

To ensure that any policy proposals aligned with the vision and principles are both impactful and effective, we chose to assess them using the Nuffield Trust evaluation of the Mayor of London's health inequality tests (Gainsbury and Hutchings, 2022; Mayor of London, 2022). Health inequalities should be a fundamental consideration across all workstreams, rather than being restricted to workstream 4, and these tests will be used to hold workstreams to account on their suggestions. We have considered all principles as we have developed our visions and recommendations, and as this is not the sole aim for other workstreams, these tests will help ensure they are considered. Each enabler group should apply these principles and demonstrate how they have done so in their final end product. These tests are particularly valuable because they prioritise key areas essential for an equitable healthcare system that can provide for those most in need.

All workstreams should consider whether their policy proposals:

- set out the current systemic health inequalities in England, including those driven by socio-economic deprivation and structural racism
- have explored how policy proposals will impact the health inequalities set out in their baseline analyses in a systematic, documented way
- ensure that services become more available to groups experiencing the most significant health inequalities
- ensure a reduction in unwarranted variation in healthcare outcomes
- set out specific, measurable goals for narrowing health inequalities

# 4. Policy proposals

Over the following pages we have set out a number of crowd-sourced and co-produced policy recommendations which we have split out under each of the 7 enabler working groups. These are to provide inspiration for further consideration how each of the enablers can contribute to tackling healthcare inequalities. We have however pulled out 7 key recommendations which we think are worth the particular consideration of the Secretary of State and the 10 Year Health Plan team. These recommendations are interdependent and

are both useful in terms of driving real improvements in addressing health inequalities, but they also send strong cultural signals that this government really means business when it comes to creating a truly equitable NHS by 2035.

#### 1. Be honest about current performance

Put tackling existing healthcare inequalities front and centre of day-to-day NHS performance management by, firstly requiring all NHS performance data to be published broken down by deprivation and ethnicity (in line with the classifications used in the 2021 Census). NHS organisations that do not publish timely and complete datasets, particularly for underserved communities, should be called out.

Secondly, defining and adopting specific measurable goals for eliminating key inequity gaps, such as the racial disparities in terms of maternal and neonatal mortality.

#### 2. Drive culture change by measuring what matters

Create an overarching, specific and measurable set of metrics to judge progress on creating an equitable NHS.

This should include a new high-level NHS target around patient experience and outcomes of LTC management. LTCs represent 70% of NHS activity and addressing them is directly linked to reducing the number of years spent in ill-health, yet current performance hides in the shadows of elective and A&E statistics.

Each ICS should be required to publish performance against national metrics, as well as locally relevant outcome indicators depending on their specific local population needs.

#### 3. Change the flow of money

Fundamentally rewire the way the NHS distributes money by:

- making the Advisory Committee on Resource Allocation independent of both DHSC and NHS England
- immediately tasking it with replacing existing funding formulae like Carr-Hill with new approaches that put levels of unmet need and socio-economic factors at the heart of decision making

#### 4. Put our staff where our patients are

Set explicit trajectories for the re-distribution of the NHS workforce by:

- moving existing and new staff to areas with the greatest levels of unmet need ideally recruiting and training from within these communities
- rebalancing the make-up of the workforce to increase the proportion of staff and roles providing outreach to underserved communities

Underserved communities should include Core20PlusConnectors, community health workers, social prescribers, district nurses, paramedics and care coordinators and recognising the value of employing people with direct lived experience of severe exclusion and marginalisation.

#### 5. Show leadership and accountability

Establish named Executive Leads for Health Inequalities nationally, regionally at ICS level underpinned by:

- creating a Health Equity Accountability Framework with defined roles responsibilities and accountabilities
- supporting this with consistent and well supported community involvement to ensure named individuals are performance managed and held to account

#### 6. Double down on Core20PLUS5

Recognise the success of the current Core20PLUS5 approach in providing a focus for ICSs and securing traction on health inequalities.

Drawing on the findings from the evaluation, work with system leaders, frontline professionals and communities to understand how to build on the Core20PLUS5 approach.

#### 7. Demonstrate that we care about more than our patient's condition

Whilst the NHS cannot address all the wider determinants of health, the system must be hyper-aware of how the context of people's lives impacts their ability to stay healthy and to manage their conditions and commit to doing what it can to help. This is the key to ensuring all the recommendations above drive the improvements we need to see in health equity.

We recommend implementing a 'social risk score' for all patients that sits alongside existing clinical risk scores, helping services to become more interested in people's housing, employment and caring responsibilities.

Information from this social risk score must be shared appropriately with other parts of the system to ensure services can be tailored, and additional support put in place to help people access the care and support they need to stay well and delay the burden of disease.

#### People

#### Strengthen cultural competency and inequalities training across the workforce

The principles set out above will require a significant culture change within the current and future NHS workforce. This needs to happen at all levels if we are to create the welcoming, culturally competent, trauma-informed and stigma-free services we need to. To gather views from different workstreams across DHSC and NHS England, we surveyed policy teams to identify interventions and structural changes that support equitable service access, and to understand how patients and communities are or should be involved in policy design. In their responses, teams expressed the need for a shift in attitudes and an intersectional approach to educating staff.

We recommend commissioning the development of a national cultural competency framework for all staff, backed up by meaningful required training. A key component of this framework should include the national implementation of trauma-informed care principles. integrated care boards (ICBs) should be required to publicly report on staff completion of the training as part of their demonstration of how they are actively tackling inequalities. Furthermore, for a cultural competency framework to work, there needs to be a desire to learn.

However, evidence shows that although cultural competency training is important, it needs to sit alongside thorough organisational performance frameworks that can assess impact (Bhui and others, 2007; Whitley, 2007). Therefore, alongside the framework we recommend commissioning the development of a thorough organisational performance framework to assess impact.

We recommend reviewing undergraduate and postgraduate curricula and ensure rigorous up-to-date training on health inequalities and cultural competency in all clinical courses.

We recommend including a requirement in professional revalidation processes for staff to demonstrate how they have applied training on cultural competency and stigma-free care into their working practices.

We recommend that all board members, including executives, non-executive directors and chairs should be required to have health inequalities training as part of their induction. They should have annual objectives linked to health inequalities with an appraisal mechanism to monitor compliance.

We recommend that trusts be held to account by the Care Quality Commission (CQC) as part of their 'Well Led' inspections to improve the experiences of staff, based feedback in the staff surveys (CQC, 2025). This is predicated on the fact that staff experience correlates with patient experience and patient safety (Janes and others, 2021).

#### Put our staff where our patients are

To address health inequalities effectively, the NHS workforce must be strategically distributed to ensure resources are put where they are needed most. This requires not only the physical moving of staff but also a re-balancing of roles to better meet the needs of underserved communities. The current and future workforce must be positioned to address unmet needs, particularly in areas with longstanding health disparities.

We recommend that ICBs and NHS England should develop clear plans to move existing and new staff to regions with the highest levels of unmet need. This should be informed by data on health inequalities and population demographics.

We recommend recruiting and training from within underserved communities. Workforce training places should be given with priority for areas of un-met need and socio-economic deprivation, like coastal communities, as discussed in the Chief Medical Officer's (CMO) Health in Coastal Communities report and by the Coastal Navigators Network (Whitty, 2021; NHS England, 2023b).

We recommend prioritising increasing the proportion of roles dedicated to outreach and community care, particularly those that can reach marginalised communities. Key roles include CORE20PLUS connectors, community health workers, district nurses, doulas, paramedics and care coordinators (Junker and others, 2023).

ICBs should publicly report progress on workforce distribution plans as part of their overall strategies for tackling health inequalities.

We recommend resources and support are provided for redistributed staff.

#### Strengthen skills and capacity in community engagement

The NHS is not engaging effectively with its local community in part because of a lack of skilled staff and routes to sharing community insights at key decision-making levels.

We recommend all NHS staff and service lines should be trained and equipped with the necessary competencies and capabilities for engaging seldom heard communities. The communication toolkit for engaging Jewish communities, published by the NHS Race and Health Observatory in December 2024, serves as an excellent example of this in practice (NHS Race and Health Observatory, 2024).

We recommend that provision of community language, translation and interpreter (CLTI) services be a requirement within NHS services, in particular for women whose first language is not English, as emphasised in the most recent MBRRACE report (2024).

We recommend the development of an independent national network of lived experience partners, supported by nationally funded development and training, to make current lay roles in NHS research, engagement and governance more than the sum of its parts.

We recommend creating a trustee level role in all trusts and ICBs responsible for oversight and scrutiny of all the community engagement activity. This post should be responsible for ensuring the board seeks assurances on inclusive engagement being carried out and action being taken, including communities being told what is being done with their contributions. The Care Quality Commission's (CQC) newly created framework on engagement and inequalities, funded by the Regulators Pioneer Fund, should provide the foundation for this.

We recommend that boards of NHS England, NHS and publicly funded healthcare providers should reflect the population demographic served by that organisation.

# Case study – The Queen's Nursing Institute (QNI) Homeless and Inclusion Health Programme

The QNI's Homeless and Inclusion Health Programme is a national network to improve the health of marginalised groups (QICN, 2025). QNI supports community nurses to achieve outstanding levels of care for people experiencing homelessness and others who may experience barriers to accessing care. This is a great example of putting our workforce where the needs are. Examples include:

- delivering flu vaccinations to rough sleepers in South London
- integrated homelessness mental health practitioner in Ipswich
- homeless health surgical screening hub in Colchester

## Finance and contracting

#### Revise key funding formulas to prioritise health equity

Current funding formulas used by the NHS tend to be based on existing workload rather than on assessing the level of need in an area. To tackle the inverse care law, this needs a complete overhaul.

We recommend replacing the Carr-Hill formula. This is the main funding route for GPs and is a key driver in why surgeries in England serving deprived areas get on average 9.8%

less funding despite having 14.4% more patients per fully qualified GP (Fisher, 2024; Fisher and others, 2024; Office for National Statistics, 2022).

Replacing Carr-Hill would send a strong signal that the government is serious about its desire to shift more care into the community, as well as tackling inequity. A new formula could properly consider current levels of un-met need, and resource the CMO's suggestion around focusing on delaying the onset of disease in middle-aged people living in deprived areas (Whitty, 2023).

This would be a bolder approach than simply bolting on an inequalities premium to the existing Carr-Hill formula. It would also go further than the NHS main 'general and acute' formula, which is also based on activity, but has an adjustment for health inequalities and unmet need. It would also be easier to achieve if there were additional funds made available to bring underserved practices up to the average without taking resources away from other areas.

#### Case study - Leicester, Leicestershire and Rutland

In Leicester, Leicestershire and Rutland (LLR), a region with significant differences in deprivation, the clinical commissioning group (now ICB) addressed the shortcomings of the Carr-Hill Formula by adopting targeted strategies to better reflect the needs of its diverse population using a programme developed by John Hopkins (Healthcare Financial Management Association, 2024; Fisher, 2024). By prioritising funding for underserved areas and focusing on health inequalities, the region made significant strides in addressing the inequities the formula often prolonged. However, replacing the Carr-Hill Formula entirely with a new framework would build on Leicester's progress, creating a system that more accurately responds to the realities of local communities.

