THE NEW STATESMAN

Spotlight

Thought leadership and policy

The Future of Care

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Date of preparation: August 2026 | M-GB-00027717
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Senses of community

In announcing plans for a National Care Service, Andy Burnham placed one of Britain's most persistent challenges at the centre of his government's agenda.

The implications extend well beyond social care. Burnham argues that improving provision will also relieve pressure on the NHS, reducing hospital admissions and helping people live independently for longer. The proposed service represents an acknowledgement that the nation's health can't be secured by the NHS alone.

That principle runs through many of the challenges examined in this edition. Hospitals remain indispensable, but too often they are the default destination when earlier intervention, community provision or support from other services is unavailable. Whether the issue is mental illness, long-term disability, addiction or end-of-life care, the consequences of fragmented provision can be felt by individuals and families long before arrival at A&E.

The government's wider ambition to move healthcare from hospitals into communities therefore raises questions about more than the location of services. How can people be supported to remain well and independent? What role should employers, local authorities and the third sector play? And can a system used to responding to illness become better at preventing it?

David Blunkett argues for wider access to occupational health to prevent Britain "sleepwalking into a sickness economy" (page 6), while Liberal Democrat MP Helen Maguire makes the case for greater focus on individual choice (page 7).

The future of social care is the subject of a cross-party symposium featuring MPs Ellie Chowns and Damian Hinds, and the King's Fund's Simon Bottery (page 14). They debate whether politicians can find the consensus needed for lasting reform. Meanwhile, Marie Curie's Matthew Reed calls for greater community provision for those in the final years of life (page 11), and Rhi Storer investigates the growing pressures on hospice and palliative care services for children and young people (page 24). Samir Jeraj examines the role of harm reduction in drugs policy, including the opening of the UK's first safe drug consumption facility (page 18).

The approaches explored across these pages differ, but they ask a common question: how can public services intervene earlier, work together more effectively and provide support where people need it, rather than waiting until their circumstances deteriorate?

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Spotlight

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BRITISH SOCIETY OF MAGAZINE EDITORS AWARDS 2017 WINNER

First published as a supplement to the New Statesman of 23 October 2026.

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The paper in this magazine is sourced from sustainable forests, responsibly managed to strict environmental, social and economic standards. The manufacturing mills have both FSC and PEFC certification and also ISO9001 and ISO14001 accreditation.

This supplement can be downloaded from: newstatesman.com/spotlight/reports

Advertorial

Rare disease affects more than one life

Policy must recognise not only patients but the people who care for them

By Deborah Richards

Sponsored and funded by ALEXION AstraZeneca Rare Disease

Behind many people living with a rare disease is a network of family members, friends and others helping to manage their care.

Parents learn the clinical language of unfamiliar conditions. Partners manage arrangements and travel for appointments. Friends provide practical and emotional support. Informal carers become advocates, administrators and sources of specialist knowledge while balancing other everyday responsibilities.

Unpaid care is not a marginal issue in the UK. Around 8.9 million adults provided unpaid care between 2023 and 2025. Working-age unpaid carers were less likely to be in paid employment – 59 per cent were in paid employment, compared with 67 per cent of working-age adults who were not carers. This fell to just 35 per cent among those caring for more than 35 hours a week. Women were also 29 per cent more likely than men to provide unpaid care.[1]

Rare diseases present distinctive challenges for individuals and the people supporting them. Many conditions are life-changing or life-limiting. Seven in ten affect children.[2] They can affect multiple parts of the body, requiring care across different clinical specialties, frequent appointments, repeated assessments and visits to multiple NHS centres. For families, this can turn already complex care into a further source of uncertainty and strain.

The burden beyond the condition

Fragmented care is a common reality for people living with rare conditions. Care may cross specialties, hospitals and public services without clear responsibility for bringing everything together.

Patients and carers can be left to navigate pathways themselves, repeatedly explaining the condition, passing information between teams and working out where to turn next.

NHS England's analysis of national patient experience surveys reinforces that continuity, coordination and well-managed transitions become especially important as care pathways grow longer and more demanding.[3]

Research examining the impact of the UK Rare Diseases Framework supports this picture. The RareCare survey found that 59 per cent of people living with rare conditions and their carers had no designated care coordinator. Forty per

cent rated collaboration between doctors and services as poor or very poor, while almost half said that healthcare providers did not share information effectively.[4]

One participant captured what this means: "It's like an octopus where everything is kind of like connected to something and you're juggling all these plates [...] my phone is never off because any call regarding her care comes at any time."[4]

These findings underline the practical consequences of poor coordination. Unclear responsibilities mean carers often fill the gaps by keeping records, relaying clinical information, chasing referrals and coordinating support across health, education and social care. This largely invisible work can disrupt employment, education and family life, adding to the demands already placed on carers.

Caring for a child or young person can be especially challenging because their physical, educational and social needs are closely connected and often change as they grow older. Parents may find themselves coordinating support across different services and settings while helping their child gain independence and prepare for the move into adult care.

The consequences for informal carers and families can be profound, affecting their health, wellbeing and everyday lives. Unpaid caring responsibilities continue to fall disproportionately on women. In families supporting a child with complex, long-term needs, parents may have to reduce their working hours, change careers or leave employment altogether. For women, who are more likely to take on these responsibilities, the cumulative impact can be particularly significant.

These are not simply short-term adjustments. They can have lasting consequences for earnings, career progression, pension savings and financial independence, while limiting the contribution that experienced carers are able to make in the workplace and wider economy.

Looking beyond the individual

The cumulative impact on carers should matter to policymakers. In his first speech as Prime Minister, Andy Burnham promised to "help people to live well" and "put the care of people at the heart of everything" his government does.[5] For rare disease, delivering that promise means recognising informal carers and ensuring that the impact on them is more routinely and appropriately valued when decisions are made about care and treatment.



SIMPLE LINE/SHUTTERSTOCK

Around 8.9 million UK adults provided unpaid care between 2023 and 2025

When treatment helps someone remain independent, avoid hospital care, need less support or return to work, the benefits reach beyond the individual. Health economists describe these as spillover effects.

For carers, this can mean better health and wellbeing, less time spent providing or coordinating care and greater freedom to work, study or contribute elsewhere in society.

These benefits are not always easy to quantify, but excluding them risks understating the true value of treatment. Forthcoming work by the National Institute for Health and Care Excellence (NICE) will examine how these wider economic and societal effects of medicines, including productivity, educational attainment and carer burden, can be better reflected in decision-making.

Alongside a review of how rare disease medicines are evaluated, this offers an opportunity to establish a systematic process for capturing a more complete picture of what effective treatment can deliver.[6]

If the UK is serious about helping people live well, our approach to valuing better rare disease outcomes must recognise not only the person with the condition but also the people supporting them. ●

Deborah Richards is UK general manager, Alexion, AstraZeneca Rare Disease

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GB-81386 / October 2026

A view from the Lords



Lord David Blunkett
Patron of the Society of Occupational Medicine

"Occupational health can help prevent us sleepwalking into a sickness economy"

"Too many GPs tell people that they will never work again," were my words back in 2005. Barely a month as work and pensions secretary and I was troubled by a system better at managing people once they had fallen out of work than stopping them dropping out in the first place.

Since then, I married a GP (now retired) and witnessed improvements in how job centres and primary care practices work together. Yet, as so often, I have seen "the tide going out" once more.

Twenty years ago, around 2.3 million working-age people were economically inactive because of long-term sickness. It is now in excess of 2.8 million. In 2005, almost four in ten people on incapacity benefit had a mental health condition. Now, among newer Universal Credit claimants going through an assessment, at least 70 per cent are recorded as having a mental or behavioural disorder.

The issue is high on the political agenda, with my friend Alan Milburn reporting soon on young people not in education, employment or training, and Sir Stephen Timms investigating welfare reform. Both build on Sir Charlie Mayfield's work on keeping people in employment, and I know the Secretary of State for Work and Pensions is determined to turn around the welfare system and the pessimism surrounding those affected.

The Prime Minister also draws on Greater Manchester's Working Well programme, which joined up health and employment support. He has pledged more mental health support for young people and a "more preventative state".

Government separates NHS waiting lists, economic inactivity, productivity, skills and labour shortages into different boxes. People do not live that way. An employee waits for treatment, takes sick leave and ultimately leaves work. The employer loses their skills, the Exchequer their contribution, and the benefits system picks up the cost. We need a whole-systems approach, locally and nationally, to save this generation from isolation and, yes, indolence, while freeing up resources to improve the world around us.

One piece of this jigsaw has to be occupational health. Former Royal College of Physicians president Dame Carol Black calls it the medical speciality sitting "at the border of health and the economy". The TUC believes it is "vital" to retaining people in their jobs. The CBI argues that wider access could keep tens of thousands in the workforce.

Occupational health is often misunderstood as another HR process, but at its best, it brings health expertise into the workplace early, maintaining wellness and the ability to work.

Our best employers recognise this. Keeping people healthy, reducing absence and avoiding the cost of replacing them is not just about "wellbeing". It is fundamental to business growth, retaining human capital and skills. Workforce health belongs on company board agendas and within public service leadership, alongside financial risk, cybersecurity and supply-chain resilience.

In 2005, I called for a "long hard look at occupational health for the nation as a whole" to "prevent people becoming ill, prevent people dropping out of work". Why are we still struggling?

Part of the answer might be that only 45 per cent of workers have access to occupational health support, with provision ranging from 92 per cent of large employers to just 18 per cent of small employers, precisely where owners and managers are least likely to have specialist health expertise.

The challenge is not simply keeping people in work but persuading them they shouldn't be on the scrapheap before starting their lifelong journey of learning, earning and becoming independent.

Above all, Britain must confront the belief we are inevitably sleepwalking into a "sickness economy". ●

HOUSE OF LORDS/ROGER HARRIS

A view from opposition



Helen Maguire MP
Liberal Democrat spokesperson for primary care and cancer

"A healthy community is a precondition for everything we want to be free to do"

One of my constituents, a deaf man, recently told me that when he went online to book a GP appointment. He selected email or text as the only way to reach him, but the default slot offered only a phone call. An older woman in my patch spent weeks housebound and in pain after an injury, yet was only offered a phone call for a problem impossible to diagnose remotely.

