



# The forgotten majority?

A new policy framework for improving outcomes for people with long-term conditions



FUTURE  
HEALTH

This independent report was commissioned and funded by AbbVie. Full editorial control rests with Future Health.

AbbVie job number: UK-ABBV-230425  
Date of preparation: December 2023



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## EXECUTIVE SUMMARY

The health needs of the population are changing as it ages. This research finds that 25 million people in England are estimated to have one long-term condition and 13.4 million people have two or more. People with long-term conditions account for 50% of GP appointments and 70% of hospital beds<sup>1</sup>. The number of people out of the labour market due to long-term sickness has increased sharply since 2019<sup>2</sup>.

The cost of long-term conditions and multiple long-term conditions is significant. According to the NHS a person with one condition has been estimated to cost £3000 per year, while for a person with two the figure is double and for three it rises to £8000. On this modelling the overall estimated cost of long-term conditions to health and care services is £115.2 billion<sup>3</sup>.

Health services, particularly in secondary care have traditionally been designed to deal with patients with a single disease. But for a growing number this is no longer a suitable model of care. Primary care has been at the vanguard of delivering more person centred and whole-person care. But many of the existing policy measures and incentives within it are outdated and aimed at managing single diseases.

Four of the five health systems with the highest estimated rates of people with multiple long-term conditions are in the South West (Cornwall and Isles of Scilly, Somerset, Dorset and Devon) with rates of 27% or more. By contrast health systems in London with younger populations have the lowest rates nationally.

Patients are receiving a mixed experience of care. Recent data from the Patients Association found that only a third of patients said their care had been well coordinated, with a third disagreeing. 40% felt they had been kept informed about what was happening to their care, a third did not. Two in three patients struggled to access at least one of the services they needed<sup>4</sup>.

The Government's Major Conditions Strategy presents an opportunity to address this<sup>5</sup>. However the Strategy comes at a time of immense challenge for the NHS in England. Funding is tight, backlogs of care are growing and the system is struggling to recover from the pandemic. There is understandable scepticism about whether the Strategy in these circumstances can deliver.

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- 1 NHS England. Making the case for the personalised approach. Available at: <https://www.england.nhs.uk/blog/making-the-case-for-the-personalised-approach/> [Last accessed October 2023]
  - 2 Office for National Statistics. Half a million more people are out of the labour force because of long-term sickness. Available at: <https://www.ons.gov.uk/employmentandlabourmarket/peoplenotinwork/economicinactivity/articles/halfamillionmorepeopleareoutofthelabourforcebecauseoflongtermsickness/2022-11-10> [Last accessed October 2023]
  - 3 NHS England. The NHS belongs to the people: a call to action. July 2013. Available at: <https://www.england.nhs.uk/wp-content/uploads/2013/07/nhs-belongs.pdf> [Last accessed November 2023]
  - 4 Patients Association. Survey of patients paints a mixed picture of experiences. March 2023. Available at: <https://www.patients-association.org.uk/blog/survey-of-patients-paints-a-mixed-picture-of-experiences> [Last accessed October 2023]
  - 5 Department for Health and Social Care. Major conditions strategy: case for change and our strategic framework. August 2023 Available at: <https://www.gov.uk/government/publications/major-conditions-strategy-case-for-change-and-our-strategic-framework/major-conditions-strategy-case-for-change-and-our-strategic-framework--2> [Last accessed October 2023]

To succeed, the Strategy will need to learn from previous approaches and be appreciative of the context in which it is landing. Our research shows a mixed picture of performance in efforts to improve care for people with long-term conditions over the last two decades through either primarily top-down or more dispersed and bottom-up approaches.

The new Strategy presents an opportunity to execute a more blended model, where Government sets the policy framework of funding, incentives and priorities and Integrated Care Boards (ICBs) working with primary care and other partners then tailor, adapt and deliver for patients locally.

However, the right policy framework will need to see the current outline of the Strategy – where six conditions are prioritised – evolve into a wider long-term and multiple conditions strategy, putting patients rather than specific conditions at the centre<sup>6</sup>. If the Major Conditions Strategy can genuinely put the patient at the centre and balance national and regional power then it could provide a platform for improved health outcomes.

This report sets out a series of recommendations for delivering this framework as well as new data on the rising challenge of long-term conditions and in particular multiple long-term conditions.

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6 Department for Health and Social Care. Major conditions strategy: case for change and our strategic framework. August 2023. Available at: <https://www.gov.uk/government/publications/major-conditions-strategy-case-for-change-and-our-strategic-framework/major-conditions-strategy-case-for-change-and-our-strategic-framework--2> [Last accessed October 2023]

## SUMMARY OF RECOMMENDATIONS

The Government should evolve the final Major Conditions Strategy into a long-term condition and multiple conditions strategy putting patients rather than specific conditions at the centre of the Strategy's design framework

The Department of Health and Social Care, NHS England and ICBs should use planned reforms for a Shared Outcomes Framework across public health, the NHS and social care to develop a set of outcome metrics that includes improvements in experience, outcomes and care for people with long-term conditions and multiple conditions

The Department of Health and Social Care and NHS England should reform the Quality and Outcomes Framework (QOF) and the Investment and Impact Fund (IIF) to improve the continuity of care for patients with long-term conditions and to better record and improve care for people with multiple conditions. Piloting financial incentives linked to improved patient experience for people with long-term conditions should be considered as part of future GP contract negotiations

The National Institute for Health Research (NIHR) should increase investment in research related to people with multiple long-term conditions. This should include a focus on engaging directly with patients on their preferences and experiences of services

The National Institute for Health and Care Excellence (NICE) should update existing guidelines for managing people with long-term conditions and multiple conditions and ensure new guidelines are digitised and easier to use to support adoption and uptake

NHS England should include an indicator within the NHS ICB Oversight Framework to track the implementation of the NHS Outpatient Transformation Programme. ICBs in their annual reports should provide an update on their progress in implementing the programme or explain their inability to do so

The Department of Health and Social Care and NHS England should publish a health literacy action plan as part of the Major Conditions Strategy. This should include plans to capitalise on the opportunities of increased health engagement through the NHS App

National accountability for the Major Conditions Strategy should be overseen at Minister of State level. ICBs should publish local plans with their Integrated Care Partnerships (ICPs) setting out how they plan to deliver the strategy

The Department of Health and Social Care should ensure that the implementation of the NHS Long Term Workforce Plan factors in the complexity of population health need when addressing regional workforce shortages so that areas with higher rates of people with multiple long-term conditions are assigned appropriate numbers of staff – particularly in primary and community care

The Department of Health and Social Care and NHS England should use the Major Conditions Strategy and the upcoming Sinker review to re-balance innovation funding more towards driving the adoption of proven innovations. NHS England's Adoption Fund should be expanded and used to deliver more co-ordinated care for patients with long-term conditions as part of work to implement the Major Conditions Strategy



**CHAPTER 1: THE RISE OF  
LONG-TERM CONDITIONS**

A long-term condition is a health problem that requires ongoing management over a period of years or decades and is one that cannot currently be cured but can be controlled with the use of medication and/or other therapies<sup>7</sup>.

Past estimates have found that 26 million people in the UK have a long-term condition such as diabetes, rheumatoid arthritis, migraine, visual impairment and psoriasis<sup>8</sup>.

The prevalence of long-term conditions increases with age and the number of people over 85 in the UK is set to rise by 1 million by 2035<sup>9</sup>. 58% of over 60s have a long-term condition compared with 14% of under 40s<sup>10</sup>. There is also higher prevalence in more deprived groups. People in the poorest social class have a 60% higher prevalence than those in the richest social class and 30% more severity of disease<sup>11</sup>.

The 2023 GP survey records 56% of the population of England with a long-term condition<sup>12</sup>. Regionally there are differences in the proportions of people with a long-term condition. Cornwall and Isles of Scilly ICB records the highest rate (63%). Ten other ICBs record rates of 60% or more.

By contrast the five London ICBs all record rates of below 50%. North West London ICB records the lowest rate of 46%.

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7 NHS Data Model and Dictionary. Long Term Physical Health Condition. Available at: [https://www.datadictionary.nhs.uk/nhs\\_business\\_definitions/long\\_term\\_physical\\_health\\_condition.html](https://www.datadictionary.nhs.uk/nhs_business_definitions/long_term_physical_health_condition.html) [Last accessed October 2023]

8 NHS England. Making the case for the personalised approach. Available at: <https://www.england.nhs.uk/blog/making-the-case-for-the-personalised-approach/> [Last accessed October 2023]