#### **Update and promote the Low-income Health Scheme**

The Low-Income Health Scheme includes financial support that the NHS offers patients in five key areas - prescription costs, dental costs, eyecare costs, healthcare travel costs, wigs and fabric support (NHS, 2020). The scheme also includes maternity exemption certificates.

For those who rely on them, these schemes are essential to making the NHS a genuinely free-at-the-point of use service. However, uptake varies significantly. For example, free prescriptions are well-used, but uptake of the travel reimbursement scheme is very low due to a lack of promotion by the NHS. National Voices research found that in 2023 to 2024 just 3,618 patients benefited from the travel scheme, down 21% since 2019. This cost the NHS just £175,602, down 25% since 2019. A HealthWatch (2022) report in Blackburn found that a lack of awareness about the Low-Income Scheme to cover

prescription costs and HealthWatch (2022) research in Croydon had similar findings in regard to access to NHS dentistry.

We recommend that:

the scheme is reviewed and relaunched with sufficient resource to promote the offer,
 so that all those who need the support are aware of their entitlement

Compensation limits agreed under the review should be linked with the Clinical Pathway Initiative, to avoid inflationary loss of the benefit. Uptake of the scheme should be publicly reported as part of ICB's demonstration of how they are actively meeting the needs of people on low incomes.

#### Health inequalities funding

We need to make sure that money set aside for health inequalities is spent on addressing health inequalities. We can do that in one of 2 ways:

1. You could decide to ringfence budgets, so funding is clearly protected. For example, a central pot for inclusion health services.

Or

2. You could give local systems the flexibility to identify where best to spend that money to address health inequalities, however this must be supported by additional, strong accountability structures.

## Physical infrastructure

The NHS, as one of England's largest landowners, has the potential to act as an anchor institution by managing its land and buildings in a way that deliver significant social, economic and environmental benefits. Effective management can contribute to healthier communities, improve wellbeing and help to reduce health inequalities (NHS England, 2024a).

#### Integrate the NHS with the community by sharing infrastructure

Making the shift from hospital to community happen is not solely about the NHS building more of its own infrastructure in the community. While investment is desperately needed to make the primary care estate fit for purpose, the NHS needs to think far more about how it works with partners to make the best use of existing community infrastructure.

For example, by working with local voluntary sector organisations, faith groups, sports clubs the NHS can provide services in community settings which local people are already

using. This has the added benefit of building trust with previously underserved communities by working through existing trusted go-betweens.

#### We recommend:

- that NHS England, NHS Estates and CQC work together to immediately review existing regulations about safe premises with a view to giving systems and providers more flexible guidance on where they can provide services from
- that the NHS commit to paying a fair price for use of existing community spaces that help support local groups and organisations with raising much needed revenue to continue their work with local people
- that if the NHS releases land for development, priority is always given to providing intermediate care, specialist supported housing, or affordable housing

#### Case study - St Basil's Live and Work scheme

The St Basil's Live and Work scheme is a powerful example of how the NHS can integrate into the community by sharing infrastructure to create real impact. By combining housing for young people with employment opportunities within NHS settings, it tackles critical issues like homelessness and unemployment while advancing access to healthcare. This partnership demonstrates how shared resources can be used to address wider social challenges, creating opportunities for individuals to build stable, healthier futures while strengthening ties between the NHS and the communities it serves (St Basils, 2023; NHS England, 2024b).

## Data and technology

To achieve equity in healthcare, we must ensure that demographic data is consistently and accurately captured to reflect the diverse needs of patients. Accountability is key: providers should report on how well services meet these needs, with clear action plans to address gaps caused by poor data quality.

#### Putting patients at the heart of equity data

We need to make health data work harder for our patients, both at an individual level and a population level.

We recommend introducing a social risk score as part of patient's clinical care. This will complement traditional clinical risk scores and ensure that people's social contexts are factored into clinical decision making.

Providers will be required to gather both clinical and real-world outcomes for their patients including how treatment has helped patients manage physical symptoms, any impact on their mental health, and achieving things like caring for loved ones or returning to or maintaining employment as well as information on housing status and digital inclusion. Gathering this data and using it to report how well services are meeting local needs can act as a morale boost to a workforce of people who largely go into the NHS to help people.

The process of developing the social risk score should create opportunities for clinicians to work with patients and their carers to understand and assess the capability and capacity for patients to self-manage their conditions and signpost to additional statutory and VCFSE run services which can help build on existing skills and knowledge.

We recommend the introduction of a new single care record. Resource and establish the necessary information governance infrastructure to enable inter-operable electronic patient records (EPR) across primary care and secondary care and wherever possible social care records. This will enable joined up care and strengthen continuity of care for people with multiple and complex needs.

This should include data captured as part of the 'social risk score'. This can then be shared appropriately with other relevant parts of the health system to ensure patients continue to receive personalised support as they move round the system and boost feelings of continuity of care.

As an example, needs captured as part of the accessible information standard will be consistently shared and met.

Current housing status should be routinely recorded for all patient interactions, including housing quality, instability, affordability, overcrowding and homelessness. These directly impact health and the likelihood of health improvement (Dorney-Smith, 2024).

# Case study: universal screening for social risk factors and social prescribing in Singapore

Healthier SG is a national initiative by the Ministry of Health (MOH) focusing on preventive health in Singapore. As part of this initiative, all 3 hospital providers in Singapore have introduced universal screening for social risk factors, and where the risk threshold is met, the patient is offered the opportunity to speak to a social prescriber (called in Singapore a 'Wellbeing Co-ordinator') to develop a personalised plan and be connected to local community services. Health leaders in Singapore visited the UK in 2019 and replicated the NHS adoption of social prescribing to develop their model. The minister, Mr Ong Ye Kung, announced a full roll out of social prescribing across all health services in Singapore last month. He is keen to visit England to discuss latest developments in social prescribing with UK health ministers (Ye Kung, 2024).

#### Mitigating digital exclusion

Digital technology offers huge potential for improving the efficiency and quality of care; however, it also carries risks if certain groups are left behind. Digital exclusion can be driven by a lack of skill or knowledge of how to use technology, a lack of trust in new systems, a lack of finances to afford devices and data, and a lack of connectivity due to infrastructure issues. It is also critical to remember that digital exclusions are not static and will change as new technologies come through (Mistry and Jabbal, 2023; Stone, 2024).

The NHS App currently has 80% of the population signed up as users, but only 3% of people are using it to book appointments. We need evaluations to be more curious and work with people to understand why technology is not always driving the behaviours or outcomes we want to see.

People want the government to focus on using digital technologies to focus on getting the basics right first, making care smoother and less frustrating to access. In our survey of DHSC and NHS England policy teams, many teams raised concerns around digital exclusion and ensuring that digital tools are accessible, with alternatives always in place for those that need it.

We recommend these practical actions to drive digital inclusion (NHS England, 2023a):

- access to devices and data so that everyone can access digital healthcare if they choose to and experience the benefits
- accessibility and ease of use of technology, so that user-centred digital content and products are co-designed and deliver excellent patient outcomes
- skills and capability so that everyone has the skills to use digital approaches, and health services respond to the capabilities of all
- beliefs and trust so that people understand and feel confident using digital health approaches
- leadership and partnerships so that digital inclusion efforts are co-ordinated and help to reduce health inequalities
- social risk scores should include identification of those with low digital literacy and those who are digitally excluded for reasons such as cost or lack of broadband, and this should be included in health records

# Case studies – 100% Digital Leeds and Digital Exclusion Risk Index, Salford City Council

100% Digital Leeds is working in economically deprived wards in Leeds to establish networks of digital health hubs. Digital health hubs are trusted community organisations in key locations with supportive staff, and they offer a wide range of digital inclusion support, such as providing access to devices and data connectivity, and helping people to build their digital skills and confidence. Through workshops, network meetings, and conversations with organisations, 100% Digital Leeds and Leeds local care partnerships built a digital support infrastructure across local voluntary and community sector organisations. They also worked with GP practices, community healthcare, social prescribers and others to promote the offer and provide a simplified referral and signposting route.

The Digital Exclusion Risk Index (DERI) was designed by Salford City Council and expanded upon by The Greater Manchester Authority to help visualise the risk or likelihood of digital exclusion for England, Wales and Scotland. The score is based on 3 component scores: demography, deprivation and broadband.

#### Research, life sciences and innovation

#### Prioritise health equity in research and innovation (R+I)

Inequity in the current system is sometimes driven unintentionally by research and implementation of new technology and medications. But by putting patients, carers and communities at the heart of the innovation life cycle, from demand signalling to adoption, we can use new advances to actively promote equity. It is important that R+I initiatives are designed thoughtfully. One team responded to our survey on fairness and inclusion in policy work stating that: "There is a risk that health inequalities can be exacerbated by poorly designed initiatives. Within research we know that the 3 main barriers for individuals to engage are access, trust and language. These need to be addressed in programme design."

#### Therefore, we recommend:

- commissioning the development of an equitable innovation framework which includes mechanisms for assessing health equity in innovation design, horizon scanning mechanisms, grant making processes, innovation pipelines and diverse innovator representation (NHS England, 2024c)
- establishing a requirement that all research, life sciences and innovation applications and business cases must outline how they will directly address inequalities - through the outcomes they aim to support and how they should be adopted by the system

- that NIHR is required to report on the collective impact of nationally funded research in terms of addressing inequalities by requiring this to be built into the evaluation of all research grants
- that National Institute for Health and Care Excellence is required to report publicly on the unwarranted variation and uptake of approved medications and technologies by population demographics, and to be given a greater role in working with the VCFSE sector to empower patients with the right information and questions to request access to new treatments

The Innovation for Healthcare Inequalities Programme (InHIP) published a report in collaboration with Accelerated Access Collaborative and the Health Innovation Network on the impact of innovative technologies and medicines used to reduce healthcare inequalities. As highlighted in the report, over 34,000 people from underserved groups or deprived areas have benefitted from InHIP Wave 1 interventions, with around 8,000 patients gaining access to an innovative product on a treatment pathway (InHIP, 2024).

# Ensure population-wide representation in data for AI, genomics and similar technologies.

One of the big risks about the rapid adoption of artificial intelligence (AI) and genomics is that the data generated is not reflective of the diverse communities the NHS serves. It the data is lacking then there is a risk the models will bake-in inequality from the very start.

We recommend establishing and enforcing standards requiring diverse representation in clinical trials, with clinical trials working more in partnership with VCFSE organisations as a trusted go-between with relevant communities, and individual trials to put in place support to help a diverse range of patients take part (MAPLE REND, 2024; National Voices, 2024; Whitehead, 2024). This proposal is supported by the Science, Research and Evidence Directorate, Chief Scientific Advisor Group and National Institute of Health and Care Research Budget Holder and Leadership teams.

