The Richmond Group of Charities



A manifesto for people with multiple health conditions

The Richmond Group of Charities

October 2023

One in four of us are now living with at least two health conditions

The Health Foundation (2018). Understanding the health care needs of people with multiple health conditions.

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# Introducing our manifesto

"There are two doctors who I have seen more than others but, on the whole, I see someone different every time. You get cycled in and out. It means every time I go in, I have to tell the same story."

Keith, 57, Northumberland

After the cost of living, the perilous state of our health system is the public's highest-ranking concern.¹ There are now greater than ever levels of unmet need manifesting across primary and community care, social care, and mental health services. One in four of us are now living with at least two health conditions.² And the gap in healthy life expectancy is growing - people living in the most deprived areas are developing poor health 10-15 years earlier than others.³

The status quo is no longer a viable option, but nor should it be. As the nation's health and the trajectory of illness change over time, our health and care system must also adapt, finding new ways to better serve us and make the best use of taxpayers' money. We should redesign health services with the expectation of multimorbidity.<sup>4</sup>

There will always be the temptation to just focus on the most acute problem and the most acute people. But in our view, this will not help move the NHS out of a state of permacrisis. When the need for care outstrips the ability to provide it, focusing only on the hyperacute and rolling back any prevention, rehabilitation, therapy or ongoing support will only lead to more acuity, more crises and more demand.

- People with long-term health conditions account for around 70% of all health and care spending, half
  of GP appointments, and two thirds of outpatient appointments and hospital bed days.<sup>5</sup>
- 2018 analysis predicted multiple conditions care would increase hospital activity by 14% and costs by £4 billion over just five years.<sup>6</sup>
- The number of people living with major illness is projected to increase by 37% over a third by 2040.7
- Over 2.5 million people report that they don't work because of illness, with mental ill health and musculoskeletal conditions cited as the most common reasons.<sup>8</sup>

### 1. Introducing our manifesto

The Richmond Group of Charities represents more than 15 million people living with long-term health conditions, and this section of the population is growing as the population ages. We think getting it right for people with multiple health conditions holds the key to a stronger NHS.

As a result of our conversations with people living with multiple conditions, we are convinced that improving care for this large and growing section of the population can improve the system for everyone. Most people visiting A&E this winter will be known to health services and will likely have more than one long-term condition. It makes sense to design care to more proactively meet their needs. It also aligns well with current policy direction - bringing care closer to home, getting upstream and supporting people to manage their health - as set out in the NHS Long Term Plan, the integration white paper, and more recently, the Fuller Stocktake and Hewitt Review.

Centring what creates health and helps people live well will ultimately reduce avoidable demand on services.

That's why we're calling on the government and national system leaders to:

- Support people with multiple health conditions to live well.
- Drive the redesign of multiple health condition care.
- Promote health in all policies.

Our manifesto is a practical case for change. We'll demonstrate why the current system is unsustainable for people with multiple conditions and our NHS, what a system that works well could look like, and what steps are required to get there. We've also included a few real-life examples of where care has been redesigned with people in mind.

# Patients, but also people: whole person care



"The doctors can only get so much time with one patient... but they still could have given me other routes, or advise me on some things more... I would have liked more support. I was young and suffering."

Kumar, 40, Birmingham

In the research we undertook for our <u>Taskforce</u> on <u>Multiple Conditions</u>, <sup>13</sup> people told us what they valued in their care - careful coordination, shared decision making, prioritisation and a longer-term perspective. This goes to the heart of what often doesn't work well in health and care, with services still characterised by siloed ways of working, a focus on acuity and a lack of forward planning.

Too often, care is designed in ways that undermine good outcomes for people with multiple health conditions – organised into body parts, fragmented pathways and focusing on crisis rather than on helping people to live well.

But this is also why getting it right for people with multiple health conditions unlocks a different way of providing health and care for everyone: one that's more health creating, personalised and outcomes focused.

### NHS productivity: what generates value for people?

We often hear political leaders demanding greater productivity from the NHS to justify ongoing investment. Productivity in the NHS cannot just be measured by how many procedures a nurse or doctor performs in a day. It needs to fully take account of how much health and wellbeing is created by what the NHS does. We believe that many services could be much more *productive* if they focused more clearly on what generates value for people: a better understanding of what they can do to support themselves, a clear sense of who oversees their care, a plan for what to do when things get worse – these are the outcomes of productive care.