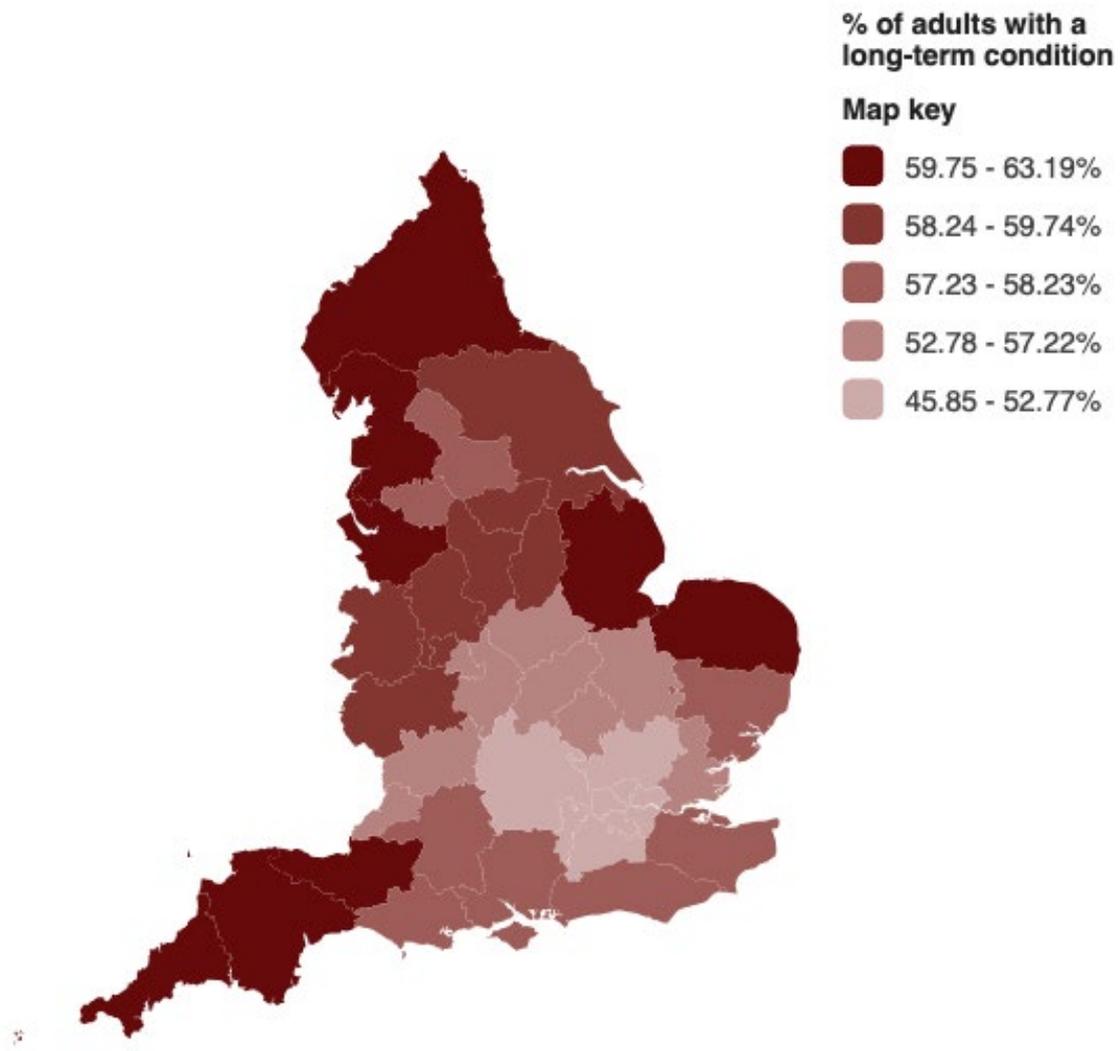
9 Office for National Statistics. Principle projection – UK population in age groups. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/datasets/tablea21principalprojectionukpopulationinagegroups> [Last accessed October 2023]

10 The Kings Fund. Long-term conditions and multi-morbidity. Available at: <https://www.kingsfund.org.uk/projects/time-think-differently/trends-disease-and-disability-long-term-conditions-multi-morbidity> [Last accessed October 2023]

11 The Kings Fund. Long-term conditions and multi-morbidity. Available at: <https://www.kingsfund.org.uk/projects/time-think-differently/trends-disease-and-disability-long-term-conditions-multi-morbidity> [Last accessed October 2023]

12 NHS. GP Patient Survey. January-April 2023 Available at: <https://www.gp-patient.co.uk/surveysandreports> [Last accessed October 2023]

Figure 1: Percentage of people with a long-term condition by ICB<sup>13</sup>



When these proportions are applied to adult ICB populations across England, it reveals that 25 million adults in England today have a long-term condition<sup>14</sup>.

Looking at specific conditions recorded through the survey, the most prevalent long-term conditions are arthritis, back or joint issues (18%). High blood pressure, mental health and asthma/COPD all have prevalence rates over 10%.

Seven conditions have prevalence rates of 2% or lower including autism, kidney/liver disease, learning disability, neurological conditions, Alzheimer’s/dementia, blindness/partial sight and stroke that impacts on people’s daily living. However,

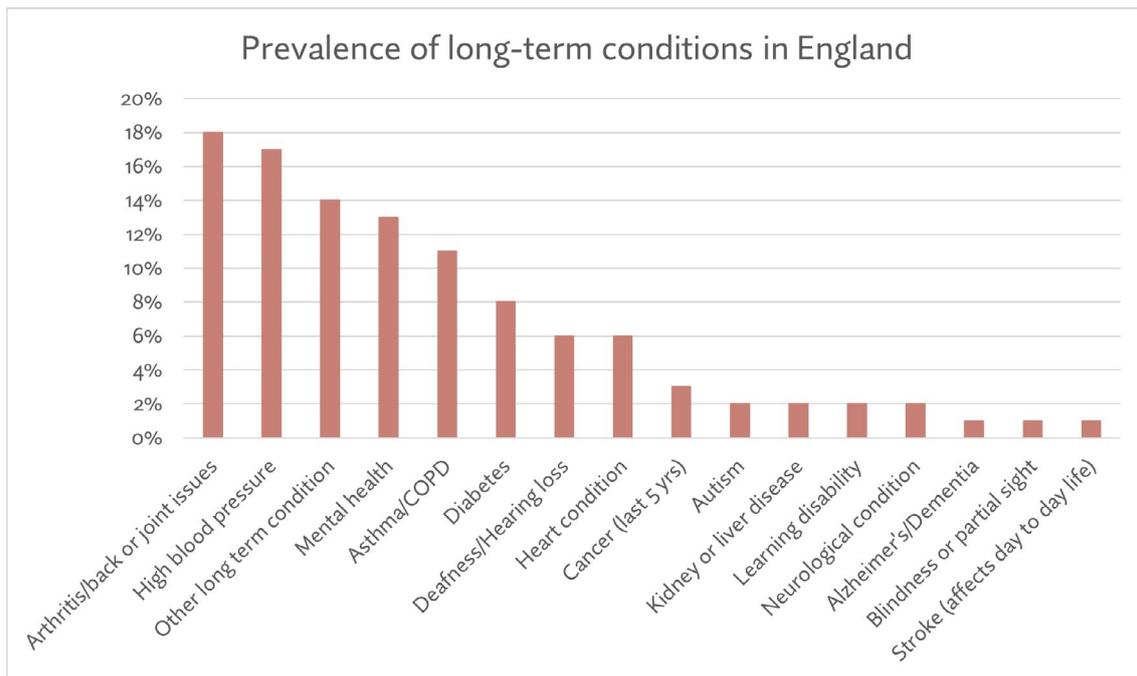
13 All maps in this report are sourced from Office for National Statistics licensed under the Open Government License v3.0. Contains OS data © Crown copyright and database right [2023]

14 Office for National Statistics. Mid-2020 Population Estimates for 2021 Clinical Commissioning Groups (CCGs) in England by Single Year of Age and Sex - National Statistics. Available at: <https://www.ons.gov.uk/file?uri=/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/clinicalcommissioninggroupmidyearpopulationestimates/mid2020sape23dt6a/sape23dt6amid2020ccg2021estimatesunformatted.xlsx> [Last accessed November 2023]

it is important to note that even with prevalence rates of 1 or 2% this equates to hundreds of thousands of people with these conditions across England.

A number of long-term conditions are not captured directly by the GP survey. 14% of people are listed as having 'another long-term condition or disability'. This includes conditions such as dermatological conditions and chronic fatigue syndrome.

Figure 2: Prevalence of long-term conditions in England<sup>15</sup>



A growing number of people have more than one long-term health condition and the numbers with multiple conditions also increases with age<sup>16</sup>. When the numbers of long-term conditions in an ICB are added together, many record above one long-term condition per person on average (100%).

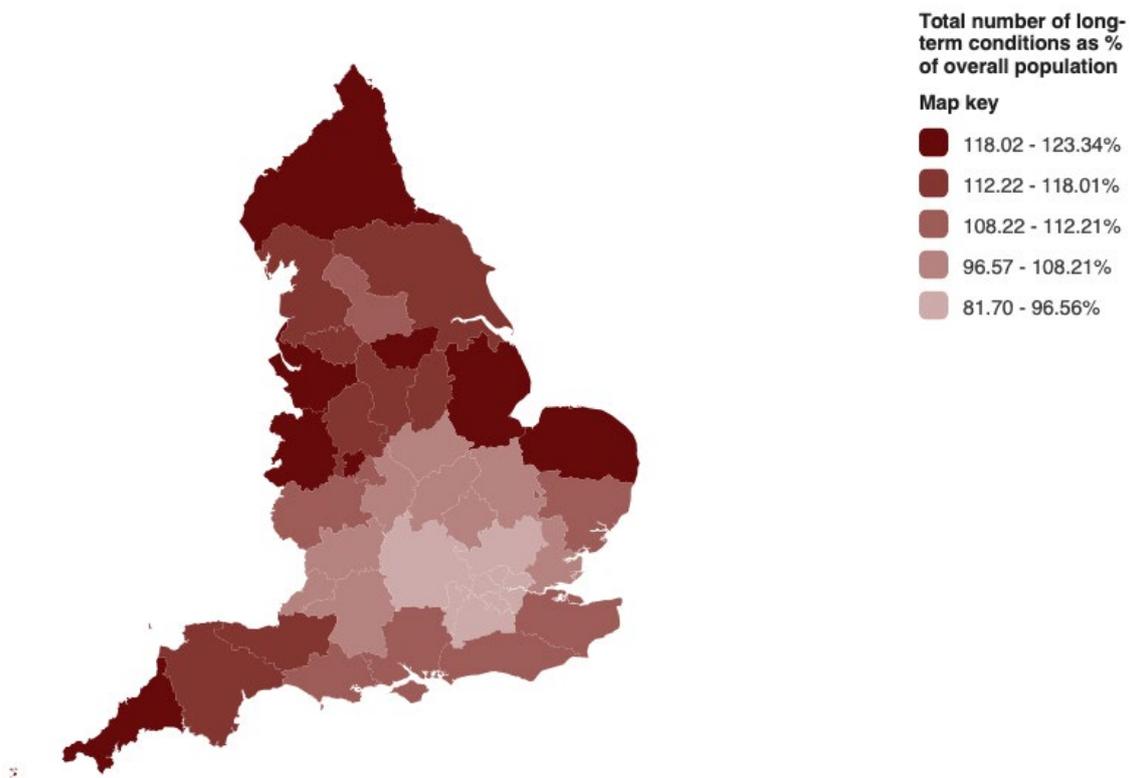
North East and North Cumbria ICB and Cornwall and Isles of Scilly ICB have a 123% recorded rate, the highest of any ICB. By contrast in the 5 ICBs in London rates below 90% are recorded.