Neither were asking for special treatment, but simply for a service that works for them. Too often, it doesn't. Primary care accounts for 90 per cent of the public's contact with the NHS; it's where our health service is judged, and the verdict is damning. Satisfaction with the NHS has fallen to 26 per cent, and nearly half of the public say they avoid contacting their GP. Millions of those who do make contact wait over 28 days for an appointment – a legacy of a decade of Conservative underfunding, followed by a Labour government that still treats primary care as an afterthought.

This has implications for our community politics, and as Liberals, we have a particular reason to care. Liberty is not simply the absence of barriers but the real capability to live the life you would choose.

Good health expands that capability: it gives us the freedom to work, travel, learn, care for others, pursue passions. It is not merely something that allows us to live but is constitutive of living well. And, if we are serious about building strong communities in which people can flourish, we should care about whether those communities are healthy in the first place.

The GP surgery, the dentist and the pharmacy are not an aside in Liberal politics. They are among the most important local institutions the state runs, and often where people encounter the state most directly. A healthy community is a precondition for almost everything else we want to be free to do.

I see three building blocks to supporting a primary care service built for the future – with Liberal principles running throughout.

First, ensure everyone knows and trusts the local services they can turn to, from walk-in mental health providers to the dentist or family doctor. Requiring people to spend hours on the phone and fill in copious online forms to access primary care defeats its purpose and hurts everyone, particularly the most disadvantaged.

The second is to use the surge in technological development to include people, not filter them out. Digitising what is inaccessible is not a sure-fire fix for accessibility. The NHS app or online GP bookings can be a gift, but only if they consider how people need to be contacted. Technology must support at an individual level and never leave behind the elderly or those who are not digitally literate.

Lastly, build primary care around the individual, not the system. The strength of primary care and community services is that they can respond to people as individuals, rather than forcing them through as one-size-fits-all.

This is the exact principle behind the Liberal Democrats' new primary care policy: guaranteeing GP access and choice, replacing the broken dental model, expanding community pharmacy services and reforming the outdated Carr-Hill funding formula to reflect local need.

The deaf gentleman and the elderly lady in my constituency are not asking for a revelatory overhaul. They just want to book a GP appointment in a way that fits their needs. A health service built for the future should start by listening to them.

HOUSE OF COMMONS/ROGER HARRIS

Advertorial

The NHS needs a new model for cardiovascular care

Meeting its ambitions will require a shift from a fragmented, reactive model to integrated, preventative pathways

By Tom Keith-Roach

Written and funded by AstraZeneca

Around 33,000 people under the age of 75 die from cardiovascular disease every year in England. Behind that statistic lies one of the country's largest health challenges, growing pressure on NHS services and widening inequalities.

This burden is not felt equally: people living in the most deprived communities are more likely to develop cardiovascular, kidney and metabolic (CVKM) diseases earlier, experience poorer outcomes and spend longer out of work due to ill health. The impact extends beyond health alone, with more than 770,000 working-age adults with cardiovascular conditions currently out of work, contributing to around £1.2bn in lost productivity annually.

The publication of the NHS Cardiovascular Disease Modern Service Framework (MSF) marks an important moment in addressing these challenges. Its ambition is clear: to reduce premature deaths from heart disease and stroke by 25 per cent over the next decade.

The ambitions set out in the MSF demand a fundamental shift in how care is delivered across the NHS. Too much of today's system focuses on managing disease after it develops, rather than identifying risk early, preventing progression and supporting people to manage their health proactively. The full value of innovative treatment, technology and data cannot be realised through fragmented pathways. Bringing these capabilities together through integrated, patient-centred, technology-enabled models of care would allow earlier risk identification, faster intervention and better support at a time when demand continues to grow.

The case for integrated care

People increasingly live with multiple interconnected health challenges, and patients do not experience CVKM conditions in isolation. That reality is reflected in the scale of cardiovascular risk across the population.

More than one-third of adults in England have hypertension, while almost 60 per cent of hypertension cases remain undiagnosed. This pattern of overlapping risk means that a person with high blood pressure is rarely managing a single diagnosis; UK health data tell us that roughly two in five adults with hypertension are also living with obesity, while over two-thirds

of those with type 2 diabetes have at least one comorbidity, the most common being hypertension, depression and coronary heart disease. Yet healthcare pathways are still designed around individual diseases, with separate specialties, services and clinical teams.

The result is a disjointed system complex, for both patients and healthcare professionals. Patients are frequently required to navigate multiple appointments, providers and care plans. Opportunities to identify risk, intervene earlier and coordinate care are often missed. In a health service under significant pressure, the NHS cannot afford to continue to operate in this manner.

How CVKM changes the conversation

With this national mandate for CVKM integration now in our hands, we have an opportunity to create a connected pathway spanning prevention, diagnosis, treatment and long-term management. By bringing primary care, community pharmacy and specialist care closer together, Integrated Care Boards can reduce duplication and ease pressure on the NHS, making every patient contact count and reducing avoidable cardiovascular events and variations in outcomes across communities.

Take risk management: traditional healthcare pathways are often activated when a person presents to the health system after having developed a condition or experienced an event. By contrast, the changing healthcare landscape could allow us to identify risk earlier and intervene before serious complications occur. With at least 70 per cent of cardiovascular disease associated with preventable or modifiable risk factors, there are proactive approaches waiting to be grasped through the expanding role of pharmacists in managing health locally through health checks; the explosion of wearable technologies building individual health awareness; and the emerging capability of AI to assist in case-finding across medical records.

Prevention at scale requires a new model

The current reactive approach to care is baked into the NHS. And while NHS England has articulated a 21st century ambition, will the health system have the courage to leave behind the 20th century model of care? Physical appointments, episodic interactions and treatment once disease has already taken hold can no longer be the norm. It is simply not capable of identifying risk across entire populations, supporting continuous management of long-term conditions, or intervening consistently before serious cardiovascular events occur.

The convergence of AI, digital health and new workforce models creates a once-in-a-generation opportunity to redesign care around patients rather than institutions. With more than 39 million registered users, the NHS app has the potential to become a gateway to more personalised, preventative and connected care. But government, the NHS and industry must work together to ensure sufficient investment in digital infrastructure, interoperability and workforce capability – so these advances in remote monitoring, digital therapeutics, population health management, proactive case finding and AI-enabled risk stratification can be scaled consistently, rather than remaining isolated examples of good practice.

We are not starting from scratch: innovative models already exist, such as the LUCID programme, delivered through a joint working partnership between AstraZeneca, University Hospitals Leicester and primary care teams. This integrated primary- and secondary-care model uses virtual multidisciplinary teams to identify high-risk chronic kidney disease patients, optimise treatment and reduce emergency admissions and long-term NHS costs.

The challenge is embedding such innovation sustainably into everyday care at scale. Local systems need flexibility to tailor services to population needs, supported by a national framework that ensures equitable access to evidence-based care wherever patients live.

Turning ambition into action

Major transformation requires collective political and financial commitment. For AstraZeneca, this means bringing innovative medicines to the UK, working with government and NHS England to redesign care around growing demand, and partnering with local health leaders to transform pathways.

This agenda can also drive growth: adopting UK-developed medicines, digital tools and health technologies can improve outcomes, create skilled jobs and strengthen local economies. Our goal is to turn the MSF's ambition into reality through partnership. By combining the NHS's reach and clinical expertise with industry's scientific, technological and delivery capabilities, the triple helix of government, NHS and industry can build a future-ready model of care that protects the nation's health. ●

Tom Keith-Roach is president of AstraZeneca UK. Full references can be found in the online version of this article at https://tinyurl.com/2bd8wjn8

GB-81415 October 2026



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Pharmacists have an expanding role in proactive health management and prevention



Mel Merritt
Head of policy, National Autistic Society

"Autistic people must not pay the price for headlines that distort Fonagy's findings"

Professor Peter Fonagy's independent report on the prevalence of mental health issues, ADHD and autism is unequivocal in its findings: successive governments have failed autistic people and currently there is no widespread overdiagnosis of autism.

The report found that being able to get a diagnosis brings substantially more benefit than harm. It finds no evidence that people coming forward today are less affected than those identified before. Yet much of the media coverage sidelines government failings and gives a misleading picture.

There is a lack of reliable, up-to-date figures showing how many people are autistic. There is no evidence that too many people are being diagnosed. Yet this has received overwhelming attention at the expense of the realities autistic people face: mental health distress; increased risk of suicide; less likely to be in education or employment; and a lack of specialist support for autistic people with a learning disability.

Diagnosis can reduce distress and help people access support. There needs to be urgent action for the more than 294,000 people who are currently waiting for an autism assessment in England, with average waiting times as high as three years in some areas of the country. Often, little support arrives while waiting for a diagnosis or after. Education and social care support is often dependent on getting a diagnosis. It shouldn't be this way, but this is how councils are gatekeeping support to manage stretched budgets.

As the report found, waiting increases harm and means people are more likely to reach crisis and need more expensive help. Yet some NHS areas have introduced minimum waits of two years for an assessment. Misleading coverage risks being used to justify policies that make diagnosis and support harder to access, deepening the harm people already face. Autistic people must not pay the price for headlines that distort the report's findings.

But a diagnosis too often still does not lead to support. Autistic people often have to fend for themselves. The Fonagy report highlights that 40 per cent of clinicians surveyed reported no ongoing post-diagnostic support: autistic people and their families describe years of waiting to get support.

Meanwhile, we have been warning – along with other autism charities – against an increasingly polarised debate. With the publication of the final report, the toxic headlines continue, leading on possible future risks over real current failures and claims that diagnosis causes harm when the review found the exact opposite.