### 2. Patients, but also people: whole service care



### "None of us want to provide ineffective care" Managing multiple conditions in Gateshead

We spoke to Dr Becky Haines, a GP Partner in Gateshead. For the last 8 years, she has worked in partnership with Year of Care, an NHS-affiliated training and support organisation helping clinical teams move towards a holistic, forward-thinking approach to long-term condition care.

All people with one or more long-term conditions in her surgery benefit from three steps:

- The healthcare assistant gathers detailed information about the patient's health status.
- 2. They share this information with the patient, allowing them time to consider what is important to them and prepare for a conversation.
- 3. They have an extended 20-30 minute consultation, allowing the GP or nurse, and patient sufficient time to understand the whole picture and agree a care plan together.

This process replaces a host of other appointments and administrative tasks, and strengthens the relationship between GP and patient. Crucially, the process supports the person living with health conditions to prepare and engage with their own health and take ownership of what needs to follow.

Becky had a patient attend due to his diabetes, but he had scrawled all over the form 'My priority is my pain which no one is helping me with.'

"He was angry and upset. There would have been no point reviewing his diabetes in isolation. He needed to have his pain acknowledged and addressed for us to move onto considering what he and we could do about his diabetes. We need to move away from siloed care where we only look at one problem. This is just not how people live their lives, or how we can organise good medicine."

In her experience, it is particularly important to address mental health issues that can arise alongside physical health challenges, and to give staff the confidence and tools to support patients who experience depression or anxiety.

"We offered training to all primary care staff in Gateshead to work across all main conditions with confidence. This means our team works in ways that mirror how people live their lives.

People really like working in this way. It is more meaningful. None of us want to provide ineffective care. We would never go back to the old way of working. It just doesn't make sense."

# The effort of being unwell: minimising treatment burden



"I deal with something health related every day, whether that's something small or big, or if it's just having to speak to a doctor or having a look at my diary or what not."

Bekele, 26, Birmingham

In our insight work to understand what it's like to live with multiple conditions, people told us time and again about 'the work of being a patient' or 'treatment burden.' Living with multiple conditions can make life difficult day to day, and will often be exacerbated by common symptoms like pain, fatigue and anxiety. And this is only made more challenging by the way the health system operates.

For example, applying single-disease National Institute for Health and Care Excellence (NICE) guidelines for an older person with five conditions (Type 2 diabetes, previous myocardial infarction, osteoarthritis, COPD and depression) could result in a minimum of 11 medications (with up to 10 other drugs routinely recommended), 8–10 routine primary care appointments and 4–6 GP appointments, as well as multiple lifestyle modifications.<sup>14</sup>

It is not unusual for patients and unpaid caregivers to contribute substantially to the coordination of care, often at a personal cost to them. In their From One To Many report, 15 Impact on Urban Health spoke to Lynda 61, from South London, who lives with a range of conditions. She was prescribed 30 tablets per day. Looking back at her previous year, she said,

"There are 52 weeks, and I had 68 appointments. It just got to the point where it was easier to give up work."

Care coordination projects have tended to focus on designing disease-based clinical pathways – for example, for diabetes or arthritis – rather than taking

a more holistic approach from the perspective of the patient with multiple conditions. The lack of coordination for these patients can be particularly damaging, given the added complexity of their conditions, medications, interactions and sometimes conflicting treatment pathways. Although the 2016 NICE guideline on multimorbidity<sup>16</sup> advises professionals to take account of the interactions between conditions and treatments, clinical practice remains very siloed.

GPs are often a key coordinator of healthcare, but there are also many others that play this coordinating or linking role, as people with complex needs often require input from a wider range of services, both within and beyond clinical settings. They could be another healthcare professional, a charity sector worker, a volunteer, peer or health coach. This is where multidisciplinary team (MDT) models aim to bring in a much wider network of support from social care, general practice, voluntary and community services and more.

However, it is possible for care to remain poorly coordinated even if services are co-located or brought within a single service framework. If clinical teams lack the time and resources to think through the practicalities of how to join up their work around patients with complex needs, plans will fail. Improving coordination is foremost about relationships between people, not structures. Patients and carers can otherwise face the challenge of 'co-ordinating the coordinators,' working within an additional tier of plans and processes, counter to the objective of reducing treatment burden and joining up care.