We also recommend creating ringfenced funding for specific research initiatives that target health inequalities in hyper-marginalised populations, in a similar way to how we promote research into rare conditions at the moment (DHSC, 2024).

We recommend that government and the NHS develop a mechanism to support VCFSE organisations and other partners to bring independently gathered data to the table. This would require support for partner organisations to meet certain standards regarding data collection, but also the NHS to acknowledge the value all quantitative and qualitative data can add even if does not meet traditional academic standards.

#### Accountability and oversight

Strengthening accountability and patient voice is essential for addressing health inequalities and ensuring that NHS services meet the needs of marginalised communities. While the UK has one of the more comprehensive health inequalities accountability systems in Europe, recent years have seen these mechanisms weaken, with insufficient attention given to the lived experiences of marginalised groups (Barsanti and others, 2017). Since 2010, accountability for health equity in England has been inconsistent, with no public health white papers published between 2011 to 2019, and austerity measures further reducing public health budgets (Allen and Boyce, 2023). NHS guidance, including the 2019 Long Term Plan, emphasised addressing inequalities but lacked a systematic or joined up approach, leaving local systems to create their own approaches (NHS, 2019). This has contributed to an 'implementation gap' between good intentions, policy and actions (Bibby and others., 2023). Therefore, to rebuild trust and ensure equitable healthcare outcomes, we propose several key reforms.

#### Putting health equity at the heart of NHS data reporting

At a population level, the NHS regularly publishes performance data against key constitutional standards such as 18-week RTT and A&E 4 and 12 hour waits. However, currently, this performance data is not broken down by any population demographics, making it hard to examine performance against tackling health inequalities. DHSC and NHS England policy teams view data as a fundamental part of reducing inequity. In our survey, they expressed the need for more breaking down of data, particularly by ethnicity. This will help teams proactively identify and reduce disparities and help target interventions or tailor approaches where needed.

NHS England says this is because they are not able to quality assure demographic data for all providers and ICSs and therefore does not publish the data it does hold. This needs to change, with NHS England publishing the data it does hold and naming those organisations who are unable to provide validated demographic data.

#### We recommend:

- NHS publishes broken down NHS operational performance measures by at least the Indices of Multiple Deprivation and Ethnicity data on a monthly basis
- each ICB is required to report against a newly developed equity dashboard, visible to and understandable by the public, which shows where resources are going and how they're improving population health equity

#### Case study: 'Was Not Brought' pilot schemes

The Children's Hospital Alliance led an innovation project to challenge 'Was Not Brought' (WNB) rates for children, of which 8 million were recorded in 2019 to 2020 (Children's Hospital Alliance, 2023). The project had 2 main components:

Developing and rolling out an NHS AI tool which uses 43 commonly available data points to identify patients at highest risk of missing outpatient appointments.

Health inequality focused transformation, with 5 pilot schemes to reduce WNB rates among children at highest risk of missing their appointments. These schemes aimed to lower the difference in rates of WNB between population groups.

The AI tool uses variables including patient demographics, Indices of Multiple Deprivation score and previous appointment attendance, and allows service improvement and outpatient teams to target support to families most at risk. A national network of 10 Children's Hospitals across the UK trialled WNB interventions. For example, Sheffield Children's NHS Foundation Trust, where parents of children with a risk of over 50% were offered support with transport. Over the course of 3 weeks, 65 additional appointments were supported by the intervention, preventing £7,800 worth of clinical time being lost (The Strategy Unit, 2023).

#### Case study: data driven health equity in Birmingham and Solihull

Birmingham and Solihull local maternity and neonatal system (LMNS) developed a health inequalities dashboard to identify health inequalities and established Maternity Link Support Workers (MLSWs) to undertake targeted health promotion for vulnerable, pregnant mothers (Birmingham and Solihull ICS, 2022).

The dashboard enables the LMNS to identify, investigate and understand population needs in near real-time, and prioritise and plan appropriate targeted interventions. It contains service-level -for example, do not attends (DNAs) - and health outcome-level indicators (for example, incidence of pre-term births, gestational diabetes, genetic disorders) to help focus service delivery on those with the greatest need. The Index of Multiple Deprivation is used to identify and understand service and health outcomes amongst the most deprived populations. The dashboard is used to:

- monitor and refine activity to help assess whether targeted interventions lead to desired effects and supports accountability
- forecast trends regarding health needs and outcomes, enabling proactive strategic intervention planning and resource distribution.

As a result, the LMNS report improved DNA rates, increased maternal vitamin update and increased breast-feeding rates, achieved through education and support provided by the MLSWs to pregnant women.

#### Updates to CQC single assessment framework

The CQC Single Assessment Framework (CQC, 2024) evaluates care quality across key domains but currently lacks explicit consideration of health inequalities. Addressing health inequalities requires embedding this focus into oversight processes to ensure accountability at all levels.

We recommend that CQC, or any future ICS oversight regimes, should update its single assessment framework to include assessment of health inequalities as a key line of enquiry across all quality domains.

We recommend CQC, and future ICS oversight regimes, should be required to report progress against the four statutory aims of ICSs outlined in the Health and Social Care Act 2022, which includes reducing inequalities in access, experience and outcomes for their populations (GOV.UK, 2022).

#### LTC management

LTCs represent around 70% of health and care spending, but currently lack a dedicated high-level key performance indicator (Department of Health, 2012). However, this figure is from 14 years ago, and prevalence of LTCs has significantly increased (Office for National Statistics, 2023). Introducing a target focused on LTC management would help to drive the 3 crucial shifts in the system: from hospital to community care, from treatment to prevention and from analogue to digital solutions.

The shift from hospital to community care would ensure patients with LTCs are better supported in local settings, reducing hospital admissions and fostering integrated care systems. At the same time, the shift from treatment to prevention would focus on proactive management, helping patients avoid further complications and additional conditions. Lastly, the shift from analogue to digital would track what type of services people are using to support their LTC management.

Hospital to community - by understanding how many patients feel they are being well supported to manage their LTCs in the community, and a supporting measure about hospital admissions for LTC symptoms (going up or down), we could develop a picture of whether the new enhanced community offer is working.

Treatment to prevention - again we could have a measure of how many patients feel they are being well supported to manage their LTC, with a supporting measure of around how

we are delaying the development of further LTCs. This would be a good way to watch performance on secondary prevention.

Analogue to digital - we could get the measure of how many feel well supported, and secondary measure about whether they are doing so through digital support. The aim being to keep improving both the proportion of people who say conditions are well managed and the proportion using digital.

We recommend introducing a national LTC management target. This would measure how well patients are supported in managing LTCs, using patient reported outcome measures (PROMs) and patient reported experience measures (PREMs) about how patients are supported to achieve real-world outcomes or feel support to self-manage.

We recommend offering all patients digital health tools for monitoring their condition, with a target to reduce hospital admissions for preventable LTC-related complications by 10% within 12 months.

#### Case study - real world outcomes

Rethinking Pain is a community-based service for adults living with long-term pain in the Bradford and Craven area, led by Keighley Healthy Living (KHL). The Rethinking Pain team work one-to-one and in groups to connect people living with persistent pain to appropriate pain information, education, support and community-based activities. There are local community support groups, including an online group for young people. This approach is designed to support physical, mental, social and environmental needs, while also understanding individual's preferences and circumstances to help them manage their pain better.

#### Success story:

"In March 2021, I fractured two of my vertebrae. The pain was so bad I needed help to dress, shower and even turn over in bed. 18 months on I still had pain, requiring frequent pain relief medication and physiotherapy. My doctor warned me that medication might not fully resolve my pain. With the support of the Rethinking Pain services, my confidence has returned, and I feel positive about the future. My wife is less worried about what the future holds. My previously frequent GP and medical visits have reduced to almost nil. I've virtually stopped all my pain medication and I'm managing my pain better. It's difficult to believe how much I have improved in such a relatively short time."

#### Establishing an independent patient council

An independent patient council, reporting directly to the Secretary of State, should be created to place patient voices at the heart of NHS decision-making. This council would:

- examine and inform the development of clinical guidelines to ensure they reflect patient needs across diverse demographics
- review reports on patients' experiences of care, with particular attention to marginalised groups often overlooked in national data sets

To support the council, a restructured and better-resourced Health Wellbeing Alliance would play an important role in collecting and analysing patient experience data. This alliance would focus on insights from VCFSEs, particularly those serving communities often excluded from decision-making. Furthermore, by integrating and streamlining existing patient feedback mechanisms, such as the national patient survey programmes, this approach would join up disparate efforts into a consistent infrastructure.

#### Case study – Health Councils in Brazil

Brazil's Health Councils provide a compelling case study of how patient participation can shape policy (de Cássia Costa da Silva and others, 2021). These councils, made up of users, workforce, and managers, have improved transparency and driven community engagement in decision-making. Though challenges remain, their successes highlight the transformative potential of embedding patient voices within governance structures.

#### Setting measurable health equity goals

Clear, nationally-mandated measurable goals are critical for driving accountability in health equity. Building on the success of the previous Labour government (Buck and Maguire, 2015) in reducing the life expectancy gap, we recommend:

- setting a time-bound target for closing the gap in healthy life expectancy between the richest and poorest communities
- setting a target in each locality to reduce the mortality gap between inclusion health groups and populations and the average
- ensuring targets include a regional or community aspect to help delegate responsibility to local authorities and ensure accurate evaluation by using geographical measures of social status, such as the Index of Multiple Deprivation

#### **Maternity disparities**

Honouring the government's manifesto pledge to eliminate the gap in racial and ethnic inequalities in maternal and neonatal mortality and morbidity, as highlighted by the recent MBRRACE (2024) report.

Setting an overarching target to close the maternal and neonatal mortality gap with yearon-year trajectories of improvement for NHS England, NHS trusts and ICBs.

Including the achievement of this goal in the annual objectives of the Chief Nursing Officers, Chief Midwifery Officers, Chief Medical Officers and Trust Chief Executive Officers.

The importance of targets in policy design has been demonstrated through numerous national government initiatives, such as the 2001 UK government target to reduce the infant mortality rate gap by 10% between the fifth of areas with the worst health and deprivation indicators and the population as a whole by 2010. The gap narrowed by 12 deaths per 100,000 births per year, despite initial reviews suggesting that the initiative was failing, and the target was unachievable (Holdroyd and others, 2022). The success of this initiative was partly due to targets being clearly quantified and regularly monitored, however, inequalities rose again post-strategy, highlighting the need for sustained investment (Bambra and others, 2023). Similarly, tackling maternal and neonatal mortality disparities will require strong and sustained monitoring, with timely and complete data sets broken down by deprivation and ethnicity to assess progress effectively. NHS organisations that fail to provide this data should be held accountable to ensure underserved communities are not overlooked.

Specific targets have a communicative role, spreading awareness of the issue and ensuring it remains a high priority in policy recommendations, even when initial reviews are less promising than hoped. It is important, however, to ensure time-bound targets consider when we would reasonably expect to see an impact, where a long-term vision is more likely.

#### **Exploring outcome-based contracting models**

To ensure resources are distributed effectively, the NHS should explore outcome-based contracting models.