15 NHS. GP Patient Survey. January-April 2023. Available at: <https://www.gp-patient.co.uk/surveysandreports> [Last accessed October 2023]

16 Watt et al. 2023. Health in 2040: projected patterns of illness in England. The Health Foundation. Available at: [https://www.health.org.uk/sites/default/files/upload/publications/2023/Projected%20patterns%20of%20illness%20in%20England\\_WEB.pdf](https://www.health.org.uk/sites/default/files/upload/publications/2023/Projected%20patterns%20of%20illness%20in%20England_WEB.pdf) [Last accessed October 2023]

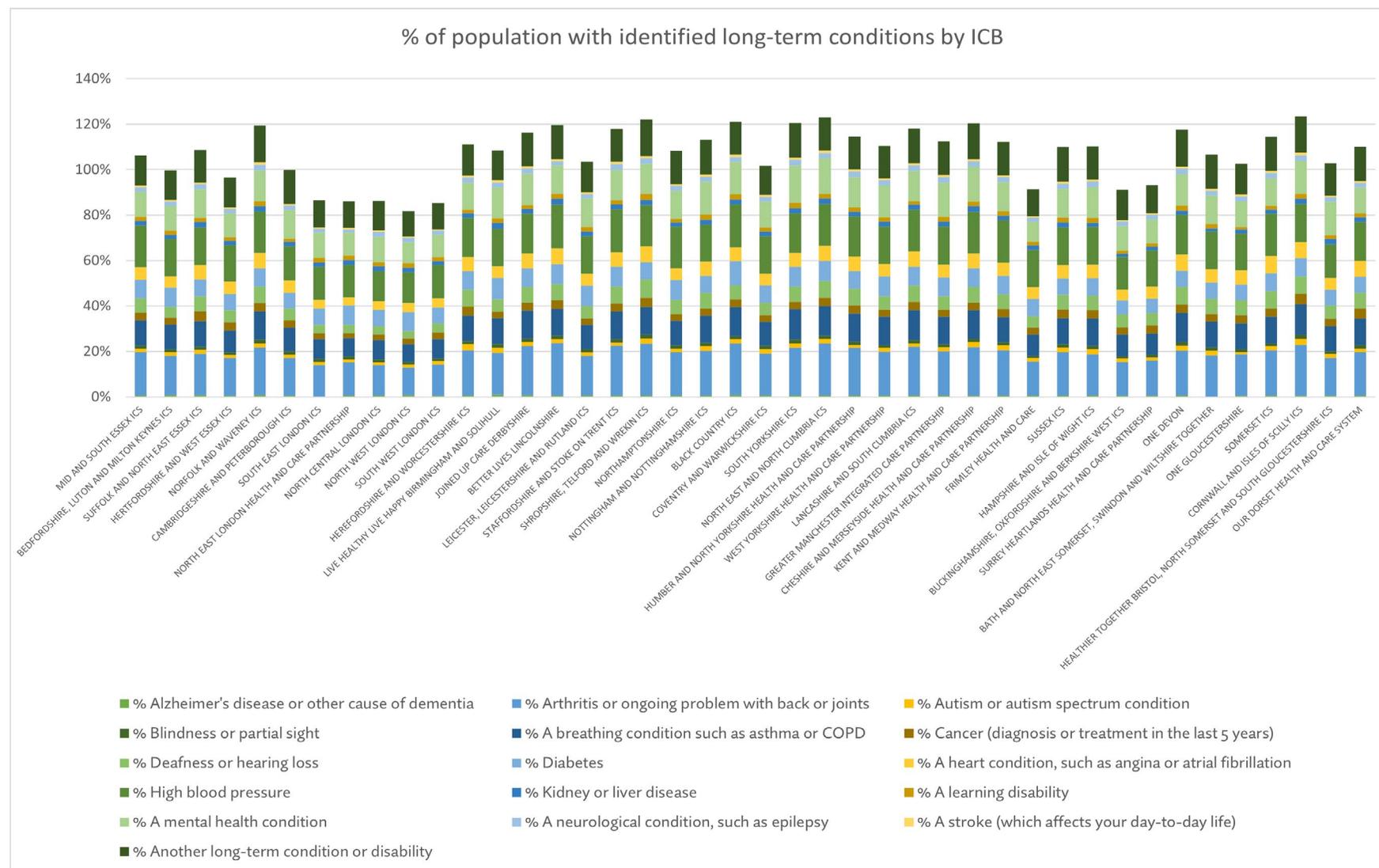
For particular conditions rates vary significantly. For example 23% of people in North East and North Cumbria ICB have arthritis or back or joint issues. This is nearly double the rate of North West London ICB (12%). Both North East London ICB and North West London ICB record a figure of 8% for those with a breathing condition such as asthma or COPD. By contrast Black Country ICB, South Yorkshire ICB, Devon ICB, Cheshire and Merseyside ICB, Lancashire and South Cumbria ICB and North East and North Cumbria ICB all record a rate 62.5% higher (13%).

Figure 3: Total number of long-term conditions as a percentage of overall population<sup>17</sup>



17 NHS. GP Patient Survey. January-April 2023. Available at: <https://www.gp-patient.co.uk/surveysandreports> [Last accessed October 2023]

Figure 4: Percentage of population with identified long-term conditions by condition by ICB



The costs of long-term and multiple long-term conditions are significant. NHS England data estimates the costs of people with long-term condition to be £3000 per year, while the figure is double for those with two conditions and rises to £8000 for three conditions. Using these figures long-term conditions and multiple long-term conditions are costing health and social care services £115.2 billion a year<sup>18</sup>.

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18 NHS England. The NHS belongs to the people: a call to action. July 2013. Available at: <https://www.england.nhs.uk/wp-content/uploads/2013/07/nhs-belongs.pdf> [Last accessed November 2023]



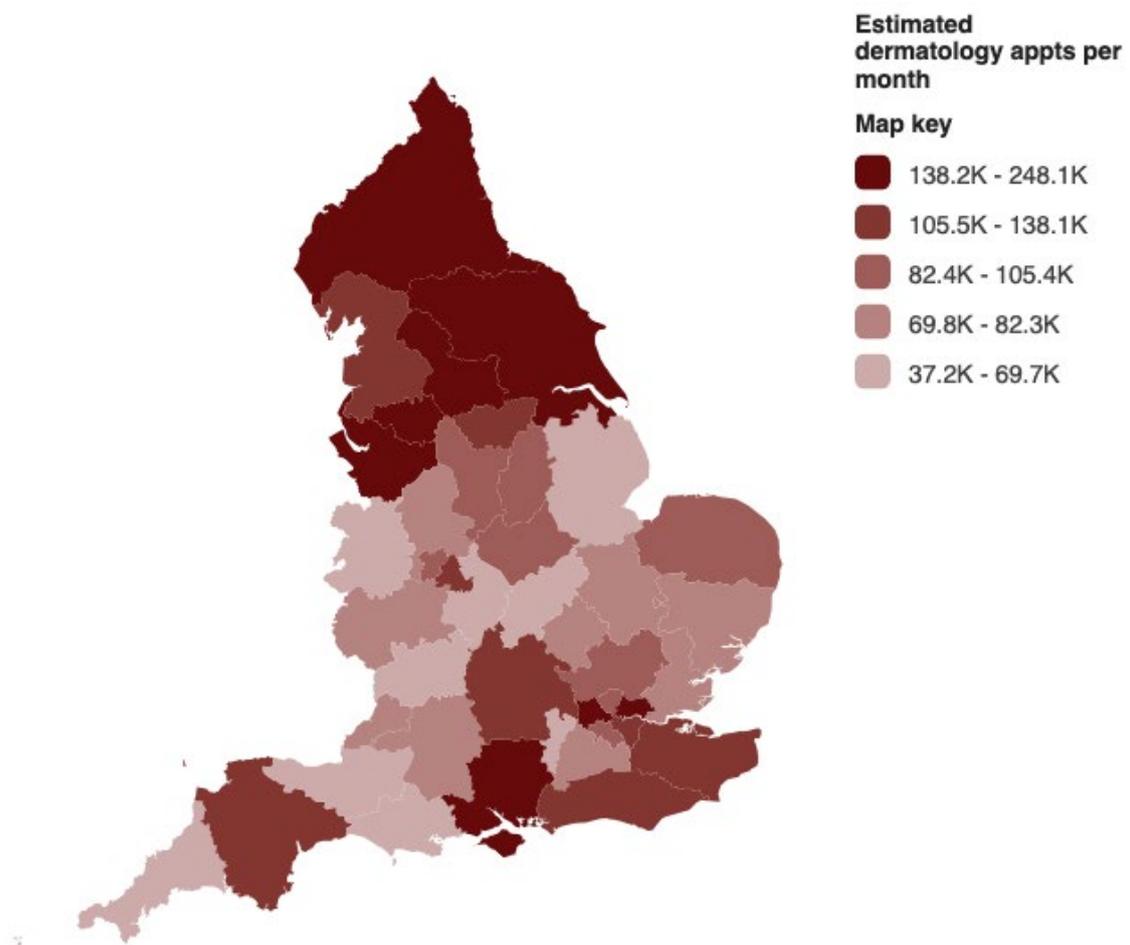
**CHAPTER 2: THE GROWING  
IMPACT OF LONG-TERM  
CONDITIONS ON HEALTH  
SERVICES AND THE  
ECONOMY**

Long-term conditions have a wider impact on health services and the economy.