### 3. The effort of being unwell: minimising treatment burden



## "We take the pain out of care coordination" Team Around the Person approach in Sheffield

We spoke to Amy May, team manager for Sheffield's innovative Team Around the Person (TAP) approach, that's now been rolled out across the city.

"Professionals and individuals using services told us that the numerous specialisms supporting people had created a myriad of complex pathways with multiple eligibility criteria, leading to a disjointed care model. Individuals felt this built unnecessary stress and a need to repeat 'their story'. They expressed feeling 'passed around from one service to the next' and/or falling through gaps in provision. At the same time, nurses and other professionals reported feeling isolated and overwhelmed in supporting those with complex needs."

TAP was created from codesigned sessions with individuals with lived experience and colleagues from Adult Social Care, Housing, and Communities departments, NHS partners (GPs, District Nurses, therapists, midwives, Ambulance services), and Police, Fire and community organisations and charities.

"TAP fosters partnerships working to support individuals with multiple escalating needs. Our vision is to place the individual at the centre of their care and support, ensuring their voice is heard and helping them to coordinate the outcomes they want to achieve. It is important to us that they receive the right care at the right time. TAP focuses all the services involved with an individual on the person and their needs, bringing everyone together to work on uncovering the root cause of issues, removing duplication in services, and supporting the redesign of the health and social care system."

TAP delivers the quadruple aim of enhancing patient experience, improving population health, reducing costs and offering peer support to our front-line workers. Developing a network within the city means that services are coordinated, providing clear communication channels to deliver outcomes of benefit for the individual. Not only has this increased safety by reducing risk, but it has also led to safer, more holistic practices in the workforce.

The service does not focus on cohorts e.g., homelessness, substance misuse, or diabetes. Its eligibility criteria is based on two or more services, which means they support cases across the health and care system. Since Covid-19, TAP has seen an increase in working-aged men, often living with health conditions, including mental illness or substance misuse.

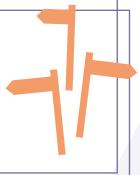
98% of caseloads are individuals with two or more long-term health conditions, and 67% of people supported are from the most deprived postcodes.

"This model delivers clear benefits for services, with improved integration, peer support for front-line workers, and improved individual outcomes. It has also produced fiscal savings of ~£1.1million per 250 cases with an estimated cost avoidance of £7.4 million. This has been across the system through reduced A&E attendances, ambulance call outs and hospital bed days, and savings in services such as community nursing being able to step back from care."



# Breaking the chain: changing the trajectory of multiple conditions

"We haven't asked the GP again to refer her to the female-only physio classes. I think I could give it a try, but I don't feel confident they will do it."



Rahmiya, Bradford

People don't tend to acquire multiple conditions in one fell swoop. Our health usually deteriorates over time, from being relatively healthy to acquiring a few conditions over the course of some years, with ageing as the biggest driver. Some conditions are clustered around shared factors such as metabolic, mental, or musculoskeletal health. There are many examples of two or more conditions leading directly to the acceleration, or increased severity, of one or more of these conditions. Clinics and clinicians must therefore better understand the diseases that cluster around individual specialisms when planning services and making treatment decisions.<sup>17</sup>

Taking a long-term, life-course perspective may seem too difficult for healthcare staff who are barely able to see everyone for ten minutes once or twice a year. But it creates opportunities for interventions that pay off for a long time, continuously generating value for the person and the provider. For example, maintaining someone's mobility for longer will not only keep them better connected or able to work, but may also slow down their arthritis, COPD or diabetes for many years. It also benefits later life resilience, improving our chance of remaining active as we get older and reducing the risk of frailty.

Yet we persistently fail at making preventive intervention the norm, often because the organisation which has to find the resource to intervene (be that through a longer care planning conversation, a set of visits with a social prescriber, or some therapeutic intervention) isn't the organisation which reaps any 'savings'. Savings of course often aren't strictly financial, but the benefits that arise from more appropriate and effective service utilisation.

Clearly, this is one of the main reasons Integrated Care Systems (ICSs) have been created, with their focus on pooling responsibility, risk and budgets for the good of everyone's health. But there is a risk that integration is framed as an issue of governance or organisational restructure, rather than needing to be focused on what will actually be different for people and communities.

In service design work, 'user personas' are often created to ensure that a particular care model or intervention works for the people they have in mind. We suggest that it makes eminent sense for ICSs to make multiple conditions a key service design lens, for example, by creating a user persona of 'an older person with multiple conditions' when designing integrated care for older people. Only if integration creates different real-life outcomes for those of us living with multiple conditions, at every life stage, can it be said to work.