These models would prioritise funding and care delivery approaches that align with health equity goals, ensuring measurable improvements in patient outcomes. Previous reforms have focused on payment by results, but that has been operationalised in terms of payment by outputs. We need to make payment by results actually work by shifting the focus on the outcomes services are achieving for people.

# Case study - Buckinghamshire, Oxfordshire and Berkshire West ICB mental health commissioning

Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB) commissions mental healthcare services and has been working with providers, service users and the public to develop a lead accountable provider contract with a capitated payment linked to outcomes. In its model, the success of healthcare provision is measured by the outcomes that are most meaningful to service users, rather than by activity. These outcomes are:

- people with mental illness will live longer
- improved level of wellbeing and recovery
- timely access to assessment and support
- people will maintain a role that is meaningful to them
- continue to live in stable and suitable accommodation
- better physical health
- carers will feel supported

This has resulted in improved joint working between organisations, greater financial security for third sector partners and improved physical health monitoring for people using mental health services (Centre for Mental Health, 2020).

## Mobilising change

To truly improve the NHS and make it work for everyone, we need to focus on how decisions are made, who is involved and whether the voices of marginalised communities are being heard. Right now, despite best intentions, many local needs are overlooked, and key players - like VCFSE organisations, are underfunded and undervalued. A recent study found that VCFSEs are struggling with short-term contracts and fragmented relationships with the NHS, leading them unable to fully meet the needs of those they serve (Sheaff and others, 2024). The Health and Care Act 2022 gave us a framework for better engagement, but the way it is currently being implemented is inconsistent and thus limiting its impact.

#### Publish a cross-government health inequalities strategy

Narrowing health inequalities in the NHS represents large scale, complex systems change. It will therefore require the use of mutually reinforcing levers, systems and mechanisms to implement and sustain. The Core20PLUS5 delivery infrastructure made up of people,

systems, and mechanisms offers a template of how to socialise, mobilise and embed large scale change (NHS England, 2024a).

Therefore, building on the last Labour government's approach and the King's Fund 7 Priorities for Health Inequalities, the first of which is a recommendation for a cross-government health inequalities strategy (Morris and Robertson, 2024), we recommend the following.

Start a National Health Inequalities Team with a cross-government departmental brief to drive implementation of the strategy by supporting Whitehall departments, ICSs and place-based teams with system capabilities, tools and resources for ensuring that the government's over-arching national goal for reducing health inequalities is achieved.

The government's annual mandate to NHS England should include a specific requirement to include reducing health inequalities in NHS England's Annual Priorities and Operational Planning Guidance

The implementation of the strategy will require alignment between the government annual mandate to NHS England, NHS England's operational priorities and planning guidance, NHS England's oversight framework and the CQC's assessment framework to ensure consistent delivery.

#### Changing how we support the voluntary sector

VCFSEs are invaluable partners in healthcare, addressing gaps in provision and work with underserved groups. However, current commissioning practices often leave them financially unstable and undervalued. They're often the ones working on the frontlines, supporting vulnerable groups who fall through the cracks of mainstream services. Yet the system treats them as an afterthought. In our survey, DHSC and NHS England policy teams discussed the value of partnerships with VCFSEs to ensure patients and communities are involved in policy design but highlighted that these organisations cannot do this without adequate resourcing. A NIHR funded study highlights the importance of long-term funding and equitable contracting practices to deliver effective services sustainably (Sheaff and others, 2024).

Therefore, we recommend introducing a national VCFSE framework that ensures long-term funding, equitable contracting practices and early engagement with organisations.

#### Case study: Sussex VCSE commission framework

An example of good practice is the voluntary community and social enterprise (VCSE) commissioning framework implemented by Sussex ICS (NHS Sussex, 2023). This framework emphasises multi-year contacts, transparent funding processes and early engagement with VCSE organisations. These principles have fostered stronger, more

sustainable partnerships and improved service delivery outcomes. Expanding such frameworks nationally will provide a more consistent and supportive environment for VCSE collaboration.

#### **Enhancing community engagement**

The Health and Care Act 2022 introduced a legislative duty for NHS organisations to engage communities in decision-making, offering a vital opportunity to bring local voices into the design and delivery of healthcare. However, the practical implementation of this duty has been inconsistent with significant variation in how systems, places and neighbourhoods involve communities (Sheaff and others, 2024).

Therefore, we recommend that the government should conduct a formal review of the legislative duty to engage communities, evaluating its effectiveness and ensuring it delivers on its promise to empower communities.

This review should examine whether current engagement mechanisms genuinely include all voices, particularly those from underserved groups. It should also clarify the role of VCFSE organisations, ensuring they are recognised as essential partners in connecting with NHS with underserved populations.

We recommend aligning these efforts with the Voluntary Sector Compact being developed by the Department for Culture, Media and Sport (DCMS) could strengthen the frameworks for engagement, setting clear expectations and supporting a culture where community input directly informs decision making (Department for Culture, Media and Sport, 2024).

Additionally, the CQC health inequalities framework, co-produced with people, VCSEs and ICSs, offers a valuable tool for this process. It is designed to help ICSs understand how well their community engagement efforts are addressing health inequalities. Although the framework will be formally launched in February, a draft version is included in the technical annex. It effectively brings together public engagement and health equity objectives, providing a ready-made tool to support improvement and accountability in engagement practices.

# Annex A concept note: VCSE support for newly diagnosed people as part of chronic condition pathways - Asthma + Lung UK, Diabetes UK and Mind partnership

# **Summary**

Every year, around 560,000 people are diagnosed with type 2 diabetes or a chronic lung condition<sup>1</sup> and there are currently 1.8 million people on a waiting list for mental health treatment.<sup>2</sup> As leading health charities who represent these people, we know that patients aren't getting adequate support, help or advice to know how to best manage their condition once they have been diagnosed. Our beneficiaries tell us they are left feeling frightened, isolated, poorly informed and alone. Lack of information about self-management contributes to unnecessary hospitalisations and worsening of their conditions. This is costing people their quality of life, precious time with their loved ones and the NHS more money in the long run. But together, we can change that.

We propose a ground-breaking charity partnership, backed by government, to ensure that newly diagnosed people with these conditions get robust help and support at the point of diagnosis and in the following year, when they need it most. We estimate this would cost around £5 million, and by 2026 we would reach 50% of those who are newly diagnosed with type 2 diabetes or a chronic lung condition and 9,520 people who are struggling with their mental health. Our organisations are uniquely placed to take up this partnership and deliver change quickly. This partnership would harness existing systems in primary care to accelerate and develop our current service offers; vastly expanding our provision of robust self-management support to keep thousands more people living well, longer and out of hospital.

<sup>&</sup>lt;sup>1</sup> A combination of COPD, ILD, Bronchiectasis and Asthma diagnosis per year, and type 2 diabetes – lung disease diagnosis ratees available at <a href="https://statistics.blf.org.uk/">https://statistics.blf.org.uk/</a> and type 2 diabetes diagnosis rates available: <a href="https://www.diabetes.org.uk/about-us/about-the-charity/our-strategy/statistics">https://www.diabetes.org.uk/about-us/about-the-charity/our-strategy/statistics</a>

<sup>&</sup>lt;sup>2</sup> Mind's (2021) Covid One Year On Survey, <u>The impact of coronavirus on mental health</u>

# **Our proposition**

We propose an innovative partnership with government and the NHS, where a patient diagnosed with type 2 diabetes, a chronic lung condition or low or moderate mental health needs, is referred to our charities from primary care for follow-up and self-management support. This will be delivered slightly differently according to condition to best suit the needs of these patient cohorts. In the case of type 2 diabetes and chronic lung conditions, patients will receive a text message from their GP offering them support from the relevant charity with tailored health advice, access to our dedicated helplines and resources to help patients manage their condition, stay out of hospital and relieve pressure on acute and emergency services. This would be the basic offer with an enhanced offer of outreach for specific identified groups to ensure they are getting the advice they need to stay well and out of hospital, with a follow-up call for evaluation. In the case of mental illness, we recommend using Mind's Supported-Self Help service which follows a similar logic but includes intensive support through 6 sessions over 8 weeks with a trained practitioner based on cognitive behavioural approaches combined with self-help resources. Our charities are in a unique position to deliver this programme as these services are already set up and running, allowing us to scale these up to deliver results quickly and have a lasting impact on health outcomes.

# The case for change

## Millions of people are affected, and numbers are growing

Mental ill-health, lung conditions and type 2 diabetes have all been identified in the government's Major Conditions Strategy as priority areas that require urgent and targeted action to improve health outcomes across the UK. In particular:

Lung conditions remain the third biggest killer in the UK, affecting 12 million people. The UK has the worst death rates for these conditions in the whole of Europe and little progress has been made to improve this over the last decade.<sup>3</sup>

<sup>&</sup>lt;sup>3</sup> NHS England (2022) Our ambition for respiratory disease Accessed here NHS England » Respiratory disease (August 2023)

3.9 million people are living with type 2 diabetes and the numbers of people affected are growing rapidly, increasing by 23% over the past 5 years in under-40s, compared to only 18% in those over-40s.<sup>4</sup>

Around 1 in 4 people will experience mental illness in any given year.<sup>5</sup> This number has grown significantly since the pandemic. Mental health services in England received a record 4.6 million referrals during 2022 (up 22% from 2019), with the number of people in contact with mental health services steadily rising.<sup>6</sup>

Every year, 250,000 people are newly diagnosed with type 2 diabetes, and around 310,000 people are newly diagnosed with a chronic lung condition, including chronic obstructive pulmonary disease (COPD),<sup>7</sup> interstitial lung disease (ILD), bronchiectasis and asthma,<sup>8</sup> alongside this there are 1.8 million people currently on the waiting list for mental health treatment.<sup>9</sup> However, we know there are many more people who are living undiagnosed or unable to access treatment, for example, an estimated 500,000 with COPD,<sup>10</sup> 850,000 with diabetes (most of whom will have type 2 diabetes) and a further 8 million who would benefit from mental health services but are not able to access them.<sup>11</sup>

1 in 4 people in the UK now live with 2 or more health conditions, <sup>12</sup> and often those with multiple morbidities have the worst-managed conditions, poorest quality of life and are at the greatest risk of premature death. As people live longer this burden is expected to grow and a number of health conditions will become more prevalent due to their link with ageing. <sup>13</sup> For example, it is estimated that 92% of people with COPD and 70% of people

<sup>&</sup>lt;sup>4</sup> Diabetes UK (2023) https://www.diabetes.org.uk/about-us/news-and-views/number-people-living-diabetes-uk-tops-5-million-first-time

<sup>&</sup>lt;sup>5</sup> NHS Digital (2014) https://digital.nhs.uk/data-and-information/publications/statistical/adult-psychiatric-morbidity-survey/adult-psychiatric-morbidity-survey-of-mental-health-and-wellbeing-england-2014
<sup>6</sup> BMA (2023) https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/mental-health-pressures-data-analysis

 <sup>&</sup>lt;sup>6</sup> BMA (2023) <a href="https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/mental-health-pressures-data-analysis">https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/mental-health-pressures-data-analysis</a>
 <sup>7</sup> NICE (2019) myCOPD for self-management of chronic obstructive pulmonary disease (COPD)
 <a href="https://www.nice.org.uk/guidance/mtg68/documents/final-scope-2">https://www.nice.org.uk/guidance/mtg68/documents/final-scope-2</a>, taken from BLF stats

<sup>&</sup>lt;sup>8</sup> NICE (2021) What is the prevalence of asthma? <a href="https://cks.nice.org.uk/topics/asthma/background-information/prevalence/">https://cks.nice.org.uk/topics/asthma/background-information/prevalence/</a>

<sup>&</sup>lt;sup>9</sup> Mind's (2021) Covid One Year On Survey, The impact of coronavirus on mental health | Research | Mind

<sup>&</sup>lt;sup>10</sup> Nacul L, Soljak M, Samarasundera E, and others. (2011). COPD in England: a comparison of expected, model-based prevalence and observed prevalence from general practice data. J Public Health.