Government and ministers should use their positions to steer the conversation away from endless harmful discussions about overdiagnosis. Instead, they should work with autistic people and their families to take action to create a system that works for all, focused on positive outcomes – not blame – and managing demand. Now is the time to stop the spread of harmful misinformation about autism and shift the conversation towards solutions that genuinely address autistic people's needs.

Denying people support will only worsen inequalities, particularly for previously under-recognised groups such as autistic women and girls, who are only now getting long-overdue recognition and support. The government has accepted the recommendations of Fonagy's report; it now needs to match with action by building and investing in a new system.

MARTA SIGNORI



Matthew Reed
Chief executive, Marie Curie

"Terminally ill people are turning to ambulances and A&E in moments of crisis... It's not where they should be"

Quite naturally, few of us spend our time thinking about whether the state provides adequate care when we die. It doesn't, by the way.

But this UK government must. The current fragmented approach to end-of-life care is crippling other parts of the NHS – ambulances, emergency departments and hospital wards – which are becoming the default. In the next 20 years, these pressures, if things aren't done differently, will mushroom. This will affect us all.

MARTA SIGNORI

The government is listening. We know it is because last November, the then minister of state for care, Stephen Kinnock, announced a Modern Service Framework (MSF) for Palliative and End-of-Life Care, now slated for this autumn. Encouragingly, we've also heard from Prime Minister Andy Burnham that palliative care needs fixing.

The MSF is, therefore, teeing up a golden opportunity for the Prime Minister to make good on this ambition. But he has a Treasury-shaped hurdle to overcome if this framework will deliver any change.

To deliver this change, we and others believe the UK government must create a transformation fund of at least £200m per year for three years, allocated through integrated care boards, to support implementation of the framework. This would kickstart the scale of service redesign required – and help the government fulfil its wider ambitions for more joined-up, community-based care.

On this we speak in unison with the royal colleges of emergency medicine, physicians, GPs, nursing, pharmacy and acute medicine, whose members feel the effects of the current gaping holes in end-of-life care.

Of all healthcare expenditure on people in their final year of life, 56 per cent is spent on emergency hospital care, while only 11 per cent is spent on primary and community care.

In short, terminally ill and dying people are turning to ambulances and A&E in moments of crisis due to an absence of alternative help. It's not where they want to be. It's not where they should be. Pain, distress, fear: we hear how these final days and hours haunt families.

We haven't been watching idly from the wings. Things must be done differently and so we have piloted new approaches that we want to see in the MSF and more widely.

In Bradford, our specialists identify people within A&E who would benefit from palliative care, and they are discharged into the round-the-clock care of Marie Curie teams for 72 hours, until mainstream services can take over.

This has reduced unplanned bed days from 38 to 17 and helped alleviate pressure on emergency departments. This is just one of many new approaches we have shared with those writing the new framework.

From the provision of 24/7 helplines to providing specialist clinical nurse support in GP surgeries, we know there are approaches to community provision that can reduce hospital admissions.

The solutions are out there. But, as with so many evidence-based policies that have involved the time and tears of people sharing their experiences of poor care, will it lead to real change?

We believe it can. But failure to finance it would consign the MSF to a bold and credible ambition that was never delivered in practice.

Advertorial

Beyond research

Building a pathway for brain cancer innovations to reach patients

By Chengetayi Pswarayi

In association with novocure®

Around 13,000 people are diagnosed with a primary brain tumour in the UK each year, and brain tumours are the leading cause of cancer death in children and adults under 40. Glioblastoma (GBM), the most common malignant primary brain tumour in adults, is highly aggressive and infiltrative. It has a poor prognosis and can profoundly affect cognition, communication, mobility and independence, placing a significant burden on patients and families. Addressing this disease burden requires treatment innovation and a clear pathway from research through assessment, funding and adoption so that promising treatments can reach the patients who may benefit from them.

Over the past two decades, there have been important advances in the diagnosis and management of GBM. Advances in genetic and biological testing are helping clinicians understand the individual characteristics of a tumour and make more informed treatment decisions, while improved imaging and surgical techniques allow surgeons to remove tumours more precisely while protecting healthy brain tissue.

However, while innovation has brought new approaches to treating brain tumours, only some of these advances have translated into treatment options that patients can access in routine care. A renewed national focus on brain cancer offers an opportunity to turn growing scientific and policy momentum into meaningful progress for patients.

In June 2007, NICE recommended temozolomide for newly diagnosed high-grade glioma. Since then, research has produced new insights and treatment approaches, but progress in expanding the options routinely available to NHS patients with newly diagnosed GBM has been limited.

A changing policy landscape

There are, however, reasons for renewed optimism. A growing focus on brain cancer in national policy creates an opportunity to address some of the barriers between research and patient access. The Less Survivable Cancers Taskforce is an initiative which seeks to improve outcomes through greater focus on earlier diagnosis, research and access to new treatments and technologies. The Rare Cancers Act 2026 aims to

strengthen research and improve access to clinical trials for people with rare cancers, while the National Cancer Plan recognises the need to improve brain cancer outcomes, including an initial £13.7m investment in the NIHR Brain Tumour Research Consortium.

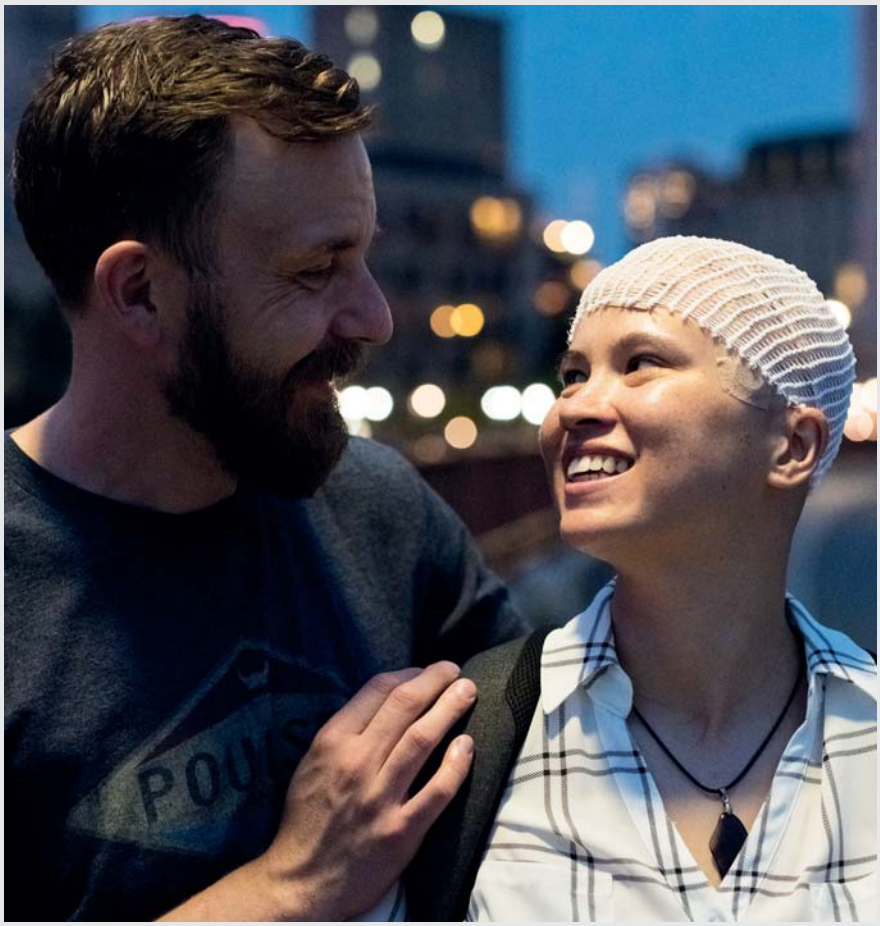
And new approaches are emerging to help promising innovations move into patient care. NICE's early-use HealthTech guidance allows selected technologies to be used in the NHS while further evidence is generated, and the National HealthTech Access Programme aims to support faster, more consistent national access to selected high-impact technologies. These are an opportunity to create a more connected pathway for clinically effective innovations to be assessed, funded and adopted.

The importance of creating such a pathway becomes clearer when considering the continuing pace of scientific innovation in GBM. Targeted therapies, vaccines, immunotherapies, novel drug-delivery techniques and device-based treatments are at varying stages of development and adoption. Tumour Treating Fields (TTFields), which use alternating electric fields to disrupt cancer cell division, are one modality that is approved by health regulators and used to treat newly diagnosed GBM in several healthcare systems, including the US, Germany, France, Sweden and Spain. TTFields are not routinely available to NHS patients.

Building a pathway from evidence to adoption

The challenge is therefore not simply to develop new approaches to treating GBM but to ensure that those demonstrating meaningful clinical benefit can reach patients. For new treatments in rare, aggressive cancers, three areas require particular attention:

- When an innovation demonstrates meaningful clinical benefit, there should be a route to national assessment that reflects the urgency of unmet need and the realities of generating evidence in small patient populations.
- Rigorous evaluation must remain the standard, but some uncertainty may be unavoidable in rare, aggressive diseases. Where appropriate, mechanisms for further evidence generation can help manage this uncertainty while supporting informed decisions about patient access.
- Researchers, innovators, regulators, assessment bodies, clinicians, commissioners and patients should engage earlier to align evidence requirements, trial design and implementation planning, allowing potential barriers to evaluation, funding and adoption to be identified before clinical development is complete.



More treatment options can deliver better quality of life for patients

Evidence generation and assessment alone cannot secure patient access; funding, commissioning and implementation must also be aligned to support equitable adoption across the NHS. Other health systems are exploring more integrated approaches. Ontario's Health Innovation Pathway brings evidence assessment together with implementation planning that considers clinical, policy, funding and supply-chain requirements, creating a roadmap towards wider adoption. Although its institutional context differs from the UK NHS, the model illustrates the value of treating evidence, assessment, funding and implementation as a coherent pathway rather than a succession of separate hurdles.