### 4. Breaking the chain: changing the trajectory of multiple conditions

At every stage of the trajectory toward multiple conditions, there are opportunities to prevent complication and slow the progression of illness. This is of course a clinical responsibility, and the failure to equitably do so for the many people who are currently missing out on hypertension medicine<sup>18</sup> or good diabetes care<sup>19</sup> is creating excessive morbidity and mortality at levels that are inexcusable. But it is also a responsibility that goes beyond prescribing medicines (and many people we speak to as part of our work are unhappy about medicine that is 'just about the pills'). Helping people cope, by supporting their mobility, their social connectedness and their mental health requires holistic perspectives and the joining up of clinical services with community and social support.

This is why we are disappointed that even the modest proposal contained in the <a href="Hewitt Review">Hewitt Review</a> to move at least 1% of NHS spend into prevention hasn't been endorsed by government. We strongly hold that the desired positive impact of 'integration' will only materialise if reflected in a shift towards more preventative and person-centred approaches at every life stage.

Moving to prevention for everyone can feel too scattergun, and that any benefits remain largely speculative. Focusing on people who are already on a trajectory towards living with multiple long-term conditions and frailty, often through ageing, is the obvious thing to do – for the NHS and social care. But if we don't focus on service design, on what will be different for a person with diabetes, arthritis and depression (or all three), we risk wasting all the energy that was and is expended on setting up ICSs. Frankly, if ICSs do not achieve a shift to preventative interventions, rather than remaining stuck in a vicious cycle of crisis management, they will have failed.

#### Future care model: slowing the trajectory of multiple conditions Health equity Current care model Future care model Primary prevention opportunities missed Strengthened primary prevention Relative good health Failure to consider health in all policies Relative good Adopt a health in all policies approach Routine screening, early diagnosis and integrated referral pathways Secondary prevention opportunities One or more conditions (minimal impact) Support for people to self-manage their conditions Lack of support for self management **BRAKES** Personalised care and support planning, annual holistic review Lack of holistic support, separate Healthy living standards for all. Focus on wellbeing, mental Multiple conditions (moderate impact) Care is coordinated with attention to symptom & treatment burden **Multiple conditions** health, care transitions, social Transactional body-part medicine connections, diet & nutrition, mobility & physical activity Lack of advance care planning, social care and carer's support Enhanced care models and anticipatory care Complexity/Frailty (high impact) Multidisciplinary teams and social support, including carers Complexity/Frailty Crisis based, frequently unplanned use Personalisation, outreach and service flexibility are required to support people who are disadvantaged and to prevent or minimise health inequalities. Health equity

**ACCELERATORS** 

Poverty, loneliness, low (health) literacy.

unemployment, exclusion, change in disease or social context, treatment burden.

### 4. Breaking the chain: changing the trajectory of multiple conditions



## **Every move enables more: physical activity for prevention and self-management**

Physical inactivity is the fourth biggest cause of disability and ill health in the UK<sup>20</sup> and substantially more people with long-term conditions are physically inactive (41%), compared to the general population (21%).<sup>21</sup> Yet, physical activity has a major role to play in the prevention, treatment and management of long-term conditions. **Described by the Academy of Medical Royal Colleges as 'the miracle cure,' it can help manage more than 20 common health conditions, 40% of which could be prevented altogether by reducing inactivity.<sup>22</sup> It can also help people to preserve function and maintain mobility.** 

The Richmond Group of Charities has set up a collaborative programme, in partnership with Sport England, aiming to support people with multiple conditions to become and remain active.

We provide practical support and resources for people through our impactful social marketing campaign, We Are Undefeatable.<sup>23</sup> The freely available campaign resources can be embedded into health plans and professional practice to help people become active in ways that work for them. Evaluation evidence shows that the campaign is making a difference - 50% of people who could recall the campaign said they took action as a result of it.

We believe reducing physical inactivity should be a key priority for improving population health, and that the health and care workforce should be encouraged to see, and use, physical activity as a valuable health intervention.



# Working together: supporting people to live well



"They [The Complex Care at Home team] are always there in the background to help. For people like me, that is so important."

Dave, Gloucestershire

No matter how many appointments a person has with their health and care team, most of the time a long-term condition is managed by the individual, often alongside family members or unpaid carers, so supporting people to manage their own health is essential.