50% of NHS appointments and 70% of hospital bed capacity are taken up by people with such conditions<sup>19</sup>. This translates into 16.3 million GP appointments per month<sup>20</sup>.

As an example it has been estimated that skin conditions account for 14% of primary care appointments<sup>21</sup>. This translates to an estimated 4.4 million primary care appointments per month. In larger ICBs such as North East and North Cumbria, West Yorkshire and Greater Manchester this results in an estimated 200,000 appointments a month related to skin conditions.

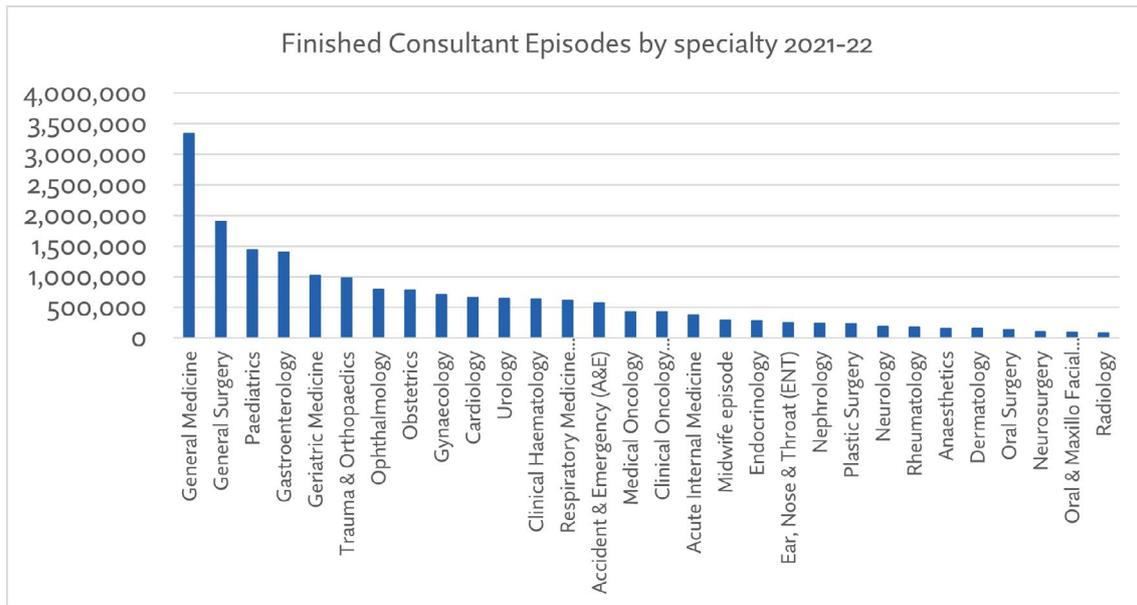
Figure 5: Estimated number of primary care appointments for dermatological conditions by ICB<sup>22</sup>



19 NHS England. Making the case for the personalised approach. Available at: <https://www.england.nhs.uk/blog/making-the-case-for-the-personalised-approach/> [Last accessed October 2023]  
 20 NHS Digital. GP appointments data September 2023. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/appointments-in-general-practice/september-2023> [Last accessed November 2023]  
 21 Le Roux, E. et al. The content and conduct of GP consultations for dermatology problems: a cross-sectional study. British Journal of General Practice, 70(699), e723-e730. Available at: <https://research-information.bris.ac.uk/ws/portalfiles/portal/250082501/bjgp20X712577.full.pdf> [Last accessed October 2023]  
 22 Future Health analysis of ICB GP appointments data available at: <https://digital.nhs.uk/data-and-information/publications/statistical/appointments-in-general-practice> [Last accessed October 2023]

In secondary care a number of specialties covering major long-term conditions are significant contributors to the overall number of NHS hospital admissions. There are nearly 1.4 million hospital admissions for gastroenterology, 800,000 for ophthalmology, 640,000 for urology and nearly 200,000 for neurology and rheumatology respectively<sup>23</sup>.

Figure 6: Finished Consultant Episodes by specialty 2021-22

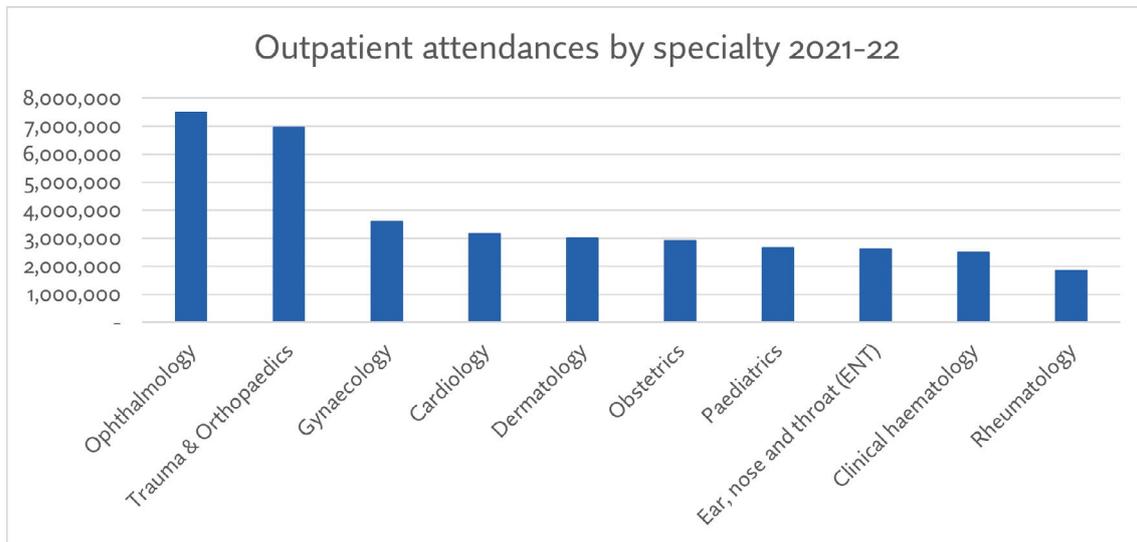


Similarly some of the major contributors to the 95 million outpatient appointments in the NHS are related to long-term conditions. Ophthalmology and dermatology are two of the largest outpatient specialties accounting for over 10.5 million appointments each year at an estimated cost to the NHS of £1.26bn<sup>24</sup>.

23 Future Health analysis of NHS secondary care activity data. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/hospital-admitted-patient-care-activity/2021-22> [Last accessed October 2023]

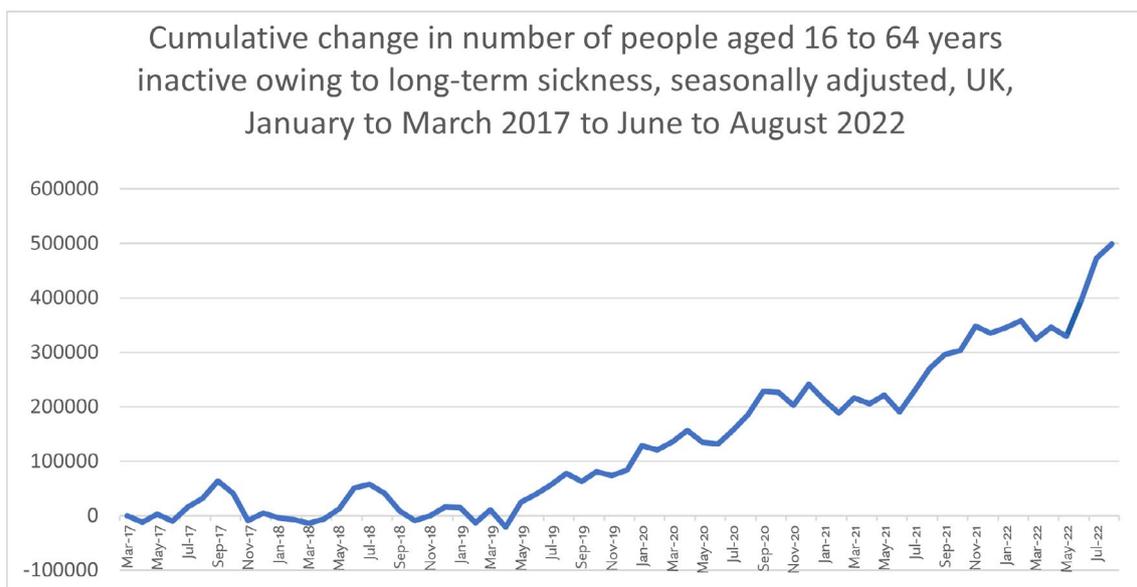
24 Assumes the cost of an outpatient appointment is £120. Reference: NHS England. NHS to trial tech to cut missed appointments and save up to £20 million. Available at: <https://www.england.nhs.uk/2018/10/nhs-to-trial-tech-to-cut-missed-appointments-and-save-up-to-20-million/#:~:text=With%20each%20hospital%20outpatient%20appointment,is%20coming%20to%20the%20NHS> [Last accessed October 2023]

Figure 7: NHS Outpatient attendances by specialty<sup>25</sup>



There are also wider economic impacts from these conditions. The number of working-age adults who are out of the labour market because of long-term sickness has been rising since 2019, from around 2 million people in spring 2019, to 2.5 million in summer 2022<sup>26</sup>.