Investment in research offers hope that the next generation of treatments will deliver better outcomes for people with GBM. Realising the ambitions of the National Cancer Plan and wider commitments to rare and less survivable cancers will require policymakers, clinicians, researchers and health system leaders to look beyond innovation itself and ask what needs to change for effective new treatments to reach patients. For people living with aggressive brain tumours, meaningful progress means more treatment options, better outcomes and ultimately more precious time with family, friends and loved ones. ●

Chengetayi Pswarayi is director, UK market access and public affairs at Novocure

NOVOCURE

Can politicians find consensus on social care?

The need for reform is widely acknowledged, but agreement on how to deliver and fund it remains elusive

WE NEED A FAIR AND SUSTAINABLE FUNDING MODEL

Ellie Chowns MP
Westminster leader,
Green Party

Successive governments have treated social care as a political football for too long, while ordinary families have paid the price for their failure to act. People are left without the support they need, unpaid carers are stretched to breaking point and care workers remain undervalued.

This cannot go on. If we are serious about delivering lasting change, MPs from across the political spectrum must put party aside and work together for the greater good.

To do that, we need to change the perception of cross-party collaboration from a "nice to have" to an "essential".

The Casey Commission provided a starting point for cross-party discussions, but meetings have been few and far between. Genuine progress requires a commitment to regular and substantive conversations, alongside willingness to work constructively with all voices. Crucially, people who use social care services, unpaid carers and those working in the sector must also help shape solutions.

The first priority should be to find consensus on a fair, sustainable funding model that pools the risk of needing care, rather than leaving individuals exposed to potentially ruinous costs.

We see in the example of the NHS how a system funded by us all benefits us all in turn; there is no reason why social care could not follow a similar model.

And we must ensure any funding model also serves to properly value the paid care workforce and unpaid carers on whom the system depends.

Parties will naturally disagree on details, but that cannot become an excuse for indefinite delay. We owe it to everyone who relies on social care to find common ground, agree a clear direction and finally start delivering the genuine change they deserve.

TRANSPARENCY FROM THE GOVERNMENT IS NEEDED

Damian Hinds MP
Shadow secretary of state for health and social care, Conservative Party

As Britain's population ages, the question of social care is becoming increasingly pressing. Conservatives recognise the scale of this challenge and will engage constructively to deliver meaningful improvements, but serious reform requires more than speeches, press releases and headlines.

I was surprised, after Andy Burnham repeatedly stressed the importance of cross-party cooperation, that he decided to announce his social care proposals unilaterally at Labour Party Conference. There was no debate or discussion. There was no coherent funding plan. And there were no measurable targets for how this would work in practice. Instead, the new Prime Minister homed in on pensioners with plans to scrap the triple lock.

He could have laid out plans to tackle the growing problem of people who can work instead of being reliant on the taxpayer, but he chose to go after people who have worked hard all their lives. He could at least have told pensioners exactly how their money would deliver better social care. But the speech was light on detail and neglected the glaring hole in the government's sums. The public deserve transparency about plans on this scale, but they aren't getting it. This raises concerns that the Chancellor will announce yet more tax hikes at the Budget.

The Conservatives are clear: Labour must not fund a new social care service by raising taxes. If they want to raise funds, they must do it by cutting spending. We are willing to work across party lines to deliver better outcomes for the public. But meaningful reform requires honesty about the scale of the challenge and the cost involved. All we have had so far from Labour is financially reckless policy. Labour must be transparent about the billions required for their plans and explain how this will be funded without further tax rises.

A "FREE AT THE POINT OF USE" SERVICE WILL BE TRICKY

Simon Bottery
Senior fellow, social care, The King's Fund

Members and politicians from most parties agree that wide reform of social care is needed. Consensus is by no means impossible.

Surprisingly diverse politicians have argued for better access to publicly funded care. When the Prime Minister speaks of care "free at the point of use", he uses the same policy language as the Greens and similar to that of the Lib Dems.

For the Conservatives, there is no clear policy line, but figures like Jacob Rees-Mogg and Damian Green have also called for at least some care to be free at the point of use. Reform's Danny Kruger has written in favour of free personal care at home.

Admittedly, the devil can be in the detail. There is no consensus about exactly what should be free, under what circumstances and when.

Yet these nuances are surely not irreconcilable if parties wanted genuinely to find common ground. It is not hard to imagine a system like that in other comparable countries where some care is free to all but the better-off must contribute. At The King's Fund, we have published work setting out what this detail should look like.

Agreement on funding a better system is harder, though, because it exposes differing political philosophies.

Some still argue for voluntary private insurance; others for a tax on wealth or inheritance – a "death tax" to its detractors.

The conversation effectively pushed concern about the latter in the 2010 election. Labour and other opposition parties used fears of a "dementia tax" in 2017 to similar effect.

The reality is that we will all need to pay, which is unpalatable to some. Should we forget cross-party talks then? No. Agreement on direction of travel is possible; the public can then decide who to believe on the detail and its funding. ●

"There is no consensus on what should be free and when"

Advertorial

The future of health could be just around the corner

Neighbourhood health could tackle inequalities, but only if communities help shape it

By Mark Heffernan

In association with Impact on Urban Health

The street a child grows up on determines their long-term health. One child could wake up in a damp and mould-infested home and walk to school bombarded by junk food adverts, breathing in polluted air.

One of their classmates, on the other hand, could wake up just a street away, benefiting from clean air, nutritious food and a financially stable home. These differences will compound over time and shape these children's health and wellbeing for the rest of their lives.

We see these inequalities starkly in the London boroughs of Lambeth and Southwark, where Impact on Urban Health calls home, and in towns and cities across the country. People living just streets apart in towns and cities can experience ten to 12 years difference in life expectancy – a stark contrast that is preventable.

The systems and decisions that lead to these differences can be changed. The shift from sickness to prevention, as proposed in the government's 10 Year Health Plan, forms the roadmap to healthier communities across the country – if done right.

At the heart of that plan is the neighbourhood health agenda, which promises to move care closer to communities. That agenda has the potential to be a vehicle for the preventative shift. Unlocking this potential requires a commitment to creating health in local areas, with the people who live there.

Most of what shapes our health happens outside the NHS. The places we live, work and spend our time have a huge impact on how healthy we are and how long we can expect to live healthy lives.

Making places work to support health requires communities and institutions to work together in a meaningful way. This means ensuring that services – including those beyond the healthcare system, such as financial or housing support services – are integrated and accessible.

There are already excellent examples of this happening across the country, including in south London. Financial Shield, a programme we fund in Lambeth and Southwark, brings together GP practices, local councils, housing associations and voluntary sector organisations to provide a holistic response to people's financial

and health support needs. It has supported over 1,000 residents with long-term health conditions and financial difficulties. Focusing on income maximisation and breathing space for rent and council tax debts has resulted in tangible improvements in mental, physical and financial health.

The neighbourhood health agenda is an opportunity for upstream interventions like Financial Shield to spread and scale. But as it stands, national policy is too narrowly focused on moving patient care out of hospital settings to relieve immediate pressures, and there is a risk that the wider, long-term potential of this agenda is not realised.

To address this, local systems should be encouraged to broaden definitions and measurements of success for neighbourhood health. If specific targets and metrics aren't put in place to reduce health inequalities and prevent ill-health before it develops, we risk worsening outcomes, even if some clinical metrics improve.

Communities already hold a lot of the answers about how to 'do' neighbourhood health well. They know what needs to change – they just need the system to listen and take action. Residents that we have engaged with in Lambeth and Southwark emphasise the importance of trusted local relationships, accessible services and stable community spaces: these are the principles for enabling a healthy and equitable neighbourhood.



Most of what shapes our health happens outside the NHS

There is a clear intention for neighbourhood health to be centred in the communities served by those leading the planning. The government has made clear that success will be measured by outcomes in the community – but has largely left the specifics of neighbourhood health planning to local areas. This includes each area's approach to involving local residents and community-based organisations in decision-making.

It's positive that local places are being given space to ensure that services and interventions reflect their unique contexts and local strengths. But there is a risk that without clear guidance, resourcing or metrics around this decision-making process, the potential for meaningful engagement could be diminished and communities could be sent the message that their involvement is 'nice to have' rather than essential. This is especially true for voluntary and community sector organisations, many of which are already delivering services and providing support that should be at the heart of neighbourhood health plans. Some could be brought into the process too late or expected to contribute more than they're able.

Health inequalities too often limit our opportunities. They reflect and affect our access to clean air, healthy food and housing free from damp and mould.

National government and local authorities can work to create health with the people who know what it's like to live in places that are working against them. This requires a new way of working locally – with local health systems, national and local government, voluntary organisations and communities coming together to address the wider determinants of health. The path to a sustainable NHS, and a healthier, more resilient society, lies in preventing ill-health before it develops. Eventually, it's a path we will have to take.