Equipping people with the skills, knowledge and confidence to live well with their conditions, in ways that are meaningful to them, improves both their experience of care and health outcomes and reduces demand for health and care services. Research shows that patients who feel most confident in managing their long-term conditions have 38% fewer emergency admissions and 32% fewer A&E attendances than those who feel least confident.<sup>24</sup>

In our <u>first report on multiple long-term conditions</u>, <sup>25</sup> we suggested a shift to understand what creates value – from the details of diagnosis to the bigger picture of impact. Naturally, this doesn't imply that diagnosis and good clinical care are unimportant. But it suggests that focusing interventions on the following common impacts of multimorbidity will realise the greatest value.

### They are:

- Loss of mobility
- Loss of social connection
- Loss of mental wellbeing
- Ineffective relationships with health care providers

It is obvious that these impacts are related. Losing the ability to move easily and leave the house can make you lonely, which in turn can make you depressed or anxious. Deteriorating health, high treatment burden, lack of trust or low health literacy all put a strain on the relationship you might have with your health care provider. We propose that these four impacts can help shape good services, add value to conversations about chronic conditions management, and can be held in mind by clinicians as prompts towards more meaningful conversations:

- What can we do to help you stay or become more mobile and active?
- What can we do to help you keep or regain social connections?
- What can we do to help you remain hopeful and feeling in control?
- What can we do to make it better for you to use our service, to feel that you can trust us, and that we are on the same team?

### 5. Working together: supporting people to live well

We need to support people to build the skills and confidence to better understand what they can do to improve their health and wellbeing. At the same time, clinicians need to create the space for different conversations, about the things that help – taking some medicines, sure, but also staying mobile, active and connected. Patients themselves will be best placed to set the agenda for these conversations, focusing on

what is most important to them. Tackling these issues in partnership will improve and sustain a person's ability to cope. Not entirely on their own (because we know people do better with support) but with planned input from services, and the help of others, in community.



### Living with multiple conditions as a carer: Marion's story

We spoke to Marion from Birmingham, who lives with a number of conditions that can interact in unhelpful ways. One of the conditions she has is rheumatoid arthritis, for which she is prescribed a 'biologic' – a drug that needs to be handled in very specific ways. Her trust has outsourced the management of this and one other medicine to two different private companies. Far too often, she is chasing a delivery, or running dangerously low; it is hard to communicate with the trust team or the private delivery company. Her care falls between the cracks.

Her medications are prescribed by two different teams working out of two different hospitals and her GP, and in her experience the information doesn't flow between them very well. It would be easier if she could do the blood test at her GP surgery, a short distance from her home. But in the past, when she had tests done at her surgery, her hospital trust claimed not to receive the results, and they stopped the prescription for her drug. This in turn meant that she ran out of medicines, which impacted her health very badly. So at least every three months, she travels on two different buses to get to the hospital, which takes half a day of her life, for a simple blood test.

"I have to take paper print outs of results to my hospital doctor, otherwise she doesn't know what is going on with me."

Marion has severe pain and mobility issues and, like many other people living with ill health, also has caring responsibilities. Her daughter became severely anorexic as a teenager and spent some time as an inpatient, followed by a period of needing very intensive support at home, including being pushed around in a wheelchair. Marion says doing this while living with her own health limitations was the hardest thing.

"Neither my own MSK team nor the team in charge of my daughter took any account of how both my needs and hers needed to be considered. I had no support."

Marion's life can feel dominated by medical appointments and the administration and coordination they involve: tests, appointments, prescriptions, physiotherapy and requesting actions from different teams.

"I just wish everybody in charge of my treatments could share information with each other and make sure my tests and drugs are delivered without me having to chase every single thing."

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# 6 Mind, body, whole: The interface between mental and physical health

"I have fought all my life to be independent. But when the pain started, I couldn't. It felt in that dark period like I'd never be independent again."



Wendy, 44, Wirral

Listening to people speak about their health and illness, you realise that they don't draw firm boundaries between their mental or physical health. Pain from arthritis is often experienced as a severe mental strain. Anxiety is often felt as a profound physical experience. People living with severe mental illness are likely to die 15-20 years earlier than the general population, mostly due to preventable physical health illnesses. Yet in the health system, mental and physical healthcare is provided by different people, in different organisations, funded by different budgets.