Figure 8: Cumulative change in number of people aged 16 to 64 years inactive owing to long-term sickness in UK



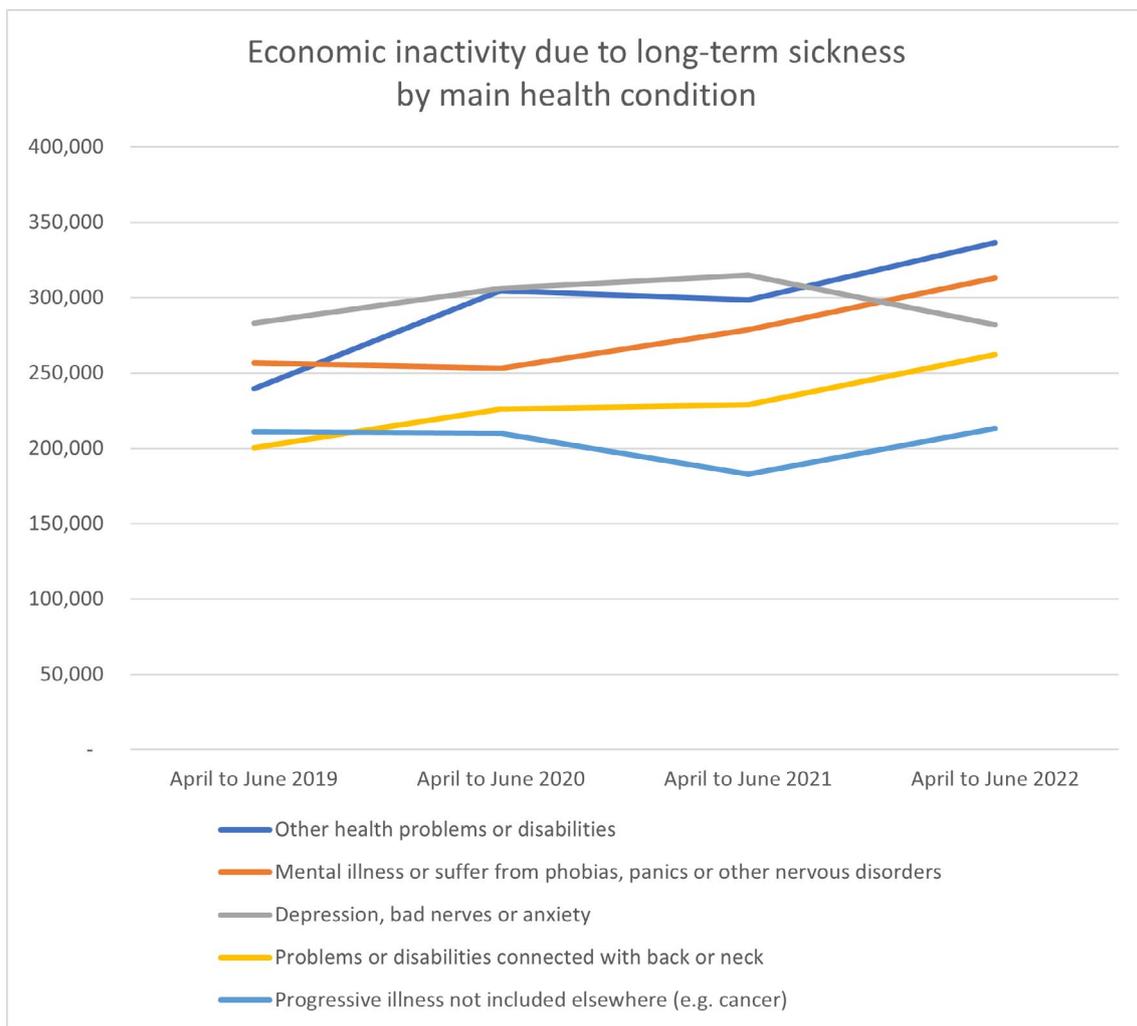
25 NHS England. Hospital Outpatient Activity 2021-22. September 2022. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/hospital-outpatient-activity/2021-22> [Last accessed October 2023]

26 Office for National Statistics. Half a million more people are out of the labour force because of long-term sickness. Available at: <https://www.ons.gov.uk/employmentandlabourmarket/peoplenotinwork/economicinactivity/articles/halfamillionmorepeopleareoutofthelabourforcebecauseoflongtermsickness/2022-11-10> [Last accessed October 2023]

There has been a particularly sharp rise (41%) since 2019 in the number of people being recorded as having ‘other health problems or disabilities.’ There have been rises in all categories, though in some categories the rises have been a lot smaller (such as progressive illness where a 1% rise has been noted).

The ONS notes that it is unlikely that COVID-19 is a major factor as the largest rises in the data were recorded between 2019 and 2020 which only covers the very early stages of the pandemic<sup>27</sup>.

Figure 9: Economic inactivity due to long-term sickness by major health condition



27 Office for National Statistics. Half a million more people are out of the labour force because of long-term sickness. Available at: <https://www.ons.gov.uk/employmentandlabourmarket/peoplenotinwork/economicinactivity/articles/halfamillionmorepeopleareoutofthelabourforcebecauseoflongtermsickness/2022-11-10> [Last accessed October 2023]

**CHAPTER 3: A BRIEF RECENT  
HISTORY OF NHS POLICY FOR  
IMPROVING CARE FOR PEOPLE  
WITH LONG-TERM CONDITIONS**

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The growth in long-term conditions and the implications for patients and the health system is not a new issue facing health policymakers. Across the last twenty years a series of policy interventions have sought to make progress on the issue.

### The 2000s: national policy incrementalism

In the 2000s and as part of New Labour's health investment and reform programme improving care for people with long-term conditions featured prominently.

The 2004 *NHS Improvement Plan* – that followed the 2000 NHS Plan – dedicated a whole chapter to the issue, noting: “the NHS needs to provide a much better service for patients with these conditions and provide high-quality personalised care to meet their needs. It needs to enable people to take greater control of their own treatment, and to spend more time at home and in the community with their families and friends. The NHS needs to do much more to support patients in avoiding the fear and anxiety of having to go to a hospital in an emergency, by anticipating problems and working with patients to prevent these worrying episodes<sup>28</sup>.”

The document called for a more responsive service that was tailored to patient needs and pledged to expand the ‘Expert Patient Programme’ that saw more people with long-term conditions taking greater control of their care<sup>29</sup>.

The 2004 GP contract established the QOF designed to incentivise GPs to deliver improvements in the quality of patient care. The QOF originally had four domains: clinical, organisational, patient experience and additional services. The clinical domain was focused on registering and tracking the care of patients in 11 clinical areas which included a number of long-term conditions (Coronary Heart Disease, Left Ventricular Dysfunction, Stroke and Transient Ischaemic Attack, Hypertension, Diabetes Mellitus, Chronic Obstructive Pulmonary Disease, Epilepsy, Hypothyroidism, Cancer, Mental Health and Asthma)<sup>30</sup>.

The Government's Public Health White Paper *Choosing Health* committed to an expansion of community matrons and further support for people with long-term conditions to improve self-care<sup>31</sup>. Subsequent guidance on models of care for long-term conditions from the Department of Health in 2005 was aimed at delivering on the Treasury's Public Services Agreement (PSA) target to reduce inpatient emergency bed days by 5% by March 2008<sup>32</sup>.

28 HM Government. The NHS Improvement Plan. June 2004. Available at: [https://webarchive.nationalarchives.gov.uk/ukgwa/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_118572.pdf](https://webarchive.nationalarchives.gov.uk/ukgwa/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_118572.pdf) [Last accessed October 2023]

29 HM Government. The NHS Improvement Plan. June 2004 Available at: [https://webarchive.nationalarchives.gov.uk/ukgwa/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_118572.pdf](https://webarchive.nationalarchives.gov.uk/ukgwa/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_118572.pdf) [Last accessed October 2023]

30 The QOF has been regularly updated and revised since, but the broad approach of a set of domains and a focus on disease prevalence and registers has remained. Reference: NHS Health and Social Care Information Centre. National Quality and Outcomes Framework statistics for England 2004/05. Available at: <https://files.digital.nhs.uk/publicationimport/pub01xxx/pub01946/qof-eng-04-05-rep.pdf> [Last accessed October 2023]

31 HM Government. *Choosing Health: Making healthy choices easier*. 2004. Available at: <https://www.yearofcare.co.uk/sites/default/files/images/DOH2.pdf> [Last accessed October 2023]

32 Department of Health. *Supporting People with Long Term Conditions*. January 2005. Available at: [https://webarchive.nationalarchives.gov.uk/ukgwa/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4122574.pdf](https://webarchive.nationalarchives.gov.uk/ukgwa/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4122574.pdf) [Last accessed October 2023]

A *National Service Framework for Long-Term Conditions* was published soon after in 2005. This was focused specifically on improving the lives of people with neurological conditions<sup>33</sup>.

*Our Health, Our Care, Our Say* published under then Secretary of State Rt Hon Patricia Hewitt MP in 2006 set better supporting people with long-term conditions as one of its four main goals. To deliver this it included plans to 'treble the investment in the Expert Patient Programme, developing an 'information prescription' for people with long-term health and social care needs and for their carers, and developing assistive technologies to support people in their own homes<sup>34</sup>.

The 2007 World Class Commissioning (WCC) programme aimed to transfer powers from providers to those purchasing services. The WCC competencies included the ability for commissioners to 'anticipate and address the needs of the whole population, including people with long-term conditions<sup>35</sup>.' A choice framework for people with long-term conditions was also published looking to extend choice beyond elective care<sup>36</sup>. The 2008 Darzi review of high quality care committed to everyone with a long-term condition receiving a personalised care plan<sup>37</sup>.

In 2010 and as a further part of the WCC process the Department of Health published *Improving the health and well-being of people with long-term conditions*. This guide for commissioners was aimed at setting out what a high quality service for people with long-term conditions should include<sup>38</sup>.