The neighbourhood health agenda offers a chance to take real steps on that journey, to meet communities where they are and to recognise that what surrounds us shapes our health. ●

Mark Heffernan is the director of policy, influencing and communications at Impact on Urban Health

IMPACT ON URBAN HEALTH

Harmful effects

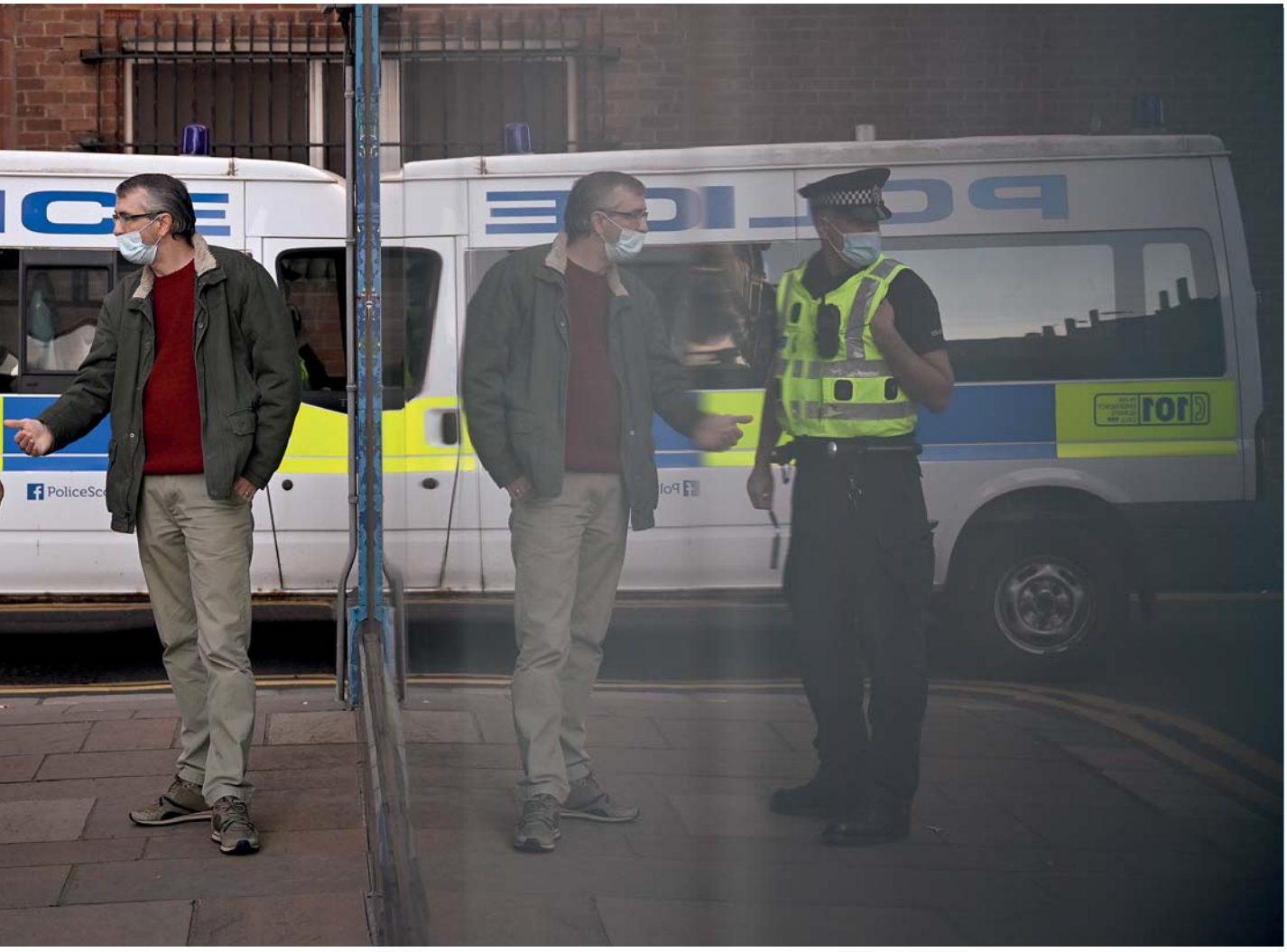
The UK's approach to illegal drugs is fuelling poor health, but there is another path government could take

By Samir Jeraj



In 2020, local activist and former drug user Peter Krykant decided that he had had enough of seeing people dying from drug overdoses in his home town of Glasgow. So he took it upon himself to set up and operate an unsanctioned harm-reduction service. He kitted out a minivan, and later a former ambulance, to provide a mobile overdose-prevention service. He did so openly in defiance of the law and was arrested, only for the charges to be dropped. Five years later, The Thistle, the first safe consumption room in the UK, opened in Glasgow. Sadly, Krykant passed away just a few months later.

If there is a consensus on drug harms, it is that the current way the UK deals with them is failing. Scotland recently recorded its highest-ever number of annual drug deaths: 1,133 – an 11 per cent rise on the previous year. It is the country with the worst



Peter Krykant talking to a police officer after opening an unsanctioned safe consumption room

GETTY

fatality rate from drugs in Europe. In England and Wales, the picture is little better, with drug deaths rising annually in recent years to reach 5,565 deaths in 2024, the last year for which public information is available.

Scotland took the step of opening the first "safe consumption" facility in the UK in an attempt to reduce the harms caused by substances such as heroin and fentanyl. People bring their drugs and can use them under supervision with provided clean equipment, meaning that if they overdose, medical intervention can happen immediately.

Around 800 people have used the service to administer over 16,000 injections in the 18 months it has been open. "We're sited within an area that has a very high prevalence of problem drug use, and that has historically been known to experience people who inject away from home in public places. So that helps us in terms of making it accessible for people who use drugs," said Dr Saket Priyadarshi, associate medical director, alcohol and drug recovery services, at NHS Greater Glasgow and Clyde.

In that time, Priyadarshi and his staff have been able to provide immediate and often life-saving medical assistance on over 200 occasions to people who have overdosed.

"I think the other strong area of learning for us has been the really dynamic and toxic nature of the drug market – and what a risk that is for people who use drugs," Priyadarshi said. While the service initially saw a lot of cocaine use, that shifted to heroin and more recently to heroin adulterated with the synthetic opioids known as nitazenes.

Beyond its role in safe consumption and overdose prevention, The Thistle acts as an access point to a range of healthcare and other services that people might otherwise not access. These include those for housing, wound care, sexual health, blood-borne diseases and getting support and treatment for drug use.

"We know of really positive cases where people have moved on in their lives quite significantly, including moving on to recovery communities and residential rehab," Priyadarshi said.

Harm reduction itself is not a new concept, but it is an approach that historically has been driven by people with lived experience. One well-known example is programmes to provide clean needles to people who inject drugs in order to reduce the transmission of HIV and hepatitis C associated with sharing needles. ▸

◂ These started in the mid-1980s with activist groups of drug users in Amsterdam working with the local government, before being adopted more widely as a way to curb the HIV/AIDS pandemic.

To date, there has yet to be a single death, not just in The Thistle but in any of the over 100 safe consumption rooms globally since the first one opened in Switzerland in 1986. Across that timespan, the harm reduction approach has expanded to include a variety of methods to help people reduce the harm to themselves and others from their drug use without criminalising them. That includes overdose prevention, providing safe equipment and even ensuring a safe supply of drugs. A small number of areas in the UK now provide drug-testing services where people can see and understand what they are about to take and what it may have been cut or adulterated with.



Staff and volunteers from Bringing Unity Back Into the Community

Lanre Babalola was a service user at the Drug Advisory Service in Haringey, north London. It was the early 2000s and he and fellow service users felt that, when their 12 week programme ended, their needs had still not been met. They went on to establish a "lived experience recovery organisation" (LERO) called Bringing Unity Back Into the Community (BUBIC), an organisation for people who use drugs established and run by people with lived experience of recovery.

Their aim was to go where no other service would, working out of hours, going into crack houses and working through peer support with people whom traditional clinical services would judge to be "too difficult", and standing with people in their journey towards recovery.

"Peer support is a thing where people identify 'I've been through it. You've been through it. I'll use what I've had to support you', and it's not clinical language. It's not a treatment language. It's lived experience," Babalola said.

For Babalola, the key role of harm reduction is to give people the opportunity and space to address the reasons why they use drugs. Often that includes trauma, undiagnosed or supported neurodivergence and mental health conditions. These are issues that cannot be addressed through a time-limited 12-week programme. Babalola would like to see more bespoke services, particularly to support people who use crack, and better understanding, awareness and recruitment of people who are neurodivergent.

"When we started, we started for us, by us black people because we were marginalised, we were the hard-to-engage group," he said.

The other significant harm comes from the crime associated with drugs. One person who has fundamentally changed his view on this is Neil Woods, a former undercover police officer who spent years working to smash drug-dealer networks only to find these efforts were largely futile and served to escalate the harms.

"[Harm reduction] doesn't just save lives; it also reduces crime, because if you stabilise somebody's life and you protect them from the exploitation of organised crime, those people are not being exploited to commit further crime to fuel an addiction," he said.

> Police never reduce the size of the drugs market

Woods is an advocate for heroin-assisted treatment, a legal but relatively expensive way to reduce the harm for heroin users by providing a safe supply of the drug under clinical supervision – and one which he points out would cost around a fifth of the outlay for incarcerating someone for a year.

Woods would go further policy-wise into the safe supply of other drugs in order to reduce the harm to children who are exploited by criminal gangs in order to sell drugs, including the "county lines" model used by gangs. "Police never reduce the size of the market; they only change the shape of the market, and that changing shape in the UK has meant an explosion of child exploitation," he said.

Up until the 1960s, the UK approach to addiction was to treat it as a health issue, Woods explains. "We used to lead the world in drug policy, which meant that if you developed a problem with drugs, you went to the doctor and got help," he said.

When the UK changed that policy and took a criminalised approach, the number of people regularly using heroin went from just over 1,000 to over

BUBIC

300,000 in 15 years. The problem, he says, is that the debate on drugs reform and harm reduction has been "poisoned" by "ideological nonsense".

"We don't need a change in the law for this, and it's the single change in drug policy that would make a bigger difference than anything," Woods said.

Harm reduction and broader drugs reform does have advocates in parliament. Jeff Smith MP, chair of the All-Party Parliamentary Group for Drug Policy Reform, believes that "successive governments have been just too timid in engaging with drug policy".

This, he says, is because of the fear politicians have of being out of step with public opinion. On top of that, the media have historically "weaponised" any attempt by government to pursue policies that are seen as soft on drugs.

Smith says it is a "frustration" that the current government claims that it will follow evidence but does not appear to be willing to do this around harm reduction, particularly on the case for rolling out more safe consumption rooms.

"It does appear as though the government have already made up their mind on this and don't want to get involved with it," he said.

In Bristol, the city council is working towards becoming a "city of harm reduction". The work is led by Cara Lavan, a councillor whose partner died of an overdose in 2014 and who has long campaigned for better support for people who use drugs. "Bristol's always been a very progressive city, and there's a lot of work that's gone on for years," she said.