<sup>&</sup>lt;sup>11</sup> Diabetes UK (2023) Strategy statistics, How many people in the UK have diabetes?

<sup>&</sup>lt;sup>12</sup> Health Foundation (2018) Understanding the health care needs of people with multiple health conditions, <u>Understanding the</u> health care needs of people with multiple health conditions | The Health Foundation

<sup>&</sup>lt;sup>13</sup> Adeloye (2022) Global, regional, and national prevalence of, and risk factors for, chronic obstructive pulmonary disease (COPD) in 2019: a systematic review and modelling analysis <a href="https://www.thelancet.com/article/S2213-2600(21)00511-7/fulltext">https://www.thelancet.com/article/S2213-2600(21)00511-7/fulltext</a>

with a mental health condition have at least one additional condition.<sup>14</sup> There is significant overlap between the patient groups we support, with higher rates of type 2 diabetes in people living with COPD in particular, and diabetes being linked with pulmonary complications.<sup>15</sup> Likewise, it is well documented that people with long-term health conditions tend to have worse mental health due to increased chances of risk factors such as social isolation, discrimination and stress.<sup>16</sup>

Establishing a robust pathway to effective self-management from the earliest possible opportunity after diagnosis would therefore offer significant long-term health and wellbeing benefits to patients, as the negative impact on both the individual and the NHS is multiplied the longer a condition goes undiagnosed or unmanaged, or when a patient is living with multiple conditions.

## Poor self-management is costing lives and money

To change this stark landscape of poor outcomes, evidence shows that supporting patients to effectively self-manage their condition is the best way for them to live well and avoid their condition flaring up, unnecessary hospital admissions and the worst-case health outcomes such as self-harm or suicide in the case of mental illness.

These are all expensive conditions to manage and treat, particularly when they become more complex, and complications arise. Every year, the combined estimated cost to the NHS reaches over £30 billion (£10 billion on diabetes, £11 billion on lung conditions and £12 billion on mental health services). <sup>17</sup>, <sup>18</sup>, <sup>19</sup> Analysis from PwC found that improving access to NICE-recommended interventions for lung conditions alone could free-up almost 312,000 bed days a year, over 100,000 of which would be during the winter period, and save the NHS £336 million a year. <sup>20</sup> Furthermore, a report by The Mental Health

38

<sup>&</sup>lt;sup>14</sup> Health Foundation (2018) Understanding the health care needs of people with multiple health conditions, <u>Understanding the health care needs of people with multiple health conditions</u> | <u>The Health Foundation</u>

<sup>&</sup>lt;sup>15</sup> Sangmi (2022) Mechanisms Linking COPD to Type 1 and 2 Diabetes Mellitus: Is There a Relationship between Diabetes and COPD? <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9415273/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9415273/</a>

<sup>&</sup>lt;sup>16</sup> Mental Health Foundation <a href="https://www.mentalhealth.org.uk/explore-mental-health/a-z-topics/long-term-physical-conditions-and-mental-health">https://www.mentalhealth.org.uk/explore-mental-health/a-z-topics/long-term-physical-conditions-and-mental-health</a>

<sup>&</sup>lt;sup>17</sup> Hex N and others. 'Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs' Diabetic medicine 2012: volume 29, issue 7, pages 855-862 9 (viewed on July 2023)

<sup>&</sup>lt;sup>18</sup> https://publications.parliament.uk/pa/cm5803/cmselect/cmpubacc/1000/report.html

<sup>&</sup>lt;sup>19</sup> Asthma + Lung UK (2023) Saving your breath, <a href="https://www.asthmaandlung.org.uk/saving-your-breath">https://www.asthmaandlung.org.uk/saving-your-breath</a>

<sup>&</sup>lt;sup>20</sup> Ibid.

Foundation states that mental health problems cost the UK economy at least £117.9 billion annually.<sup>21</sup>

## People living in the poorest communities are being hit hardest

Cancer, circulatory diseases, chronic lung conditions and mental ill-health account for nearly 60% of the gap in life expectancy between the most and least deprived areas of England. Recent figures from ONS found that lung health has in fact the strongest correlation with poverty of all major conditions, with those from the poorest communities five times more likely to die from COPD and 3 times more likely to die from asthma compared to those in the richest. Likewise, 24% of people diagnosed with type 2 diabetes live in the UK's most deprived areas, compared to 15% in the least deprived. It's also well-established that poverty can be a driving cause of poor mental health and that the cost of living crisis has been detrimental to many people's mental health and wellbeing. Englished

Taking action on these condition areas together therefore has huge potential to drive down health inequalities, improve the quality of life of millions of people and reduce the number of people dying unnecessarily each year in the UK.

# Support in and around diagnosis is lacking

Evidence shows that diagnosis happens too late across conditions, often due to low symptom awareness from healthcare professionals and the public, and that ongoing access to treatment and self-management support is patchy and inadequate across the country.

1 in 3 people waiting for mental health support report experiencing a decline in mental health while waiting for a doctor's appointment.<sup>26</sup> If people are unable to get the support

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<sup>&</sup>lt;sup>21</sup> Mental Health Foundation <a href="https://www.mentalhealth.org.uk/about-us/news/mental-health-problems-cost-uk-economy-least-gbp-118-billion-year-new-research">https://www.mentalhealth.org.uk/about-us/news/mental-health-problems-cost-uk-economy-least-gbp-118-billion-year-new-research</a>

<sup>&</sup>lt;sup>22</sup> OHID (2023) Inequality tools: Fingertips <a href="https://fingertips.phe.org.uk/profile/inequality-tools">https://fingertips.phe.org.uk/profile/inequality-tools</a>

<sup>&</sup>lt;sup>23</sup> Office for National Statistics (ONS). 2023. Inequalities in mortality involving common physical health conditions, England: 21 March 2021 to 31 January 2023. <u>Inequalities in mortality involving common physical health conditions, England - Office for National Statistics Accessed (August 2023)</u>

<sup>&</sup>lt;sup>24</sup> NHS Digital (2021) National Diabetes Audit, 2020 to 2021

<sup>&</sup>lt;sup>25</sup> Earwaker, R., Johnson-Hunter, M., (2023) Unable to Escape Persistent Hardship: JRF's cost of living tracker, summer 2023

<sup>&</sup>lt;sup>26</sup> Picker & Mind, Big Mental Health Survey, 2017

they need when they need it, they face long waiting lists which often worsen mental health for those presenting with mental illness. This increases their risk of self-harm and suicide, and results in higher costs for the NHS as they need more intensive support.

For diabetes, an estimated 1 in 3 people already have complications of type 2 (which can affect their eyesight, feet and kidneys, amongst other difficulties) when they are diagnosed. People also report they want a more personalised experience, and research suggests that a better experience of diagnosis and intervening in the first 12 months makes a big difference to long-term outcomes. Research suggests that patients who recall being reassured by their health care professional and presented with a clear plan of action at diagnosis, tend to have lower diabetes distress and better self-management 1 to 5 years later.<sup>27</sup>

Similarly, poor treatment and support after diagnosis for lung conditions is placing a significant and often avoidable burden on primary and secondary care. We know from Asthma + Lung UK insight surveys and wider evidence that a large majority of those with lung conditions aren't receiving the basic standards of care detailed in NICE guidelines to enable them to do this. Only 18.4% of people with COPD who responded to our survey reported receiving best practice care, and only 30% with asthma. Readmission rates to hospital post respiratory diagnosis are particularly high (43.2% within 3 months for COPD)<sup>29</sup> and lung conditions continue to be a leading cause of winter pressures every year for the NHS. This is even more acute for those diagnosed with ILDs, which have an average prognosis of 3 to 5 years; many patients tell us they have to spend far too much of the precious time they have left fighting to get a diagnosis and access treatments.<sup>30</sup>

# Expanding our reach to the communities that need it most

Across our charities we speak to around 300,000 people every year on our expert helplines, providing specialist advice and guidance. We provide robust and tailored health

<sup>&</sup>lt;sup>27</sup> Polonsky, W. H., Fisher, L., Guzman, S., Sieber, W. J., Philis-Tsimikas, A., & Edelman, S. V. (2010). Are patients' initial experiences at the diagnosis of type 2 diabetes associated with attitudes and self-management over time?. The Diabetes educator, 36(5), 828–834. <a href="https://doi.org/10.1177/0145721710378539">https://doi.org/10.1177/0145721710378539</a>

<sup>&</sup>lt;sup>28</sup> A+LUK patient survey (2022) Best practice defined as: For COPD: those receiving the 'Five Fundamentals of COPD care as outlined by NICE, For Asthma: those receiving an annual asthma review, inhaler technique check and written action plan

<sup>&</sup>lt;sup>29</sup> NACAP (2020) Outcomes of patients included in the 2017/18 COPD clinical audit: <u>National Asthma and COPD Audit</u> Programme Accessed (August 2023)

<sup>&</sup>lt;sup>30</sup> Asthma + Lung UK (2015) Lost in the System: https://www.asthmaandlung.org.uk/sites/default/files/BLF-IPF-Report-2015---Lost-in-the-System---250215.pdf

advice viewed by millions of people looking for help and advice. And we support around 500 local peer support groups up and down the country.

Service users have demonstrated a need for formalised education, such as the service offerings outlined in this proposal. For example, 56% of A+LUK website visitors who responded to our question stated they were seeking basic education to help them understand their condition, navigate NHS services, especially at the key times of diagnosis or flare-up. They consistently report that our helpline and health advice information boost confidence and knowledge and provide reassurance.

However, there are thousands more people who we know we're not reaching, especially in some of the most deprived communities in the UK who are most at risk and have the worst outcomes. Through this proposal, we would substantially expand our reach and ability to help more people who newly diagnosed, at the point when they need our help and support the most. This would also improve access to the interventions that newly diagnosed patients need to keep them well and out of hospital.

# Our proposal

We propose a national partnership with the government, Asthma + Lung UK, Diabetes UK and Mind to roll out a holistic package of supported self-help advice and support to thousands of newly diagnosed people across the country in their first 12 months after diagnosis.