This is particularly problematic for people living with multiple conditions. Chronic health conditions substantially increase your risk of mental ill health. Research evidence consistently demonstrates that people with long-term conditions are two to three times more likely to experience mental health problems than the general population. Overall, evidence suggests that at least 30% of all people with a long-term condition also have a mental health problem. This is a conservative estimate given the high prevalence of mental health problems in the general population.<sup>27</sup> In order to help people adapt to the life-changing consequences of physical health conditions, peer and community support should be built into all long-term condition pathways.

And the opposite is also true: mental health problems complicate your physical health and your ability to self-manage or to engage with health services. The King's Fund has estimated that by interacting with and exacerbating physical illness, co-morbid mental health problems – anxiety and depression being the most common - raise total health care costs by at least 45% for each person, and that this is highest in areas of deprivation.<sup>28</sup>

Supporting people with mental ill health to access high quality help to improve their physical wellbeing and to prevent, treat and manage physical health problems is as important as supporting people with ongoing physical health problems to look after their mental health, for example through peer support. Even a professional acknowledgement that living with the burden of ill health creates mental strains and anxiety can be helpful and can strengthen people's ability to cope.<sup>29</sup> It can also be useful to have mental health staff on teams that look after people with chronic ill health, strengthening holistic care.<sup>30</sup>

### 6. Mind, body, whole: the interface between mental and physical health



## The voluntary sector as a system leader: Somerset Open Mental Health<sup>31</sup>

The voluntary sector has a key role to play in getting it right for people with multiple long-term conditions. We come together around health conditions, but also places, helping to create and support communities.

In Somerset, Rethink Mental Illness works collectively with other voluntary sector organisations, housing providers, social care, and the NHS to ensure that residents get the support they need, when they need it. By suspending their individual interests and working together, the alliance provides truly community centred, seamless support, ensuring there is 'no wrong door' for anyone who needs help. Instead, an individual or professional can contact one of four Open Mental Health Locality Hubs across Somerset for an assessment, with support available from holistic recovery and wellbeing workers, peers and a range of specialists.

Between April 2019 and December 2022, local data indicates that there was a 15% decrease in emergency department mental health presentations for adults and 24% for older adults. Across all ages there was a 30% reduction in admissions for a mental health need.

This example is typical of the way charities work, adopting a holistic model of health and wellbeing reflective of people's daily experiences of long-term conditions. Recognising that physical and mental health are connected, charities can complement the more clinically focussed care provided by statutory partners. Voluntary sector services, such as peer support, money advice, emotional support and care navigation, bridge the gap between the physical, psychological, social and practical challenges of ill health. Richmond Group members organisations - and our sector as a whole - can play a leading role in shaping systems and how they respond to people with complex needs.



# Drivers of deterioration: Closing the gap in healthy life expectancy



"The thing that has been stressing me lately is my benefits. I have a review of my benefits soon because I want to get paid for my work at the café. You are allowed to get paid for a bit of work without losing your benefit, but they need to review it."

Megan, 42, Lambeth

Only some health outcomes are connected to the availability and quality of health services – most of our health is created or undermined by wider factors impacting how we live our lives. These are often called the social, environmental and commercial determinants of health.

Having multiple long-term conditions is both a driver and an outcome of huge health inequalities between us all, which influence our years spent in ill health. As a result, women living in wealthier communities can expect around 72 years of healthy life compared to 47 years for women in the poorest communities.<sup>32</sup> As the Joseph Rowntree Foundation says, "having 25 years of good quality of life snatched away from so many constitutes a societal failure."<sup>33</sup>

There are factors that drive forward a trajectory of deterioration, making it harder for people themselves to stay in control, and harder for services to be effective.

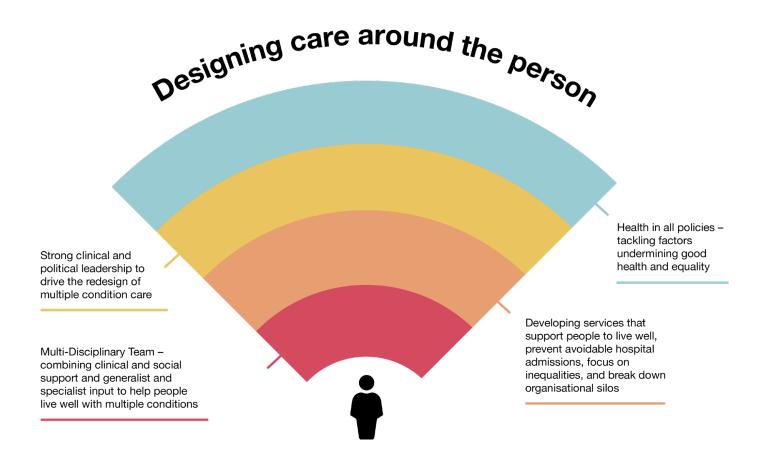
Poverty is a clear driver, moving the trajectory from relative health to profound ill health – and vice versa.