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33 Department of Health. The National Framework for Long-term Conditions. March 2005. Available at : [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/198114/National\\_Service\\_Framework\\_for\\_Long\\_Term\\_Conditions.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/198114/National_Service_Framework_for_Long_Term_Conditions.pdf) [Last accessed October 2023]

34 HM Government. Our health, our care, our say: a new direction for community services. January 2006. Available at : [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/272238/6737.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/272238/6737.pdf) [Last accessed October 2023]

35 NHS. World Class Commissioning: Vision. December 2007. Available at : [https://webarchive.nationalarchives.gov.uk/ukgwa/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_080952.pdf](https://webarchive.nationalarchives.gov.uk/ukgwa/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_080952.pdf) [Last accessed October 2023]

36 Department of Health. Generic choice model for long term conditions. Available at : [https://webarchive.nationalarchives.gov.uk/ukgwa/20130104184944/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_081105](https://webarchive.nationalarchives.gov.uk/ukgwa/20130104184944/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081105) [Last accessed October 2023]

37 NHS. High Quality Care For All. June 2008. Available at : [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/228836/7432.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/228836/7432.pdf) [Last accessed October 2023]

38 Department of Health. Improving the health and well-being of people with long term conditions. World class services for people with long term conditions: information tool for commissioners. January 2010. Available at : [https://www.yearofcare.co.uk/sites/default/files/pdfs/dh\\_improving%20the%20h%26wb%20of%20people%20with%20LTCs.pdf](https://www.yearofcare.co.uk/sites/default/files/pdfs/dh_improving%20the%20h%26wb%20of%20people%20with%20LTCs.pdf) [Last accessed October 2023]

## What progress was made?

In 2011 Ipsos Mori published its final study on the care recorded by people with long-term conditions between 2007 and 2011<sup>39</sup>. Three quarters of people with long-term health conditions (73%) felt that they got some or all of the support they require from local services and organisations, an increase since 2009 (67%)<sup>40</sup>.

Progress had also been made in the following areas:

- More people with long-term conditions were taking an active role in their health
- More people with long-term conditions in hospital were being provided with a care plan
- Four in five people were receiving written instructions for taking medicines, another significant increase over previous years
- An increasingly large majority of patients said they were provided with support to help them understand the information they received
- Those who asked for self-care advice were happy with the service they received

But awareness of the support and health training courses available for people was still low and fewer respondents to the survey were saying that their health was either 'excellent' or 'very good' when compared with 2007<sup>41</sup>.

## The 2010s – Dispersing power and developing new models of care

The Quality Improvement Prevention and Productivity (QIPP) programme began towards the end of the Labour Government in response to the need for the health service to make savings of £20bn by 2014/15<sup>42</sup>.

The programme established a workstream on long-term conditions focused on joining-up care for patients through the introduction of a year of care funding model<sup>43</sup>.

QIPP was passed to NHS England as part of the health reforms in 2013<sup>44</sup>. NHS England continued to publish a series of guides related to improved long-term condition management<sup>45</sup>. In 2017 based on the work of the Early Implementer Sites, NHS England published guidance for commissioners on how to commission the year of care funding

39 Ipsos. Long Term Health Conditions 2011. April 2011. Available at : [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215340/dh\\_130806.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215340/dh_130806.pdf) [Last accessed October 2023]

40 Ipsos. Long Term Health Conditions 2011. April 2011 Available at : [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215340/dh\\_130806.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215340/dh_130806.pdf) [Last accessed October 2023]

41 Ipsos. Long Term Health Conditions 2011. April 2011. Available at : [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215340/dh\\_130806.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215340/dh_130806.pdf) [Last accessed October 2023]

42 The Health Foundation. Quality, Innovation, Productivity and Prevention (QIPP) programme. Available at: <https://navigator.health.org.uk/theme/quality-innovation-productivity-and-prevention-qipp-programme> [Last accessed October 2023]

43 Department of Health. QIPP Long Term Conditions. April 2012. Available at : [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215060/dh\\_133652.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215060/dh_133652.pdf) [Last accessed October 2023]

44 Department of Health and Social Care. QIPP national workstream updated. March 2013. <https://www.gov.uk/government/news/qipp-national-workstreams-updated> [Last accessed October 2023]

45 NHS England. Resources for long term conditions. Available at: <https://www.england.nhs.uk/ourwork/clinical-policy/ltc/resources-for-long-term-conditions/> [Last accessed October 2023]

model<sup>46</sup>. Whilst nationally the QIPP programmes were ultimately discontinued, there is still evidence of local systems using the framework for the management and delivery of services<sup>47</sup>.

The Coalition Government's health reforms transformed health structures significantly but for long-term conditions the July 2010 White Paper *Equity and Excellence: Liberating the NHS* primarily built from previous work on long-term condition management. The paper set out a desire for shared decision making to become the norm as part of efforts to improve health outcomes and reduce health service pressures<sup>48</sup>.

The subsequent public health white paper *Healthy Lives, Healthy People: Our strategy for public health in England* identified the transfer of public health responsibilities from the NHS to local government as a chance to more widely improve population health and wellbeing<sup>49</sup>.

Government instruction to NHS England on service priorities and improvements came through the creation of a 'mandate'. The first mandate in 2013 included a chapter on improving care for people with long-term conditions and a set of objectives linked to Domain Two of the new NHS Outcomes Framework<sup>50</sup>.

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46 NHS England. The Long Term Conditions Year of Care Commissioning Programme Implementation Handbook. February 2017. Available at : <https://www.england.nhs.uk/wp-content/uploads/2017/02/ltc-yoc-handbook.pdf> [Last accessed October 2023]

47 NHS South East London Clinical Commissioning Group. QIPP 2022/3. Available at: <https://selondonccg.nhs.uk/healthcare-professionals/medicines-optimisation/greenwich-medicines-optimisation-team/qipp/> [Last accessed October 2023]

48 Department of Health. Equity and excellence: Liberating the NHS. July 2010. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213823/dh\\_117794.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213823/dh_117794.pdf) [Last accessed October 2023]

49 HM Government. Health lives, healthy people. Available at : [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216096/dh\\_127424.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216096/dh_127424.pdf) [Last accessed October 2023]

50 This framework was also introduced as part of the 2012 reforms: Department of Health. The Mandate. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/256497/13-15\\_mandate.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/256497/13-15_mandate.pdf) [Last accessed October 2023]

Figure 10: Long-term condition management indicators in Government Mandate to NHS England 2013 and NHS Outcomes Framework 2012/13

Enhancing quality of life for people with long-term conditions: Key areas where progress will be expected (Part two of the NHS Outcomes Framework)
<i>Overarching indicator</i>
<b>2 Health related quality of life for people with long-term conditions</b>
<i>Improvement areas</i>
<b>Ensuring people feel supported to manage their condition</b>
<b>2.1</b> Proportion of people feeling supported to manage their condition
<b>Improving functional ability in people with long-term conditions</b>
<b>2.2</b> Employment of people with long-term conditions
<b>Reducing time spent hospital by people with long-term conditions</b>
<b>2.3.i</b> Unplanned hospitalisation for chronic ambulatory care sensitive conditions (adults) <i>(Chronic ambulatory care sensitive conditions are those where the right treatment and support in the community can help prevent people needing to be admitted to hospital.)</i>
<b>2.3.ii</b> Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s
<b>Enhancing quality of life for carers</b>
<b>2.4</b> Health-related quality of life for carers
<b>Enhancing quality of life for people with mental illness</b>
<b>2.5</b> Employment of people with mental illness
<b>Enhancing quality of life for people with dementia</b>
<b>2.6.i</b> Estimated diagnosis rate for people with dementia
<b>2.6.ii</b> A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life

In 2012 the Department of Health and Social Care ran a consultation on the development of a long-term conditions strategy. This strategy was cross Government in approach. However the challenges with the wider set of health reforms saw work paused, ultimately passed to NHS England and then not taken forward<sup>51</sup>.

NHS England instead chose to deliver improvements in long-term conditions through a 'matrix, organisational structure, seeking co-operation and communication across the organisation in order to achieve objectives with substantial delegation of responsibilities to Clinical Commissioning Groups (CCGs)<sup>52</sup>.'

51 Department of Health & Social Care. 2010 to 2015 government policy: long term health conditions. Available at: <https://www.gov.uk/government/publications/2010-to-2015-government-policy-long-term-health-conditions/2010-to-2015-government-policy-long-term-health-conditions> [Last accessed October 2023]

52 House of Commons Health Committee. Managing the care of people with long-term conditions. June 2014. Available at: <https://publications.parliament.uk/pa/cm201415/cmselect/cmhealth/401/401.pdf> [Last accessed October 2023]

In 2013 an NHS Call to Action to mark the organisation's 65<sup>th</sup> birthday identified an ageing population and the rise in long-term conditions as areas that were threatening the financial stability and sustainability of the NHS. The paper noted that patients with one long-term condition cost £3,000 a year, but for people with three conditions the cost was £8,000<sup>53</sup>.

The NHS *Five Year Forward View* in 2014 provided some further policy continuity in seeking to empower people with long-term conditions to take greater control of their care through improvements in information, new technology and greater choice<sup>54</sup>. It also went further, calling the management of long-term conditions a 'central task' for the NHS. It argued that a one-size fits all approach to healthcare delivery no longer reflected different population health needs and that new more integrated models of care would be needed in the future<sup>55</sup>. By the time of the *Next steps on the Five Year Forward View*, two of these models, Multispecialty Community Providers and Primary and Acute Systems had seen lower growth in emergency admission rates where they had been implemented<sup>56</sup>.

The *NHS Long-term Plan* in 2019 focused on improving out of hospital care and integrating services, with the planned creation of Integrated Care Systems (ICSs). These new models were identified as being critical for supporting the growing numbers of people with multiple long-term conditions; particularly in joining-up their data and care records<sup>57</sup>.

### What progress has been made?

When assessing progress on long-term conditions in the 2010s the NHS Outcomes Framework provides a helpful dataset for analysis. The picture is mixed.