Lavan's aim is to push harm reduction further in the city, but she has come up against the constraints of central government policy. That includes legal restrictions on opening a safe consumption room along the lines of The Thistle, which is only allowed to operate because the Scottish Lord Advocate effectively directed the police not to prosecute anyone working there for criminal offences under Scottish law.

"The police also have a certain amount of discretion to decide whether it's in the public interest to prosecute people," Lavan explained. This discretion underpins drug diversion schemes, where possession of small amounts of drugs can be dealt with through treatment and rehabilitation rather than criminal sanctions. But discretionary policing also raises questions about unequal treatment, particularly given the disproportionate targeting of black and brown people in drug enforcement.

There is a drug-testing service in the city, one of a handful across the UK, where people can bring their drugs to test what is in them and discover if it has been cut with anything harmful.

Bristol Council has approached the Home Office to ask for permission to establish a safe consumption room similar to The Thistle. However, thus far the Home Office has not shown enthusiasm for expanding the scheme to other cities.

The evaluation of The Thistle will not conclude until late 2029, which will determine if it is allowed to continue. If trends continue, England and Wales will have recorded at least another 20,000 deaths by this time.

For Lavan, there is fundamentally a lack of ambition on the part of government when compared to other causes of death. She gives the example of Vision Zero, a strategy to reduce the number of deaths and serious injuries on roads to zero.

Sweden has taken this idea further and applied it to deaths by suicide, aiming to reduce them to zero. By contrast, the Sunak government set a target of preventing 1,000 deaths from drugs in the three years up to 2025 – a period during which drug deaths increased. The Starmer government said it hoped to save "hundreds" of lives by providing the opioid overdose-reversing treatment naloxone to homelessness shelters – a proposal that has still not made it into practice nearly a year later.

"In the context of Labour, we certainly haven't seen a resistance to harm-reduction interventions that are already permitted under the policy," said Niamh Eastwood, executive director of Release, a charity that works on drugs law and policy. This is a change from policy under the Coalition and Conservative governments, which prioritised recovery leading to abstinence over harm reduction, she continues. This, Eastwood argues, together with cuts to drug and alcohol services during this period, are key reasons as to why the UK has such a high rate of drug deaths.

Andy Burnham recently rejected one of the more radical proposals available to him, decriminalisation of drugs, which has been the policy in Portugal since 2001 and is supported by the SNP, Plaid, the Green Party and Liberal Democrats to an extent. Compared with the UK, Portugal records around 100 deaths from drugs each year, one of the lowest rates in Europe.

"I think pragmatically that something government could do is give clear signals to local public health commissioners that we need to have low-threshold services, so services where people can walk in through the door and access whether it be OST [opioid substitution therapy] or needle and syringe programmes, or individual support, peer support – those are the kinds of services that we do need to be investing in," Eastwood said.

Its advocates argue that harm reduction represents an effective and pragmatic response, one which can happen under the UK's current criminalised approach to drug use.

But attempts to deliver it at scale are still hamstrung by political reticence and lack of willingness to change a system that almost all agree is broken. Until the status quo is changed, we risk thousands of people continuing to die needlessly each year. ●

1,133
Number of drug deaths recorded in Scotland in 2025

0
Number of deaths recorded in safe consumption rooms globally

£9.4BN
Estimated size of UK drugs market

Advertorial

Why faster patient access drives UK growth

By Kate Rowbotham

Written and funded by Roche Products Limited

The UK is a global leader in life sciences, researching and developing pioneering diagnostic tests and innovative treatments that transform lives. However, the true measure of the nation's life sciences ecosystem is not judged by R&D success alone.

It depends on how swiftly and equitably those tests and treatments reach the patients who need them. Currently, patients in the UK wait significantly longer to access approved medicines than many of their peers across Europe, such as Germany (source: EFPIA Patients W.A.I.T. Indicator 2025 Survey) and persistent systemic barriers mean some medicines never reach the NHS front line.

For the UK to maintain life sciences leadership, the pace of developing medicines must be matched by equal ambition in NHS adoption.

Strategic assessment

Bringing a new medicine from bench to bedside is a long and complex process. Researching and developing an innovative medicine takes around ten to 15 years, with costs frequently surpassing £1bn to run rigorous clinical trials to satisfy regulatory requirements (source: IFPMA, 2024. Always Innovating: Pharmaceutical Industry Facts & Figures). Yet regulatory clearance is only part of the journey. The next critical step is evaluation by reimbursement authorities, ensuring a medicine's clinical benefit represents meaningful value to the NHS and taxpayers.

Today's industry pipelines are defined by complex, targeted therapies that continually test the boundaries of traditional health technology assessment (HTA) frameworks. While the recent update to the National Institute for Health and Care Excellence (NICE) cost-effectiveness thresholds is a welcome step forward, the evaluation framework must evolve further. To capture the true, holistic value of modern medicines, HTA methodologies need to appraise wider societal and productivity gains and the impact on informal carers, and be flexible enough to realise the unique realities of ultra-rare conditions.

From national evaluations to local implementation

Once a medicine has been deemed to

offer clinical and cost-effective value to the NHS, the system must pivot decisively from evaluation to adoption. A national recommendation should translate into rapid, equitable care for patients in every postcode. Timely access is critical to tackling health inequalities. When widespread adoption stalls, unwarranted variation grows, deepening existing regional health disparities.

To support widespread access, there must be a clear framework for collaborative adoption and alignment of system incentives. This framework should empower Integrated Care Boards (ICBs) to ensure equitable access across the UK, creating a clear and more consistent route from national assessments to local clinical practice, without unnecessary administrative burden.

Any national reform, like the proposed Single National Formulary, should enable high-value care, empowering doctors to prescribe the right treatment for the right patient at the right time.

The value of innovation as an economic engine

The dividend of timely access to effective treatment extends far beyond hospital walls. Innovative therapies help protect national productivity at every stage of life. They may enable children to stay in education, alleviate informal caring responsibilities on families, and help people stay in or return to work and maintain their personal independence. Spending on innovative medicine is not merely a healthcare cost, it is a direct reinvestment in national productivity and economic resilience.

Patient access is equally important for sustaining UK life sciences competitiveness. If local care falls behind international countries, we become a less attractive market for hosting future clinical trials, draining vital life science investment away from our economy. Furthermore, reimbursement appraisals rely heavily on head-to-head comparisons against current practice.

When UK care drifts out of step with global standards, international trials no longer compare new drugs directly against our current treatments. This makes securing access for future innovations significantly harder. Ultimately, this means poorer outcomes for UK patients and a healthcare system lagging behind comparable economies.

Having spent over two decades working across global biotechnology and healthcare ecosystems before relocating to lead Roche Products Ltd in the UK, I have seen firsthand how international capital flows. Global R&D investment gravitates towards countries that can not only research new treatments but predictably adopt them effectively.

Stronger adoption pathways attract more clinical trials, creating opportunities for UK patients to participate in cutting-edge research while strengthening our innovation ecosystem as well as creating high-value jobs.

A health system designed around outcomes

The UK has an opportunity to build upon its progress by creating an end-to-end healthcare system where innovation moves seamlessly from development to assessment to adoption.

Industry must play its part in delivering this ambition. At Roche Products Ltd, we are deeply committed to the UK's life science ecosystem, investing around £300m annually into R&D and running 163 active clinical trials across 200 NHS institutions.

But investment is only part of the picture. Together, we must aim to be a country where innovation is developed quickly, assessed holistically and adopted effectively. A system where the value of a medicine is judged by the totality of the patient and societal outcomes it delivers, and where a national decision ends the "postcode lottery".

Measuring a successful outcome of the UK's approach to medicine innovation can be straightforward. Do breakthrough treatments reach patients more quickly, and more equitably, than before?

That is the ultimate outcome our health system should be designed to achieve – strengthening the intrinsic connection between health and wealth that helps people stay working, living well and contributing to their communities.

About Roche Products Ltd

Roche, established in the UK since 1908, is a top UK life sciences company. Each year, we contribute approximately £1.5bn to the UK economy through direct business activities, supply chain and employee spending. ●

Kate Rowbotham is general manager of Roche Products Limited



ROCHE

Patient access is equally important for sustaining UK life sciences competitiveness

A complex crisis

Overstretched services force parents to become carers, nurses and advocates

By Rhi Storer

"I want to be William's dad," Gareth Birkett says. "That's really important to me."

But caring for his 11-year-old son, born with a rare form of epilepsy and needing care around the clock, often requires Birkett to act as a healthcare professional as much as a parent. There are appointments, prescriptions, admissions into hospital and endless phone calls.

"The administration burden is complex," he says. "I don't really want to be a nurse. The whole thing is a shambles."

Every child with complex needs has unique circumstances, but the difficulty William and Gareth have accessing care will be familiar to many parents. While medical advances mean the number of children living with life-limiting conditions in England has almost trebled since 2003-04, the scaling up of care has not kept pace.

The Modern Service Framework (MSF) for Palliative and End-of-Life Care, expected to be published this autumn, is intended to counteract variation in palliative care standards and availability in England. But campaigners warn babies, children and young people are not explicitly referenced, risking that the specific requirements of children's palliative care are overlooked.

That sense of being unseen gnaws at parents. When asked about the day-to-day care of William, Birkett says he is frustrated by the "lack of pragmatism" by local clinical services.

Capacity is a recurring issue. Together for Short Lives (TFSL), a charity that helps children living with serious illness and their families, estimates only 973 children's community nurses are employed in England, short of the 4,963 needed to meet safe staffing levels recommended by the Royal College of Nursing (RCN).

Recent figures show the UK having just 24.4 whole-time-equivalent specialist paediatric palliative medicine consultants, against an estimated requirement of 40 to 60.

Like most parents of children with complex needs, Birkett can cite numerous examples of the failures in his son's care driven by workforce challenges. "William has to have a nurse go to school with him every day because of his respiratory management," he says. "If they're not available, he can't go to school. This Thursday, the nurse is not available because something has come up, so William is off school, and that's a day off work for one of us. That's really common."