Our organisations are uniquely placed to take up this partnership, using this funding to accelerate and scale up existing services, meaning we would be able to quickly start delivering results with lasting impacts and changing thousands of people's lives for the better. In order to be agile and ensure evidence-based approaches that work for different patient cohorts, we have outlined below the different ways our organisations will deliver this support. We have also included a more detailed outline of our service approaches in the accompanying document which we would welcome developing in partnership with government.

We would also work closely together to ensure complementary approaches across our organisations, including signposting service users to each other when relevant, providing holistic advice to those with multimorbidity, and sharing costs where possible such as on the Accurx service. We estimate this would cost around £5 million, and by 2026 we would reach 50% of those who are newly diagnosed with chronic lung conditions and type 2 diabetes, and 9,520 people with a mental illness.

### **Diabetes UK**

Our service would be integrated with primary care, and mean the GP or practice nurse at point of diagnosis would flag that information and support is available through Diabetes UK and would ensure that:

The patient receives a text message which links to our support (through the GP messaging systems we already use),

Or - with consent - gets a phone call from a trained Diabetes UK advisor.

The patient will also have the opportunity to sign up for a series of emails from us to support them in their first-year post-diagnosis. Content will include understanding their diabetes, eating well with diabetes, and exploring their diabetes remission options.

Through this referral, people newly diagnosed with type 2 diabetes would have access to support and self-management guidance from across our charity, including our expert helpline, peer support groups and health advice. This offer could be enhanced by targeting it at the ICBs with worse outcomes, populations most at risk for type 2 diabetes and/or deprivation.

# Asthma + Lung UK

Our model follows a similar service design as the above. At the point of a chronic respiratory diagnosis being logged on the patient system in primary care:

The person newly diagnosed with a chronic lung condition (children and adults with asthma, COPD, bronchiectasis or an ILD) would receive a text message automatically with a link to our 'newly diagnosed' information offer and/or booklet in a range of languages, tailored to their condition, and a helpline telephone number to access further advice. Patients will be able to sign up to a year-long journey of support from Asthma + Lung UK. If they opt in, they will receive further emails over the course of the year with further information resources, and signposting.

For now, we assume that after the initial outreach, the support will consist of a minimum of three emails over the course of the year, signposting to resources on inhaler technique, pulmonary rehabilitation and/or our online physical exercise offering, self-management guides and advice on how to stay well in winter including accessing winter virus vaccines (flu, RSV and pneumonia).

We also propose to offer additional support to people newly diagnosed with asthma and COPD, living in the most deprived areas, with the offer of an outreach phone call. We

would do this by targeting people living in specific integrated care system (ICS) areas where we know health outcomes for those with lung conditions are significantly worse.

As a result, those newly diagnosed with a chronic lung condition would have access to a range of our services to support and enable self-management of their condition, such as our tailored health advice for those newly diagnosed, expert helpline (consisting of healthcare advisors, specialist respiratory nurses, physios and a dietician) and support groups. We would recommend targeting this offer to ICBs that have the most deprived communities given the strong link between respiratory ill health and deprivation.

## Mind

We would use this funding to scale up and roll out our Supported Self-Help (SSH) service that we have piloted in Wales and parts of England and deliver through our network of Local Minds. This is an early intervention service supporting people aged 18 and over with low to moderate mental health needs and was designed as a waiting list intervention. It complies with the NICE Guidance [CG123] definition of 'Facilitated' or 'Guided' self-help, where participants will have access to a combination of 1-2-1 sessions with a practitioner as well as helpful tools and strategies in workbooks and self-management resources.

The programme consists of up to 6 sessions over an 8-week period and is based on cognitive behavioural therapy approaches (CBT), with the added benefit of self-directed exercises using our workbooks. Everyone receives an initial 40-minute assessment to ensure suitability for the service and to identify the most appropriate pathway, depending on condition:

- depression and low mood
- anxiety and panic attacks
- stress
- low self-esteem
- feeling alone
- grief
- managing anger
- general wellbeing

Remote delivery will be the standard delivery option, but face-to-face support could be offered.

SSH is cost effective and has been robustly evaluated, demonstrating that the programme improves outcomes at the individual level and has the potential to reduce health service costs over the longer-term by limiting the need for more intensive (and more costly) interventions. Other economic benefits include improved physical health and job retention.

# **Expected outcomes**

This programme is expected to contribute to:

Better and swifter self-management resulting in cost savings to the NHS in emergency and acute admissions in targeted areas, helping more people get the care they need and stay well out of hospital. For example, Mind pledges that all Supported Self-Help journeys will start within 28 days.

A more confident and empowered diabetes population leading to improved glycaemic control and reduced complications.

Improved optimisation of medicines and treatments through better advice and support provision. It's estimated that prompting healthcare professionals to review patient use of inhalers alone would result in savings of over £7 million per year alone, as well as a 70% reduction in hospital bed days amongst people with asthma. Around 40% of this reduction in bed days is likely to occur over the winter months.<sup>31</sup>

Increased physical activity and movement, helping people stay well at home. For example, the expansion of pulmonary rehabilitation to more people with lung conditions would result in £142.6 million of direct NHS savings related to reduced exacerbations, as well as a reduction in bed days of 194,000, of which 66,000 of which would be over the winter period.<sup>32</sup>

Reduced levels of depression and anxiety (the most common mental health conditions). 82% of those who access Mind's Supported Self-Help service report a reduction in anxiety and 87% of those who access Supported Self-Help report a reduction in feelings of depression.

44

<sup>&</sup>lt;sup>31</sup> Asthma + Lung UK (2023) Saving your breath, <a href="https://www.asthmaandlung.org.uk/saving-your-breath">https://www.asthmaandlung.org.uk/saving-your-breath</a>

<sup>32</sup> Ibid.

Reduced loneliness and isolation, through peer support resources and support during diagnosis journey. For example, 85% of those who have accessed Mind's Supported Selfhelp service state that their general mental well-being has increased.

Increased choice and control for patients, through more information, guidance and support. This is likely to increase their sense of empowerment and better enable them to make decisions regarding their own care.

# Annex B: concept note appendix

Diagnosis connect - an innovative partnership between Asthma + Lung UK, Diabetes UK, Mind and government to support people who are newly diagnosed to manage their condition

## Our proposal

We propose a national 2-year partnership with Asthma + Lung UK, Diabetes UK, Mind and the Department of Health and Social Care (DHSC). Initially for 2 years, our partnership will use an innovative new model which brings together the voluntary sector and DHSC to roll out a holistic package of supported self-help, advice, and support to thousands of newly diagnosed people across the country. Together, we'll help them better self-manage their condition, stay well, and avoid having to go to hospital. This will herald an ongoing, intertwined relationship between our three charities and government that puts patients at the heart by providing aligned and integrated services.

Our organisations are uniquely placed to drive this partnership, using this funding to accelerate and scale up existing services. This means we would be able to quickly start delivering results with lasting impacts, changing thousands of people's lives for the better. To be agile and ensure evidence-based approaches that work for different patient cohorts, we have outlined below the different ways our organisations will deliver this support. We would welcome developing these approaches in partnership with the DHSC. This programme could start quickly but build and develop over time. We will create deeper integration between the services and a model for collaboration which could be extended to other conditions.

We have also shown how we would bring our offer together for people who live with more than one condition, providing more holistic support and advice that patients so often say they struggle to find. This will be easier for users to navigate and will integrate operations and sharing costs where possible, such as the Accurx service. We have also set out how we will evaluate the programme and capture the impacts of the programme. We estimate the programme would cost around £5 million, and by 2026 we would reach 50% of those

who are newly diagnosed with chronic lung conditions, 25% with type 2 diabetes, and 9,520 people with a mental illness.

### How we will bring our services together

1 in 4 people in the UK now live with 2 or more health conditions.<sup>33</sup> This programme would provide an innovative model not just of how government and the voluntary sector could work more closely together, but also how health charities supporting different conditions can integrate their support so that people with multimorbidity receive more holistic support and advice, making it easier for them to navigate the system. This would be done through 'warm' or guided referral of people with more than one condition between charities, joint training of staff and a shared vision.

#### Initial referrals

From day one, all 3 charities will build in an opportunity for referral to the other 2, so that when a person contacts Asthma + Lung UK or Diabetes UK through the link or telephone number provided in the GP text from Accurx, or when they are referred to Mind's Supported Self-Help service, they are asked whether they have been diagnosed with any other conditions. If relevant to other charities in the partnership, they would be directly referred. This referral would allow them to access the service in this programme from the other charity or charities, but it would also provide them access to all of the other services available in the charities such as peer support, local support groups and advice or information (both paper and online).

## Joint working

We will bring the staff working on this project at the 3 organisations together to share intelligence and learnings. Together we will co-create better solutions for patients and iterative improvements to the service.

We will seek to combine resources to develop a robust evaluation approach across organisations, as well as a shared plan to communicate this unique and innovative partnership.

<sup>33</sup> Health Foundation (2018) Understanding the health care needs of people with multiple health conditions <a href="https://www.health.org.uk/publications/understanding-the-health-care-needs-of-people-with-multiple-health-conditions">https://www.health.org.uk/publications/understanding-the-health-care-needs-of-people-with-multiple-health-conditions</a>

Finally, the partners would work together on a shared vision for the programme to ensure that there is consistency of quality and approach across all 3 providers, so that the experience is as seamless as possible for people with multiple conditions.

#### Outcomes and evaluation

Regardless of how often a person meets with their health and care team, a lot of the time a person's long-term health condition is managed by the individual with the support of their family or unpaid cares. That's why this programme is critical in helping more people manage their own health after diagnosis. If people are given the skills, knowledge and confidence they need to live well with their own condition this then improves their chances of better care and longer-term outcomes. For example, research shows that patients who feel most confident in managing their long-term conditions have 38% fewer emergency admissions and 32% fewer A&E attendances than those who feel least confident.<sup>34</sup>

Similarly, evidence shows that patients who recall being reassured by their health care professional and presented with a clear plan of action at diagnosis, tend to have lower diabetes distress and better self-management 1 to 5 years later.<sup>35</sup> We also know that of those who completed Mind's Supported Self-Help model, 82% reported improvement in their feelings of anxiety, 87% reported improvement in their feelings of depression, 85% reported improvement in their mental wellbeing and 100% said they would recommend the service to friends and family.

#### Programme outcomes will therefore include:

Better and swifter self-management. Resulting in cost savings to the NHS in emergency and acute admissions in targeted areas, helping more people get the care they need and stay well out of hospital. For example, Mind pledges that all Supported Self-Help journeys will start within 28 days.

A more confident and empowered diabetes population leading to improved glycaemic control and reduced complications.