There has been an increase in the proportion of people with long-term conditions in employment<sup>58</sup>. However the number of people feeling supported to manage their condition has fallen sharply from two thirds to 54%<sup>59</sup>.

Health related quality of life for people with long-term conditions has also fallen

53 NHS England. The NHS belongs to the people: A call to action. July 2013. Available at: <https://www.england.nhs.uk/wp-content/uploads/2013/07/nhs-belongs.pdf> [Last accessed October 2023]

54 NHS England. Five Year Forward View. October 2014. Available at: <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf> [Last accessed October 2023]

55 NHS England. Five Year Forward View. October 2014. Available at: <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf> [Last accessed October 2023]

56 NHS England. Next Steps on the Five year Forward View. March 2017. Available at: <https://www.england.nhs.uk/wp-content/uploads/2017/03/NEXT-STEPS-ON-THE-NHS-FIVE-YEAR-FORWARD-VIEW.pdf> [Last accessed October 2023]

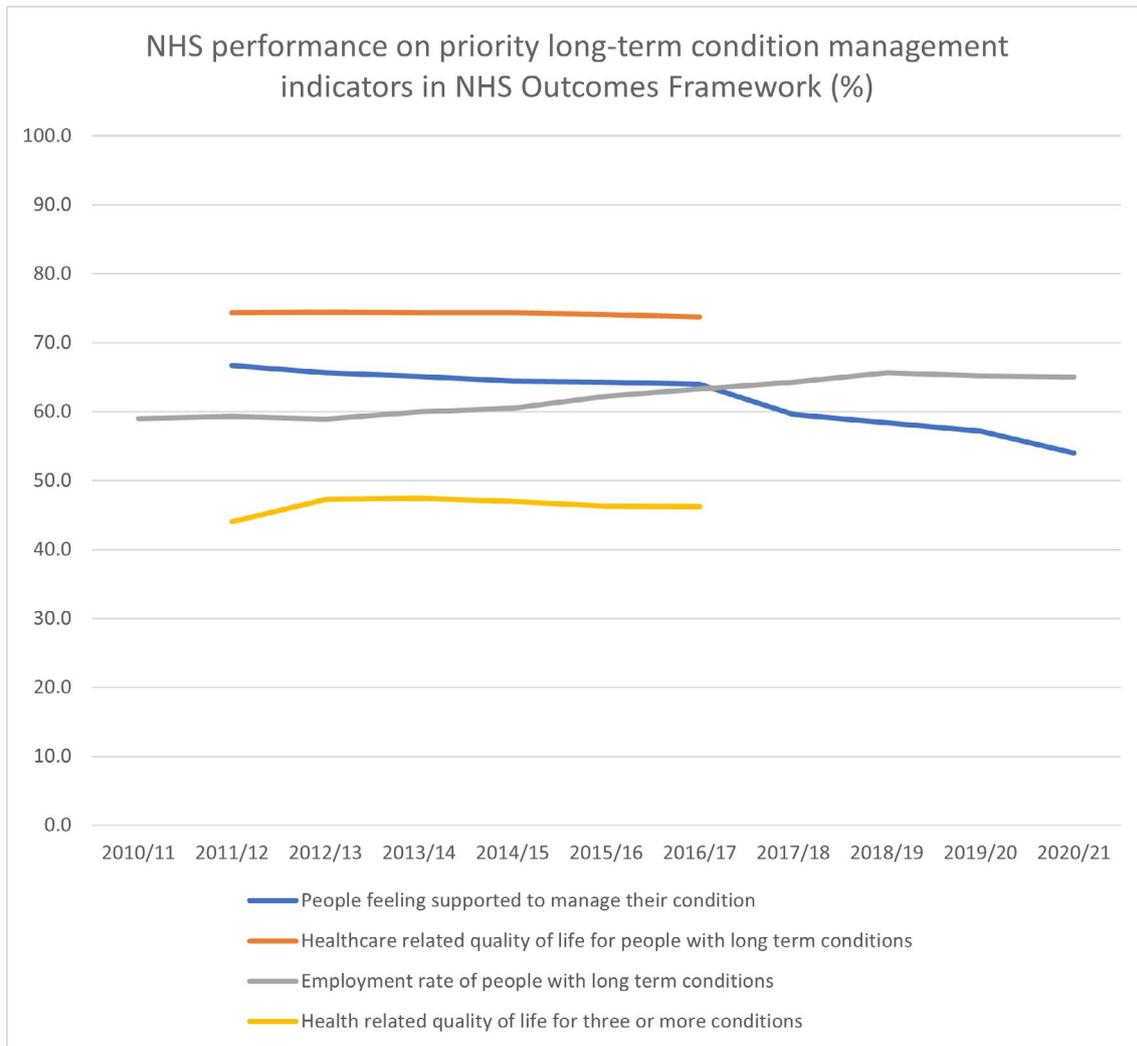
57 NHS. The NHS Long Term Plan. January 2019. Available at: <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf> [Last accessed October 2023]

58 NHS Digital. 2.2 Employment of people with long-term conditions. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/nhs-outcomes-framework/march-2022/domain-2---enhancing-quality-of-life-for-people-with-long-term-conditions-nof/2.2-employment-of-people-with-long-term-conditions> [Last accessed October 2023]

59 NHS Digital. 2.1 Proportion of people feeling supported to manage their condition. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/nhs-outcomes-framework/march-2022/domain-2---enhancing-quality-of-life-for-people-with-long-term-conditions-nof/2.1-proportion-of-people-feeling-supported-to-manage-their-condition> [Last accessed October 2023]

slightly, though it has slightly improved amongst those with three or more conditions (the latest data on these measures is from 2017<sup>60</sup>).

Figure 11: Performance on long-term condition management indicators in NHS Outcomes Framework<sup>61</sup>



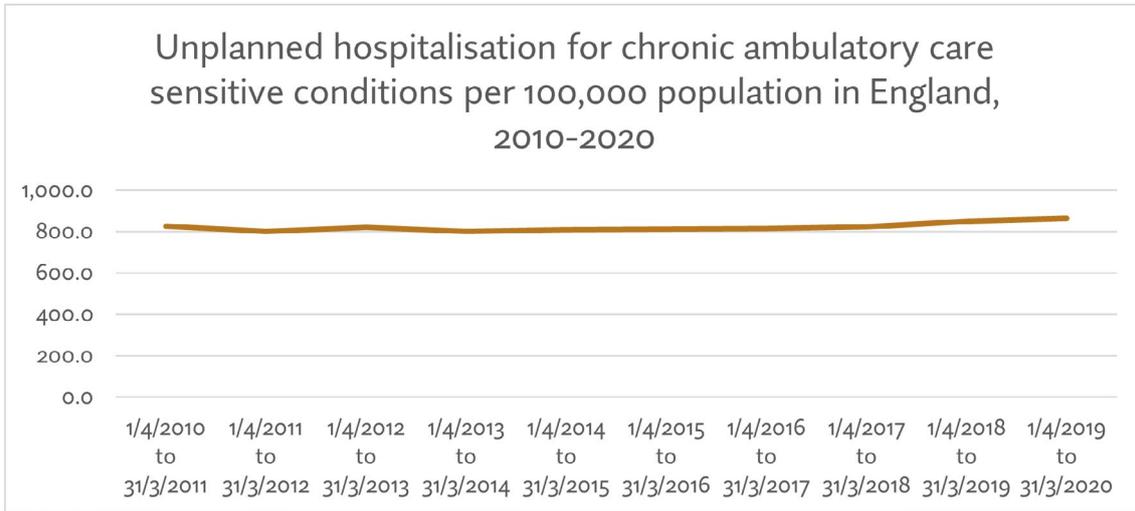
One of the main identified priorities for improving care for people with long-term conditions was to reduce pressures on the wider NHS. But this has not been realised. The numbers of unplanned hospitalisations per 100,000 population in

60 NHS Digital. 2.2 Employment of people with long-term conditions. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/nhs-outcomes-framework/march-2022/domain-2---enhancing-quality-of-life-for-people-with-long-term-conditions-nof/2.2-employment-of-people-with-long-term-conditions> [Last accessed October 2023]

61 For the purposes of this graph EQ5D scores have been converted to percentages

England for chronic ambulatory care conditions has risen slightly since 2010 from 825.3 per 100,000 to 862.1 per 100,000 in 2019/20 – an increase of 4.5%<sup>62</sup>.

Figure 12: *Unplanned hospitalisation for chronic ambulatory care sensitive conditions per 100,000 population in England, 2010-2020*<sup>63</sup>



### Summary

Despite a plethora of health reform, the policy approach for improving outcomes for the growing number of people with long-term conditions over the last 20 years has been fairly consistent. The primary focus has been on seeking to empower patients to improve self-care and self-management, using levers such as personal care plans, choice and new technology to deliver improvements in outcomes. This approach has had mixed results.

In the 2000s national policy helped create a range of levers and schemes including expert patient programmes, information prescriptions and care plans. Choice and commissioning frameworks and guides were also published for local NHS organisations to deliver improvements in quality. This led to patients reporting improvements in the support available, though self-reported health outcomes did not noticeably improve as fewer patients recorded that they were in either

62 NHS Digital. 2.3.i Unplanned hospitalisation for chronic ambulatory care sensitive conditions. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/nhs-outcomes-framework/march-2022/domain-2---enhancing-quality-of-life-for-people-with-long-term-conditions-nof/2.3.i-unplanned-hospitalisation-for-chronic-ambulatory-care-sensitive-conditions> [Last accessed October 2023]; Numbers fell sharply in 2020/21 due to the pandemic (662.2 per 100,000)

63 NHS Digital. 2.3.i Unplanned hospitalisation for chronic ambulatory care sensitive conditions. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/nhs-outcomes-framework/march-2022/domain-2---enhancing-quality-of-life-for-people-with-long-term-conditions-nof/2.3.i-unplanned-hospitalisation-for-chronic-ambulatory-care-sensitive-conditions> [Last accessed October 2023]

excellent or very good health<sup>64</sup>.