The challenges facing families like Birkett's also expose a wider problem with how children's palliative care is understood and delivered. Unlike the end-of-life care with which the term is often associated, children's palliative care can span years, encompassing symptom management, respite and support for the wider family.

James Cooper, associate director of external affairs and membership at TFSL, tells *Spotlight* that policy on palliative care is often planned around 'all-ages', and while he does not want to see two parallel systems, structures designed with adults in mind are not always helpful for children. "We're not just talking about adults in the last moments of their life; we're talking about families and siblings around them. Getting this wrong has a lifelong impact on all of them."

Last year, the government pledged £80m over three years to children's and young people's hospices, which offer services ranging from respite and symptom management to end-of-life care. The multi-year settlement was intended to provide "certainty for vital services".

While Cooper welcomes the increase, he still sees it as "inadequate", citing his charity's own estimates that there is a £310m annual funding gap. "The key thing is that no one really knows how much money specifically there is for children's palliative care."

Compounded by the funding gap are the blurred lines between integrated care boards (ICBs), local authorities, and the voluntary sector. ICBs are legally obliged under the Health and Care Act 2022 to commission palliative care that meets local needs. Freedom of information requests sent by TFSL found that only 31 per cent of ICBs provided evidence that they formally



William (pictured) celebrating his eighth birthday. His family are frustrated by the "lack of pragmatism" in local clinical services

commission round-the-clock end-of-life care for children at home, while 36 per cent were unable to provide such evidence.

"I don't think ICBs have much sense of what they're actually putting into children's palliative care," Cooper says. "There's no nationally collected data about the extent to which integrated care boards are commissioning any of the standards around children's palliative care, except for the work we do. That should be a job for the government."

Cooper would like to see a national standard set across all ICBs delivering this legal duty and implementation. "It shouldn't be left to the charity sector to find out whether national standards are being met. We need a clear mechanism to enable the NHS to scrutinise ICBs to meet their legal duty on children's palliative care."

A lack of 'joined-up planning' between services and councils can also make access to care difficult. Zoe Warner has two children. Aidan, aged eight, has cerebral palsy, epilepsy and severe gastrointestinal complications requiring highly specialised care, while his younger brother, Kylan, is autistic and also has epilepsy.

Warner has accessed valuable support and care from Helen & Douglas House, a hospice in Oxford. "They've been a lifeline for us," she says. However, she experiences inconsistent support for her son at school. "[Kylan] goes to school outside of the county. He can access some of the school's therapies, but there is always a debate whether he should.

"With Aidan, he requires deep suctioning. The NHS will allow their carers to do that, but the education carers are not allowed to, even if the NHS provides the funding, because of the policies that are done by the education system.

"I find it quite baffling. Why should he miss out because of red tape? I know a lot of other complex-needs mums are exactly the same. Unless they know what they're entitled to, they don't get it. And even then you still have to fight for it."

Baroness Ilora Finlay, a professor of palliative medicine, sits on the APPG for Children Who Need Palliative Care. She tells *Spotlight* that siblings of children with complex needs also risk becoming victims of the system. "Quite often you'll find that the other child in the family, the one who is well, effectively becomes a carer."

Palliative care, she says, needs to consider the whole family and not just the patient: "You're storing up problems for the long term."

She argues that the government needs to do more to ease the palliative care transition in adult services. Young people turning 18 can find themselves moving from highly specialised children's services into adult provision offering a different level of support.

"It's really difficult when children are under different services, and that becomes much harder when they transition towards adult services," she says. "It is quite rare for all the services to come together."

The experiences of the Birkett and Warner families reveal a care system struggling to adapt to children living longer with complex illnesses. Without better coordination between health, social care and education, much of the responsibility for holding those services together will continue to fall to families themselves.

GARETH BIRKETT

Advertorial

Don't take the biscuit

How to incentivise investment in healthier diets

By Amy Glass

In association with fdf food & drink federation

If you walk down a supermarket aisle today, it looks very different from 20 or 30 years ago.

From low-calorie and low-fat options to higher-fibre choices, the food industry has acted on calls from government and consumers to provide many more options that support healthier diets.

This change on supermarket shelves hasn't happened by accident, or with ease. Changing the recipes of the well-loved, iconic British products that people enjoy in order to make them healthier has taken decades of investment and challenging technical work.

A recent piece of research by consultancy Argon & Co, in collaboration with the Food and Drink Federation (FDF), found that a healthier product innovation project can cost a company up to £5m. Of these costs, ingredients and testing are just the tip of the iceberg. There's also the cost of labour, packaging changes and the risk of a product never reaching the shelves if it doesn't pass consumer testing.

Despite the cost and difficulty for businesses, FDF members have nonetheless succeeded in cutting the salt, fat and sugar in their products by nearly a fifth in just the last five years, according to Worldpanel by Numerator.

Over two billion portions of fibre have also been added to popular British products through innovation and ambition from industry to bridge key gaps in nutrition.

This is because, ultimately, food and drink manufacturers know they have a part to play in tackling obesity and want to rise to the challenge. The problem is, they are doing so against the tide of an uncertain and unstable policy environment, which is putting future progress at risk.

Developing healthier options

It's easy to imagine that making a product healthier is as simple as taking out a pinch of salt or a spoon of sugar. But when product shelf life, safety and consumer acceptance come into the picture, it gets far more complicated. Often their innovative, healthier products don't make it through the testing process to sale and, if they do, don't stay on supermarket shelves, simply because not enough customers buy them.

Approaching the nation's health by

expecting consumers to forgo a usual treat isn't realistic, and we know that if we push healthier product innovation too far, consumers simply won't buy it. It's a careful balance for brands to achieve, but worth doing so. Findings from the research and innovation foundation, Nesta, shows that if people make consistent, small healthier swaps, this can reduce calorie consumption by 8.5 per cent and halve obesity in the UK in five years. That's why so much work has gone into making changes to recipes, as well as developing new, healthier – but still tasty – alternatives. These simple swaps provide a small change to the diet that can add up to a big difference to health over time.

For example, following three years of testing, Mr Kipling launched the first full cake range compliant with government high fat, salt and sugar regulations – with 30 per cent less sugar and up to ten times more fibre. Similarly, through significant investment and testing, McVitie's was able to launch the classic Rich Tea biscuit with 30 per cent less sugar. And in soft drinks, two-thirds of Coca-Cola's sales now come from zero- or lower-sugar products, where sugar has fallen by 43 per cent since 2015.



ADOBE

Food and drink businesses are investing to meet guidelines on healthy diets

Moving the goalposts

Food and drink businesses want to go further. But committing investment to these high-risk projects gets harder and harder against a backdrop of regularly changing policy.

Much of the work into supporting healthier diets pre-dated government policy, with manufacturers also investing in healthier product development in response to consumer preferences, their own health commitments and retailer expectations. But 50 per cent have said that they have also increased innovation in response to regulation, including restrictions on the advertising and promotion of products high in fat, salt and sugar.

Despite the latest wave of these regulations only coming in in January, the Department of Health is now looking at changing the Nutrient Profiling Model – the definition of 'healthier food' underpinning the regulations – making the criteria far stricter.

Updating regulation as science develops is reasonable. But policy also needs to be practical and recognise the real-world consequences of changing the benchmark that businesses have spent many years and millions of pounds working towards.

If the benchmark keeps changing, the certainty and stability that businesses need in order to keep committing investment to healthier product innovation is jeopardised. It can take years for a new product to end up on the shelf. So how can businesses commit to those projects now, if they don't know if they'll be able to promote the healthier product to consumers in even a year's time, or if the criteria might change again?

The prize is in partnership

There's no doubt that food and drink businesses have shown commitment and willingness to support healthier diets, and they have no plans to stop. But government must work with, and not against, us to help us get there.

When food and drink businesses are up against rising production costs across the board – from energy, to ingredients, to labour and packaging – investment decisions come with weight. Regulatory stability of at least five years would give businesses confidence to continue investing in healthier product innovation. This timeframe would also allow for proper evaluation of whether an intervention on healthy eating is working, before shifting focus.

Some FDF members have already committed to voluntarily reporting on their healthier food sales to provide valuable data in order to help inform future health policy.

Overall, the prize will be found in partnership: government setting ambitious and consistent objectives, industry investing and innovating to reach them, and consumers being given more healthier choices that are affordable and, crucially, that they actually want to eat.

We're all working towards a shared goal to support the nation's health, so rather than undermining good-faith investments by businesses, government can work with us to make real-world progress. ●

Amy Glass is head of UK diet and health policy at the Food and Drink Federation

The case for continuous care

Mental health reforms promise care closer to home. Success depends on services built around individual needs, not just symptoms

By Phin Foster

When Jen Craft told a mental health professional that the pressures of her job were affecting her well-being, the response was an offer to write a letter recommending time off work.

For the Labour MP for Thurrock, who lives with bipolar disorder and OCD, the suggestion missed something fundamental: yes, her work is a source of stress, but it is also a vital part of what helps her stay well.

"She didn't ask, 'What does my job mean to me? What do I get out of it? Where's the purpose that I derive from it?'" Craft recalled during a *New Statesman* panel discussion at the Labour Party Conference. "It misses a huge part of seeing a person as an individual."

This reflects a wider challenge facing mental health services: how to support people with long-term conditions without reducing their needs to symptoms or episodes of illness. Family, work, housing and a sense of purpose can all be central to recovery, yet services do not always account for them.

The government's Ten Year Health Plan promises a shift from hospital-based treatment towards prevention and care closer to home. Delivery requires putting people's individual needs and circumstances at the heart of care.

The stakes are considerable. NHS figures show adults with severe mental health problems are nearly five times as likely to die before the age of 75 as those without. Cancer, cardiovascular disease, liver disease and respiratory illness account for more than half of deaths among those affected, underlining the importance of addressing physical health alongside psychiatric treatment.

For Craft, who sits on the Commons Health and Social Care Committee, one of the most serious shortcomings is the lack of support between episodes of illness. The committee's inquiry into community mental health services heard from people who had been discharged once their condition stabilised, only to find themselves without help when they began struggling again.