Improved optimisation of medicines and treatments through better advice and support provision. It's estimated that prompting healthcare professionals to review patient use of

<sup>34</sup> The Health Foundation (2018) Reducing emergency admissions <a href="https://www.health.org.uk/publications/reducing-emergency-admissions-unlocking-the-potential-of-people-to-better-manage-their-long-term-conditions">https://www.health.org.uk/publications/reducing-emergency-admissions-unlocking-the-potential-of-people-to-better-manage-their-long-term-conditions</a>

<sup>&</sup>lt;sup>35</sup> Polonsky, W. H., Fisher, L., Guzman, S., Sieber, W. J., Phillis-Tsimikas, A., & Edelman, S. V. (2010). Are patients' initial experiences at the diagnosis of type 2 diabetes associated with attitudes and self-management over time?. The Diabetes educator, 36(5), 828–834. https://doi.org/10.1177/0145721710378539

inhalers alone would result in savings of over £7 million per year, as well as a 70% reduction in hospital bed days amongst people with asthma.<sup>36</sup>

Increased physical activity and movement, helping people stay well at home. For example, through accessing A+LUK support it can be assumed more people would access pulmonary rehabilitation services which has been shown to reduce costs to NHS through reduced chances of exacerbations and hospital bed days.<sup>37</sup>

Reduced levels of depression and anxiety (the most common mental health conditions). 82% of those who access Mind's Supported Self-Help service report a reduction in anxiety and 87% of those who access Supported Self-Help report a reduction in feelings of depression.

Reduced loneliness and isolation, through peer support resources and support during diagnosis journey. For example, 85% of those who have accessed Mind's Supported Selfhelp service state that their general mental well-being has increased.

Increased choice and control for patients, through more information, guidance, and support. This is likely to increase their sense of empowerment and better enable them to make decisions regarding their own care.

We have budgeted for a full economic evaluation of the programme across the 3 charities. For those who received the enhanced offer, we will conduct a follow up call for those with a series of questions to ascertain whether they had been hospitalised, how many GP visits they have needed, how they felt about the support they received, what they have done differently and any areas for improvement. We could then compile this into a public-facing evaluation to showcase this innovative partnership and inform future programme design.

48

<sup>&</sup>lt;sup>36</sup> Asthma + Lung UK (2023) Saving your breath, https://www.asthmaandlung.org.uk/saving-your-breath

<sup>&</sup>lt;sup>37</sup> Ibid.

## Diabetes UK detailed service model and budget

We propose to support both the NHS and people newly diagnosed with type 2 diabetes with a joined up, coherent, consistent, accessible and inclusive support offer for the first 12 months after diagnosis. This support offer includes:

Our Helpline - Monday to Friday 9am to 6 pm. This team already receives over 150,000 calls and enquiries on social media per year from people asking questions about living with diabetes

Our online <u>Forums</u>, enabling information exchange on issues ranging from remission to technology

Patient Information, including some publications in different languages.

Our <u>Learning Zone</u> platform which is Diabetes UK's free online education service to help people manage their diabetes at home. Learning Zone uses the latest approaches in education and behaviour change theory to give people living diabetes the tools to live well and improve their health outcomes.

### Diabetes UK website

Our local Diabetes UK support groups: 185 groups, supporting over 30,000 people.

Outreach events and partnership working through community groups, faith groups etc.

Our membership offer which includes our magazine and newsletter.

Our work with GP systems for example, Accrux to send texts to patients with links to our info, and our <u>Information Prescriptions</u> which provide GPs with simple handouts they can give to patients

On 15 January we launched a Remission Support and Info Hub and a Learning Zone course to really support people to explore remission more and take the next steps. This complements the dedicated space we've launched on the forum for people interested in remission.

We envisage that the GP or practice nurse (and at times other HCP) at point of diagnosis would flag that information, and support is available through Diabetes UK and would ensure that:

The patient receives a text message which links to our support (through the GP messaging systems we are already working with),

Or - with consent - gets a phone call from a trained Diabetes UK advisor.

Either way, a holistic, comprehensive support and advice package would be offered to the newly diagnosed, which straddled patient education, information and advice on the practical implications of living with diabetes, and mental health and emotional support.

#### How this would work

#### Stratification

In order to maximise scale, but also focus spend on those most at need, we suggest stratifying the people in receipt of this new support offer. We believe that this ambitious approach allows us to be both targeted and universal, which is something both the NHS and voluntary sector tend to struggle with. We suggest stratifying by either age or deprivation, or both (there is an overlap, of course). This is because the evidence shows that people from deprived neighbourhoods have much higher prevalence of type 2 diabetes, at earlier ages, and also have worse outcomes. Targeting young people responds to the insight that they, too, are heading for much worse outcomes than people who acquire type 2 diabetes later in life, and that deprived people are overrepresented amongst younger patients.

## Core offer: a package of support for all in their first year after diagnosis

Our core offer is based on a text message being sent automatically by GP systems to around 25% of people newly diagnosed with type 2 diabetes with a QR code or similar linking people to our 'newly diagnosed' information offer and/or booklet.

People will at this point also be able to sign up to a year long journey of support from Diabetes UK. If they opt in, they will receive further emails over the course of the year with further information resources, recipes, meal planners and signposting to our <a href="Learning">Learning</a> <a href="Loos Diabetes UK's free online education service">Learning</a> <a href="Loos Diabetes UK's free online education service">Loos Diabetes UK's free online education service</a> to help people manage their diabetes at home.

For now, we assume that after the initial outreach, the support will consist of 3 emails over the course of the year, signposting them to resources on emotional wellbeing, eating and cooking with type 2, physical exercise, working with diabetes, support with remission and with weight management.

#### **Assumptions and costings:**

We assume we reach 25% per cent of newly diagnosed through GP systems who we contact in this way, reaching 62,500 people per year (125,000 in total over the 2 years). We assume that 1 in 10 people who receives our message will want to call one of our trained helpline advisers, this is around 6,250 people per year and will cost us £500,000

for direct support. We also assume this will generate 6,250 requests for printed information and around 6,250 additional sign-ups to our online, ongoing self-management tool, Learning Zone, at the cost of £115,000.

Enhanced offer: additional outreach support for groups with highest unmet need.

We also propose additional support to young people newly diagnosed and/or those living in the most deprived postcode areas, with the offer of an enhanced outreach phone call.

The issue we would need to discuss with DHSC and NHS, and with GP message providers, is how we could reach these people without them having to take action to start with. The whole point of proactive outreach is to ensure people who are less activated and less able to advocate for themselves are being supported. So, any process that requires them to take action first, undermines some (but not all) of this goal. Proactive outreach (obviously with consent) would require the messaging providers to know who is in the target age or income bracket. This can be done (for example message providers target only the elderly for flu jabs, which requires age stratification), but it would require further exploration.

The following costings therefore assume that we ask people to answer a couple of short questions as they reach out to our core offer, and then target our phone calls to those who indicate that they are in the cohort with larger unmet needs. For all people who tell us they are under 40 or who live in in the 20% most deprived post code areas in England, we would follow up with a proactive call of support to them from a member of our helpline team.

Non-diabetes specific evidence shows that proactive outreach is required to reduce health inequalities for people who are less likely themselves to avail themselves of all available services.

#### Assumptions and costings:

From our modelling we can estimate that there are just under 10,000 people aged under 40 diagnosed with type 2 diabetes each year, and 55,000 people diagnosed from the 20% most deprive postcode areas. We assume that from the GP text messaging service our text message reaches 50 per cent of both of these groups: 5,000 people aged under 40 each year and 27,500 in the most deprived areas. We might assume that half of these people provide their details, totalling 1,625 outbound calls to this group of people with highest unmet need. We propose to reach out to all of this cohort each year. In order to meet such need and provide this outward-bound call offer we would have to recruit a small team of trained advisors - this is also where the cost is generated in addition to the patient information packs costing £50,000.

### Overall package and cost

We believe that this ground breaking, innovative way of including a voluntary sector led, non-clinical, self-management support offer in the pathway of a major, costly and damaging condition would unlock new ways of working for the NHS and VCSE, create major insights on how best to support different cohorts of people with their condition management, and would improve outcomes for a condition that creates huge costs for the NHS, individuals and the economy.

Making all the assumptions set out above and allowing funds for programme management and evaluation, we arrive at an overall indicative cost of £1.5 million.

There are also different approaches to roll out and scale - start in a small number of places or start just with deprived communities. We are also open to exploring this way of working with other chronic condition organisations.

# Asthma + Lung UK's detailed service model and budget

Our approach is similar to the proposed model above but tailored to those with a range of chronic lung conditions - chronic obstructive pulmonary disease (COPD), asthma (children and adults), bronchiectasis and interstitial lung disease (ILD). We propose to support both the NHS and people newly diagnosed with lung conditions with a joined up, coherent, consistent, accessible and inclusive support offer for the first 12 months after diagnosis. This support offer includes:

Our Helpline - Monday to Friday 9am to 5 pm. This Helpline is multidisciplinary with respiratory specialist clinicians and health care advisors. It already receives over 26,000 calls per year from people asking questions about living with lung conditions.

Patient Information, including videos and publications in different languages.

Our website health information is viewed over 12 million times annually and includes specific information to support asthma and COPD self-management.

Our local Breathe Easy support groups: 150 groups across the country, providing face-to face support to over 12,000 people.

Our online support, and exercise groups that support over 8,000 patients annually.

Our Health Care Professional Hub which will launch in April 2024 to provide information on lung conditions designed to support NHS staff to be able to provide the best possible respiratory care.

We envisage that the GP or practice nurse (and at times other HCP) at point of diagnosis would flag that information, and support is available through Asthma + Lung UK and using Accurx would ensure that:

The patient receives a text message which links to our support (through the GP messaging system),

Or - with consent - is referred to us for a phone call from a trained Asthma + Lung UK Helpline advisor.

#### How this would work

#### Stratification

To maximise scale, but also focus spend on those most at need, we suggest stratifying the people in receipt of this new support offer by deprivation. This is because the evidence shows that people from deprived neighbourhoods have much higher prevalence of lung conditions, and burden on the NHS - with those in the poorest 10% 5 times more likely to die of COPD and 3 times more likely to die of asthma.

### Core offer: a package of support for all in their first year after diagnosis

Our core offer is based on a text message being sent automatically by GP systems to all people newly diagnosed with a chronic lung condition and provide them tailored support through our 'newly diagnosed' information offer and/or booklet. This would be broken down for the following 6 patient cohorts: children with asthma, adults with asthma, COPD, ILD and bronchiectasis. We would ensure all these materials were available in a range of languages in order to support a diverse range of communities.

People will at this point also be able to sign up to a year long journey of support from Asthma + Lung UK. If they opt in, they will receive further emails over the course of the year with further information resources, and signposting.

For now, we assume that after the initial outreach, the support will consist of at a minimum 3 emails over the course of the year, signposting them to resources on inhaler technique, pulmonary rehabilitation and/or our online physical exercise offering, self-management guides and advice on how to stay well in winter including accessing winter virus vaccines (flu, RSV and pneumonia).