Other dimensions of exclusion work in the same way: marginalisation, racism, stigma – all can make it harder for people to cope, and harder for them to reach services, particularly those aimed at prevention.

All these questions have clear inequality implications, with lack of transport, or bad housing, for example, exacerbating issues around mobility or mental health. Identifying people living with multiple conditions is therefore a pragmatic lens for systems to look at intersecting social structures that are perpetuating this unjust health gap.

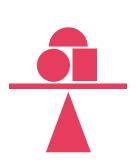
Many of the causes of inequality lie outside of the health system (including lack of clean air, poor housing, insecure work) and therefore require cross-governmental action. But health and care services have a responsibility to respond meaningfully to the inequalities people live with, which in turn impact their ability to engage with services.

### 7. Drivers of deterioration: closing the gap in healthy life expectancy





# Recommendations for government and national system leaders



"The benefits have not only been experienced by patients and carers, but also GPs like myself who are now more able to use their time to care for the most complex long-term healthcare needs – helping to manage workloads."

Dr Steve Edgar, GP, South Somerset

Much of the action to improve outcomes for people with multiple conditions will need to be taken at ICS level. Local systems know what drives unsustainable demand in their places. A significant proportion is generated by the lack of effective, timely, preventative support and anticipatory care for people living with multiple conditions, leading them to lurch from crisis to crisis, often in the context of lives that are impacted by inequality and disadvantage. But this does not mean that national leaders can sit back. Much of the dysfunction of services - its short-term perspective, its overreliance on acute and crisis care, and its blind spot where good community and partnership-based models should be - is driven by national policy decisions and priorities.

Local systems need the support and challenge of national system leaders to focus on this driver of poor outcomes and to build services that help people with multiple conditions to live full lives in their communities. The role of the national decision makers and system leaders in all this is not to pull some imaginary lever that will ripple through the whole complex system with impressive effects, but to set the direction of travel; to convene, curate and coordinate the efforts of others to

facilitate the re-design of multiple condition care. To secure the fundamental shift towards a system that better serves people with multiple health conditions, national decision makers and system leaders must take the following actions:

### 1. Support people with multiple health conditions to live well

This means understanding and addressing the ways that health conditions affect a person's everyday life, supporting people to manage their own health and care, live as well as they can, and thereby prevent or slow the progression of their health conditions.

Much of health is created and maintained outside of hospitals and acute care. However, community-based services – both clinical and non-clinical – which could prevent or slow the progression of chronic health conditions, are extremely patchy. Community rehabilitation provision has suffered from years of under-investment and workforce shortages, which has led to a postcode lottery of provision and many patients facing lengthy waits for appointments. For example, only 15% of people with lung disease eligible for pulmonary rehabilitation are referred for it,<sup>34</sup> and only one in five

### 8. Recommendations for government and national system leaders

services provide patients with rehabilitation on discharge after a hip fracture operation.<sup>35</sup> Support for people with long-term health conditions to stay in work is variable at best and at worst non-existent.

Many of the services and activities which help people with long-term health conditions to lead healthier lives, remain physically active or maintain social connectedness are provided by the voluntary and community sector. Yet these 'community assets' are plagued by a reliance on insecure funding contracts and short-term commissioning cycles. As the National Academy for Social Prescribing has identified, there is a pressing need for long-term investment to rebuild the depleted infrastructure of our communities. The continued underfunding of social care also greatly exacerbates the demand on health services.

### Recommendations

- Invest in community rehabilitation provision, including support for working age people with longterm health conditions to stay in, or return to, work. We support the Community Rehabilitation Alliance in calling for every ICS to have a single accountable rehabilitation lead to drive the expansion and transformation of services.<sup>37</sup>
- Ensure long-term funding for voluntary and community-based support that improves wellbeing, reduces social isolation and enables people

   particularly those from under-served communities and vulnerable groups - to lead healthier, more active lives.
- Set targets for reducing physical inactivity amongst people with long-term health conditions.