"There are not really the mechanisms in place for when you start to recognise that your mental health is taking a dip," she said. Instead, people find themselves waiting until they reach crisis point.

Josh Fenton-Glynn, Labour MP for Calder Valley and another committee member, argued that the NHS must

better recognise the long-term nature of severe mental illness. Parity between mental and physical healthcare should not mean treating them identically. "It's not a broken leg," he said.

Witnesses described patients who had established relationships with professionals, only to lose that continuity when services changed. Their mental health subsequently deteriorated. For people experiencing mental illness, Fenton-Glynn noted, completing forms or repeatedly chasing services can itself be a considerable challenge.

"Once you get hold of these people, you have to keep with them and you have to keep holding on to them," he said.

The government's neighbourhood health agenda offers an opportunity to address some of these weaknesses. Building on six pilot sites, ministers have announced plans for 100 new community mental health centres, alongside 59 dedicated mental health emergency departments, backed by £343m, providing earlier support closer to home and reducing numbers reaching crisis point. Craft believes such centres could make a difference, provided they are accessible, welcoming and designed around the people who use them.

"We need one in every community," she said, emphasising the importance of locating services where people can realistically reach them.

But the gap between promising models of care and what is routinely available remains substantial.

Jeremy Bernhaut, director of policy and practice at Rethink Mental Illness, recalled visiting an impressive community mental health service in east London. When he described it to clinicians working elsewhere, their response was markedly different.

"They looked at me like I was crazy," he said. "They said, 'A, we don't have one, and B, we're currently trying to deliver services that are hugely under-resourced'."

The clinicians' frustration pointed to a fundamental difficulty with reform: effective approaches may already exist, but access depends heavily on where someone lives and what local services can provide. "We know a lot of things that work for people that we simply cannot deliver to them," Bernhaut recalled being told.

Quality of care also depends on what happens outside clinical settings. Housing, social care and community



People can struggle to find support from the system between episodes of illness

JUN HUANG/SHUTTERSTOCK

connections can determine whether people maintain their independence or become increasingly isolated.

Fenton-Glynn warned that moving someone away from familiar surroundings can sever relationships on which they rely: "If you lose community, then you lose your mental health support network with it."

Sojan Joseph, Labour MP for Ashford and a former NHS mental health nurse, has seen the consequences of services being unable to meet local needs. During his 22 years of working in mental health, patients from Kent were sometimes admitted to hospitals hundreds of miles away because beds were unavailable closer to home.

"Mental health is not just the NHS's responsibility," he said. "We can't over-medicalise mental health. Schools, charities, organisations, religious institutions all have a crucial role to play."

Joseph argued that prevention and early intervention should be priorities in the government's forthcoming Mental Health Strategy for England, intended to coordinate action across departments and public services.

For Bernhaut, the strategy also offers an opportunity to address fragmentation that leaves people moving between organisations with different responsibilities and priorities. But he warned that it would achieve little without the resources and staff to implement it. "It needs to be funded. It needs to have the workforce planning behind it in order to be able to deliver for people and communities," he said.

That delivery challenge runs through the wider reform agenda. New neighbourhood centres may improve access, but their success will depend on whether patients can build lasting relationships with professionals, whether services work together and whether help is available before a crisis develops.

Effective local initiatives must also become the norm, rather than exceptions available only to people who happen to live nearby.

For Craft, the measure of success is ultimately what services enable people to do with their lives, rather than simply how effectively they manage an illness.

"What is important to that person and to their family? What is the sort of care package that they need to receive to enable them to continue to do the things that they love for as long as possible?"

The challenge for reform is to make that kind of personalised, continuous support an ordinary part of care, rather than something people have to reach a crisis in order to receive.

Breathing new life into lung health

We must take action to address the inequalities in respiratory disease

Where you live in Britain influences both your risk of developing lung disease as well as your survival chances. Pulmonary fibrosis is a telling example of this inequality – people living in the most deprived communities die from this progressive, terminal lung disease at rates over a third higher than those in the least deprived areas.[1]

The Prime Minister has pledged to improve outcomes for everyone in every postcode. Pulmonary fibrosis highlights the disparity that this commitment needs to address.

Respiratory mortality rates are two to three times higher in the most deprived parts of England than in the least deprived. Someone from Blackpool is almost three times more likely to die from respiratory disease than someone from Kensington and Chelsea.[2,3]

Idiopathic pulmonary fibrosis (IPF) is one of the most common and severe forms of lung fibrosis; "idiopathic" means "no known cause".

Sadly, as many as 60 per cent of people with IPF will die within five years of diagnosis, an outcome worse than many common cancers.[4,5]

Diagnoses have been rising for 20 years. Despite this increased identification and an improved understanding of the disease burden, pulmonary fibrosis remains relatively overlooked compared with other disease areas.[6,7]

Pulmonary fibrosis is a condition in which the lungs become scarred, making breathing increasingly difficult and reducing their ability to transfer oxygen into the body.

People with the condition may experience breathlessness, a persistent dry cough and fatigue.

There are many challenges for patients accessing care for pulmonary fibrosis. One in three waits more than a year for a confirmed diagnosis.

One in five needs to see a healthcare professional at least five times before receiving a specialist referral.[7] There are also wide inequalities in access to care, with waiting times for specialist centres ranging from under five weeks to 33 weeks.[8]

These challenges have a direct and very real impact on patients' lives. While people wait to see a specialist, the scarring in their lungs continues to

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worsen. Any lung function they lose cannot be recovered.

The experience and course of the disease vary considerably between patients, but the physical and emotional burden cannot be underestimated.

The Pulmonary Fibrosis Trust kindly shared quotes taken from a recent survey of its members for this article. "The fear of suffocation is constant," one patient said. Another cited "unpredictability, fatigue and physical decline". A third patient described being essentially housebound and less able to do their daily activities.

As the Action for Pulmonary Fibrosis *State of the Nation Report 2026* made clear: "Even though up to 150,000 people in the UK are currently living with this devastating illness, there are no dedicated programmes in place to ensure fast and accurate diagnosis, nor equitable access to treatments and supportive care."

Why it's time to act

The government's 10 Year Health Plan sets out an ambition to reduce health inequalities, act earlier and deliver consistent care for long-term conditions.

Pulmonary fibrosis is a test of whether those commitments can be delivered in practice. Without reform in how services are planned and delivered, earlier diagnosis will simply surface greater unmet need in a system already under pressure.

A flagship commitment from the government is to deliver a series of modern service frameworks (MSFs) that will translate clinical evidence into consistent NHS practice. Through the Taskforce for Lung Health, patients, carers, clinicians, professional and voluntary organisations, among others, all support the need for a respiratory MSF.[9]

The government is currently deciding which conditions will be covered; respiratory disease is not yet among them. It should be – and it should cover all aspects of respiratory care, including pulmonary fibrosis.

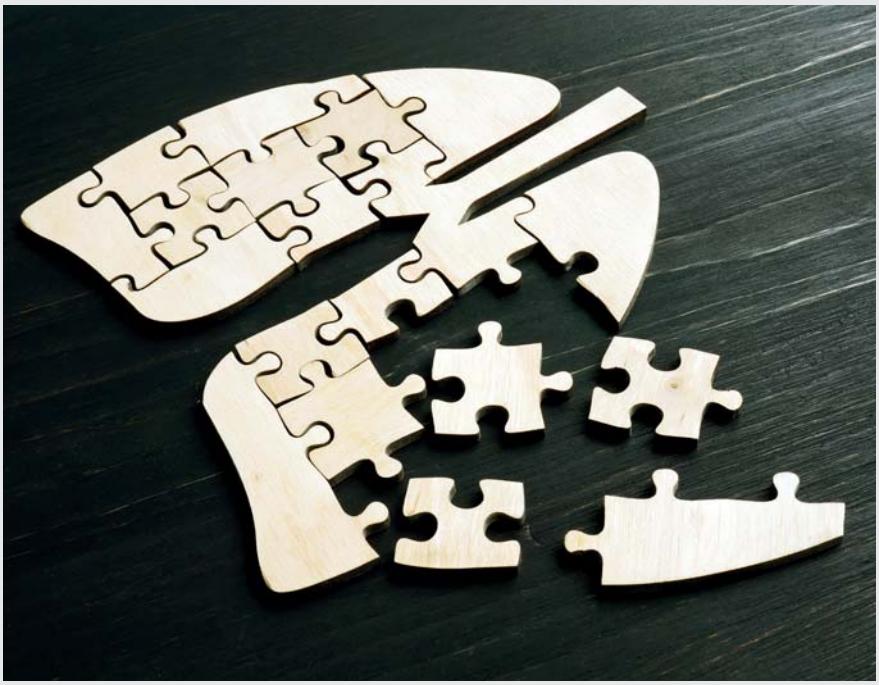
As we head into winter, the pressure on NHS services from respiratory diseases becomes more acute. People living with pulmonary fibrosis may be fearful of picking up infections that could severely exacerbate their condition. Mortality from pulmonary fibrosis is greater compared with other times of year.[10]

Now is the time to take action to address the inequalities that have persisted in respiratory health. ●

This article was written by Boehringer Ingelheim. We are a pharmaceutical company with 100 years of heritage in respiratory disease, having developed several treatments in a range of respiratory conditions including asthma, chronic obstructive pulmonary disease (COPD), pulmonary fibrosis and lung cancer.

Our focus is on improving the quality of life of patients who have debilitating respiratory diseases and enabling them to maintain a more independent life. For more information, visit https://www.boehringer-ingelheim.com/uk/human-health/lung-diseases

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VITALII VODOLAZSKY/SHUTTERSTOCK

Puzzle to solve: pulmonary fibrosis is a test of the 10 Year Health Plan's ambitions

NP-GB-108091, October 2026

The future of health could be just around the corner

In our towns and cities, the street a child grows up on determines how healthy they will be — from the air they breathe, to the food they have access to and the quality of their home.

At Impact on Urban Health, we work to make urban areas places that support health, not limit opportunities.



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