#### **Assumptions and costings**

We assume we reach 50 per cent of newly diagnosed through GP systems in this way, reaching 155,000 people per year. This is based on: 310,000 people are newly diagnosed

with a chronic lung condition, including chronic obstructive pulmonary disease (COPD),<sup>38</sup> interstitial lung disease (ILD), bronchiectasis and asthma.<sup>39</sup> We assume that 1 in 10 people who receives our message will want to call one of our trained helpline advisers.

## Enhanced offer: additional outreach support for groups with highest unmet need

We also propose that we can offer additional support to newly diagnosed living in the most deprived areas, with the offer of an outreach phone call, costed at £38 each. We would do this by targeting people living in specific integrated care system (ICS) areas where we know health outcomes for those with lung conditions are significantly worse.

The issue we would need to discuss with DHSC and NHS, and with GP message providers, is how we could reach these people without them having to take action to start with. The whole point of proactive outreach is to ensure people who are less activated and less able to advocate for themselves are being supported. So, any process that requires them to take action first, undermines some (but not all) of this goal.

The following costings therefore assume that we ask people to answer a couple of short questions as they reach out to our core offer, and then target our phone calls to those who indicate that they are in the ICB catchment area with larger unmet needs. For all people who live in the agreed targeted ICB's, we would follow up with a proactive call of support to them from a member of our helpline team.

Evidence shows that proactive outreach is required to reduce health inequalities for people who are less likely themselves to avail themselves of all available services.

#### Assumptions and costings:

From our modelling we would initially target 20 ICB's with the poorest health outcomes for those with a lung condition.

We assume that from the GP text messaging service our text message reaches 50 per cent of those people within the selected ICBs: approximately 32,700 people in the most deprived areas.

We might assume that 50% of these people provide their details, totalling 16,300 in this group of people with highest unmet need. At £38 per call this would cost an estimated

<sup>&</sup>lt;sup>38</sup> NICE (2019) myCOPD for self-management of chronic obstructive pulmonary disease (COPD) <a href="https://www.nice.org.uk/quidance/mtg68/documents/final-scope-2">https://www.nice.org.uk/quidance/mtg68/documents/final-scope-2</a>, taken from BLF stats

<sup>39</sup> NICE (2021) What is the prevalence of asthma? https://cks.nice.org.uk/topics/asthma/background-information/prevalence/

£620,000. To meet such need, we would have to recruit a small team of trained advisors - this is where the cost is generated.

We also assume that the same number, 16,300, would request a Patient Information Pack to be sent to them at a cost of £47,000.

Overall package and cost

We believe that this ground breaking, innovative way of including a voluntary sector led, non-clinical, self-management support offer in the pathway of a major, costly and damaging condition would unlock new ways of working for the NHS and VCSE, create major insights on how best to support different cohorts of people with their condition management, and would improve outcomes for a condition that creates huge costs for the NHS, individuals and the economy.

Making all the assumptions set out above we arrive at an overall indicative cost of £1.5 million. This cost would not necessarily accrue in total in the first year, since we would have to stand up the comprehensive service over time.

There are also different approaches to roll out and scale – start in a small number of places or start just with deprived communities. We are also open to exploring this way of working with other chronic condition organisations.

#### Set-up

5 chronic conditions @ £60,000 to set-up plus £150,000 equals £450,000

**Evaluation** 

£80,000

Annual delivery

18 months of programme plus 6 month start up @ £700,000 delivery per year equals £1.5 million.

Estimated total cost equals £1.5 million

# Mind's detailed service model and budget

Supported Self-help (SSH) is an early intervention therapeutic service supporting people aged 18 and over with low to moderate mental health needs. It was designed as a waiting

list intervention. It complies with the NICE Guidance [CG123] definition of 'Facilitated' or 'Guided' self-help, where participants will have access to a combination of 1-2-1 sessions with a practitioner as well as helpful tools and strategies in workbooks and self-management resources.

SSH is cost effective. Evaluations have shown that the programme improves outcomes at the individual level and has the potential to reduce health service costs over the longer-term by limiting the need for more intensive (and more costly) interventions. Other economic benefits include improved physical health and job retention.

Our aim is to reach people swiftly when their mental health problem is first identified, offering support within 28 days. We estimate that we can support 9,520 people across 2024 to 2026 through our evidence-based Supported Self-Help programme.

#### How this would work

Core offer: supporting up to 9,520 people across 2024 to 2026

Supported Self Help:

Supported Self-Help gives people the chance to get mental health support quickly when they need it, when they are first diagnosed or first reach out for help. Aimed at people with mild-moderate mental health needs, it can help prevent peoples' mental health problems from escalating, improve their outcomes, and means that people are less likely to need to wait for more intensive NHS support.

SSH supports adults over the age of 18 with 8 possible pathways, including:

- depression and low mood
- anxiety and panic attacks
- stress
- low self-esteem
- feeling alone
- grief and loss
- managing anger
- menopause
- general wellbeing

SSH runs in 28 local Minds across England. SSH is not placed based, as all individuals are assigned to a practitioner based on availability, no matter where the practitioner is based in the country. This means that SSH is not subject to the usual postcode barriers that can impede access to healthcare in England.

Practitioners are experienced mental health professionals employed by local Minds. All practitioners have a Level 3 qualification in health and social care plus specific training in the model and receive clinical supervision.

The programme consists of up to 6 sessions over an 8-week period and is based on cognitive behavioural therapy approaches (CBT), with the added benefit of self-directed exercises using our workbooks. Remote delivery will be the standard delivery option. However, face-to-face sessions can be requested if the participant is able to travel to the nearest local Mind delivery site. The service can be delivered outside of traditional working hours, including evening and weekend delivery. SSH is available in English, Welsh, Polish and Arabic.

Mind began running SSH at scale in Wales during the pandemic, rolling out across England in late 2023. It has been robustly evaluated, demonstrating consistent outcomes for clients via both face-to-face and remote delivery. Supported Self-Help, which was previously known as Active Monitoring, has been proven to have a significant positive impact on service user outcomes, including wellbeing (WEMWBS) and clinical measures of anxiety (GAD-7) and depression (PHQ-9).

#### Evidence base

Published in March 2023, Mind Cymru's evaluation of clients between October 2022 and January 2023 showed outcomes improving for clients at a statistically significant level:

- 82% reported improvement in their feelings of anxiety
- 87% reported improvement in their feelings of depression
- 85% reported improvement in their mental wellbeing
- 100% said they would recommend the service to friends and family

#### **Demand**

SSH went live in England in August 2023 initially with 2 local Minds, then our local Minds in Wales, followed by 28 local Minds in England. Since then, over 3,000 people have signed up using our online triage and assessment system, which uses an Al Chatbot. During January 2024, we had 2,018 active users at various points in their SSH journey. This shows significant, sustained demand for SSH.

We manage demand through our ability to stop advertising and shutting the chatbot temporarily when demand is too high. This means that we are able to keep to our target of seeing people within 28 days.

#### Referrals

Mind has purchased a sophisticated digital triage portal including an artificial intelligence chatbot (Limbic). The portal improves efficiency and access to the service by providing a single point of entry. The chatbot also gives responses that encourage engagement through the referral process in a way that a form would not. We market SSH through various channels including social media, which helps to reach people who might not otherwise access the service through traditional healthcare avenues.

People can also be referred via their GP and other healthcare professionals, and with support from DHSC, we will increase engagement from primary care networks. Many local Minds will already have strong relationships with their local primary care network, and Mind's dedicated Mental Health System Influencing Team will help all local Minds involved in SSH to strengthen these relationships. In addition, we would seek to work with Diabetes UK, Asthma and Lung UK and other providers of services to Major Conditions to leverage our joint relationships as part of this offer.

Once a referral has been received, either through Limbic or otherwise, practitioners undertake an initial assessment to ensure SSH is the most appropriate mental health support for each individual, including assessing the severity of their mental health need.

#### Further signposting and support

While for many people, SSH offers the help they need to manage their mental health, others will require further support after their SSH sessions end. Practitioners can offer signposting to more intensive mental health services, and as they are part of the local Mind network, they are able to signpost to services offered by local Minds (and other partnered providers) in the individual's local area.

The Supported Self-Help journey:

Feeling overwhelmed? We're here to help. You can access support via your GP, online or local Mind.

No problem is too small, and once you've spoken to someone, you'll meet with a Mind practitioner within a week.

After an initial conversation, your Mind practitioner will help identify the best mental health support for you.

And perhaps signposting elsewhere when people need extra support. You'll receive:

6 guided support sessions over eight weeks. Online or face-to-face, it's your choice!
 self-guided wellbeing exercises and workbooks

If you need ongoing support your practitioner can refer you back to your GP so they can continue to support your mental health.

### Enhanced offer: supporting people who are most in need.

Mind recognises the disproportionate impact of mental health problems on specific groups within England, particularly our 3 strategic priority audiences (young people up to the age of 25, people experiencing poverty and people from racialised communities).

With additional support from DHSC, we could expand Supported Self-Help to better target these audiences, including focusing on areas which are highest on the Indices of Multiple Deprivation, and targeting our advertising at young adults aged 18 to 25 and people from racialised communities.

This would require further discussion and additional budget to ensure SSH best met the needs of these groups and maintain our target of seeing people within 28 days, while delivering on the Major Conditions Strategy.

### Overall package and cost

Our costings assume that DHSC would support 9,520 people to receive support from SSH in 2024mto 2026, at a cost of £261<sup>40</sup> per person. This will be delivered through a maximum of 28 of our local minds across the 2 years.

Mind has already secured some funding towards SSH in 2024 to 2025. The cost to DHSC would therefore be £2.1 million.

<sup>&</sup>lt;sup>40</sup> This cost is based on Mind's budget developed in 2023-24. Mind is in the process of reforecasting for 2024-25, and this cost is therefore subject to change. We do not expect this change to be substantial.

# Access to additional support

Patients referred into Diagnosis Connect will also gain access to the range of additional support offered by Asthma+ Lung UK, Diabetes UK, and Mind. For example:

Access to online Side by Side, Mind's peer support platform. With over 55,000 users, Side by Side provides a safe space to listen, share and be heard, and connect with others experiencing mental health problems.

Access to local services across Mind's network of over 100 local Minds. Supported Self Help advisors will be able to signpost users to specific local support based on their needs and interests.

Asthma + Lung UK's local Breathe Easy support groups: 150 groups across the country, providing face-to face support to over 12,000 people.

Asthma + Lung UK's online support, and exercise groups that support over 8,000 patients annually.

<u>Diabetes UK support groups</u>: 185 groups, supporting over 30,000 people.

Diabetes UK <u>Outreach events</u> and partnership working through community groups, faith groups and Diabetes UK's <u>membership offer</u> which includes magazine and newsletter access.

# **Contact details**

Thank you for your consideration of Diagnosis Connect. For more information please contact:

Henry Gregg - Asthma + Lung UK (hgregg@asthmaandlung.org.uk)

Stewart Lucas - Mind (<u>s.lucas@mind.org.uk</u>)

Charlotte Augst - Diabetes UK (<a href="mailto:charlotte.augst@diabetes.org.uk">charlotte.augst@diabetes.org.uk</a>)

21 February 2024

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