### 2. Drive the redesign of multiple condition care

This means articulating a clear direction of travel and ensuring that local systems have the tools, data, resources and the workforce they need to redesign care for people with multiple conditions so that it is joined-up and preventative.

At a national level, there is no strategy for people living with multiple conditions, nor any national leadership or programme dedicated to drive this step-change in approach. Some of the component parts of such a strategy can be found in NHS England programmes for ageing well, personalised care, prevention and health inequalities programmes, but there is nobody responsible for joining the dots.

At a local system level, patients are treated in disease silos. In fact, policy levers, such as the Quality and Outcomes Framework (QOF) in primary care, often incentivise or reinforce the fragmentation of care. Pockets of good, joined up care exist in some places, as our case studies illustrate, but these remain the exception rather than the norm.

### Recommendations

- Provide leadership and set direction: Improving multiple condition care must be a national priority for the NHS in England; it should be explicitly included in national strategies and planning guidance; and there should be senior NHS leadership – including clinical leadership – for multiple conditions to provide oversight and drive change.
- Set up a national improvement programme to support ICSs to transform multiple condition care, providing resources (funding, tools, communities of practice and change management support) to accelerate the spread of multidisciplinary and anticipatory models of care.
- Ensure that policy levers and incentives support the shift towards joined-up multiple condition care. This means greater use of patient-report outcomes and experience measures; reforming QOF and other incentives so that they encourage better care coordination and reduced treatment burden; and reviewing single condition guidelines to ensure they take account of co-morbidities.
- Equip the workforce with the skills and tools
  to deliver person-centred multiple condition care.
  Workforce training, development and competency
  frameworks should be reviewed to ensure clinicians
  have the skills to effectively manage multimorbidity,
  particularly in shared decision-making and
  interdisciplinary working.

### 8. Recommendations for government and national system leaders

### 3. Promote health in all policies

This means recognising that our health is created or harmed by factors outside the health and care system and making people's health and wellbeing the 'North Star' that guides national policymaking.

The government must recognise that its policies can inadvertently erode people's ability to lead healthier lives and, thereby, negate its own health ambitions. The Health Foundation also estimates that public health funding has been reduced by 21% since 2015/16. This has meant a 45% reduction in spend on smoking cessation services and tobacco control and 17% reduction in alcohol and drug services for adults.<sup>38</sup>

If we want to tackle the root causes of ill health or reduce the disparities in health outcomes, for which poverty is a key driver, we need to go further upstream and widen our scope beyond the NHS. We need a cross-departmental 'health in all policies' approach, including the retail, transport, welfare benefits and employment sectors. Only by cutting the prevalence and slowing the trajectory of long-term conditions, particularly for those who are otherwise set to develop ill health earlier in life, will the government be able to slow the rising demand on health and care services.

### Recommendations

- Establish a cabinet committee on health inequalities, focussing on the health impacts of all government decisions, aimed at closing the gap in healthy life expectancy.
- Go further faster on plans to reduce tobacco and alcohol dependency, problem gambling, obesity, the consumption of high salt, fat and sugar foods, air pollution and physical inactivity, taking on destructive commercial interests where they drive dysfunctional outcomes.
- Reverse cuts to public health which have most heavily impacted disadvantaged communities, and fully reinstate the public health grant to local authorities.

# 9 Conclusion

We are leading national charities, many of us focused on just one condition. We are at our best when we focus on the needs of the communities we support. But we have come together around the issue of multimorbidity because we recognise that most of the people we work with have more than one health problem. And that they need more holistic solutions than we can provide on our own. The NHS needs to do the same: a kidney or lung doctor knows best what people with a particular set of conditions need. But they can only provide good care when they also take into account what else is going on for the person in front of them, not least the fact that they are likely to live with other health conditions and the treatment and illness burdens this creates.

We need to build services around this reality and around these people. This manifesto sets out clearly how this requires decision makers at all levels to focus on the needs of people with multiple conditions, by aligning a whole number of purposeful steps into a coherent strategy.

The Richmond Group of Charities stands ready to help.



The Richmond Group is a coalition of 12 major health and care charities, working together to help people with long-term conditions live well and thrive. Together, we represent more than 15 million people, many living with multiple health conditions, who often face common challenges accessing the services and support they need.

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- ✓ RichmondGroup@macmillan.org.uk
- nichmondgroupofcharities.org.uk
- @RichmondGroupOC

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