In the 2010s policy power was more distributed across the system through the creation of NHS England, clinical commissioning groups and latterly ICBs. A focus on choice and patient empowerment has remained but a national strategy for long-term conditions was never published. Instead the primary levers for change have been new models of care and service design measured against patient and service outcomes. Some of the local models as part of the Five Year Forward View did demonstrate reductions in hospital admissions, but for long-term conditions nationally relative hospital admissions rose, fewer patients felt supported to manage their condition and healthcare related quality of life fell.

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<sup>64</sup> The reasons for this drop are unclear. One possible hypothesis is that the fall is the result of an older population where overall health outcomes are lower at the end of the study period than at the start. But it is not possible to prove this.

A photograph of an elderly woman with short white hair, wearing a white cable-knit sweater, sitting in a wheelchair. She is smiling broadly and looking towards a younger person whose hand is visible on the right, holding a chess piece. They are playing chess on a checkered board. The scene is set indoors, possibly in a home or a care facility, with a bookshelf visible in the background. The entire image has a warm, reddish-orange tint.

**CHAPTER 4: THE MAJOR  
CONDITIONS STRATEGY: AN  
OPPORTUNITY FOR PROGRESS  
ON IMPROVING CARE FOR  
PATIENTS WITH LONG-TERM  
CONDITIONS?**

In January 2023 then Secretary of State for Health and Social Care Rt Hon Steve Barclay MP announced that the Government would develop a Major Conditions Strategy. The Strategy has broad aims and ambitions:

“The Strategy will set out a strong and coherent policy agenda that sets out a shift to integrated, whole-person care, building on measures that we have already taken forward through the NHS Long-Term Plan. Interventions set out in the Strategy will aim to alleviate pressure on the health system, as well as support the government’s objective to increase healthy life expectancy and reduce ill-health related labour market inactivity<sup>65</sup>.”

The Secretary of State identified the six major conditions for the strategy as:

- Cancer
- Dementia
- Respiratory
- Musculoskeletal
- Cardiovascular disease – including diabetes and stroke
- Mental health

The six it was noted account for 60% of total Disability Adjusted Life Years in England<sup>66</sup>.

The strategy was he noted a way to combine ‘our key commitments in mental health, cancer, dementia and health disparities into a single, powerful strategy<sup>67</sup>.’

A call for evidence was launched in May 2023, with three main objectives:

- How to improve outcomes for people suffering from a combination of conditions
- What impactful interventions can be adopted and scaled quickly – in the next 1 to 2 years
- How we can tackle disparities in health outcomes and experiences - including disparities that exist by gender, ethnicity, and geography<sup>68</sup>

A case for change and strategic framework has subsequently followed, summarised in the graphic below.

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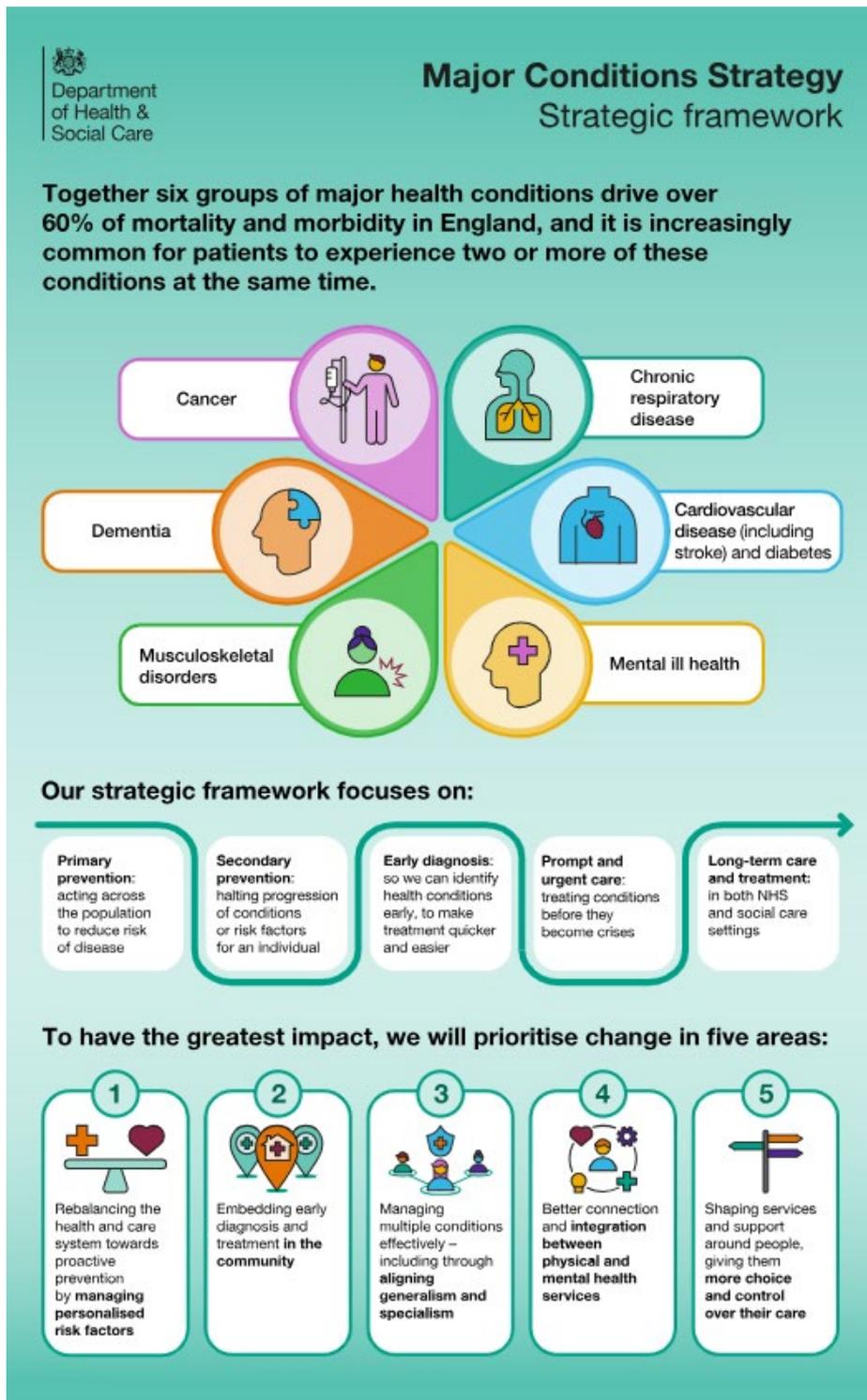
65 UK Parliament. Written questions, answers and statements. Government Action on Major Conditions and Diseases. January 2023. Available at: <https://questions-statements.parliament.uk/written-statements/detail/2023-01-24/hcws514> [Last accessed October 2023]

66 UK Parliament. Written questions, answers and statements. Government Action on Major Conditions and Diseases. January 2023. Available at: <https://questions-statements.parliament.uk/written-statements/detail/2023-01-24/hcws514> [Last accessed October 2023]

67 UK Parliament. Written questions, answers and statements. Government Action on Major Conditions and Diseases. January 2023. Available at: <https://questions-statements.parliament.uk/written-statements/detail/2023-01-24/hcws514> [Last accessed October 2023]

68 Department of Health & Social Care. Major conditions strategy: call for evidence. May 2023 Available at: <https://www.gov.uk/government/calls-for-evidence/major-conditions-strategy-call-for-evidence/major-conditions-strategy-call-for-evidence> [Last accessed October 2023]

Figure 13: Major Conditions Strategy: case for change and strategic framework<sup>69</sup>



69 Department for Health and Social Care. Major conditions strategy: case for change and our strategic framework. May 2023 Available at: <https://www.gov.uk/government/publications/major-conditions-strategy-case-for-change-and-our-strategic-framework/major-conditions-strategy-case-for-change-and-our-strategic-framework--2> [Last accessed October 2023]

The strategy seeks to make change in five key areas. These are:

- Rebalancing the health and care system, over time, towards a personalised approach to prevention through the management of risk factors
- Embedding early diagnosis and treatment delivery in the community
- Managing multiple conditions effectively - including embedding generalist and specialist skills within teams, organisations and individual clinicians
- Seeking much closer alignment and integration between physical and mental health services
- Shaping services and support around the lives of people, giving them greater choice and control where they need and want it and real clarity about their choices and next steps in their care<sup>70</sup>

### **From a Major Conditions Strategy to a Long-Term and Multiple Conditions Strategy**

The rationale for the six prioritised conditions in the strategic framework is (a) their overall contribution to mortality and morbidity in England and (b) the growing prevalence of people with more than one of these conditions.

The focus on people with multiple conditions in the Strategy feels particularly important. The Hewitt review of ICSs argued that the NHS is not set-up to deal with the current health needs of the population noting that: “despite many impressive examples of innovative working, the NHS in general is not yet currently configured to optimise the management of complex, long-term conditions<sup>71</sup>.”

A review of multi-morbidity by the NIHR in 2021 found that:

- More than 1 in 4 adults live with 2 or more health conditions
- Problems of multi-morbidity have not been well addressed by health services or research
- Evidence of what works to effectively address multiple conditions is sparse
- There is a greater need to recognise the interplay between physical and mental health
- Multiple conditions drive increased healthcare costs and the use of hospital and primary care
- They also result in people being prescribed multiple medications, which can have adverse outcomes. Treatment guidelines and drug efficacy trials are generally based on people with single conditions

<sup>70</sup> Department for Health and Social Care. Major conditions strategy: case for change and our strategic framework. May 2023 Available at: <https://www.gov.uk/government/publications/major-conditions-strategy-case-for-change-and-our-strategic-framework/major-conditions-strategy-case-for-change-and-our-strategic-framework--2> [Last accessed October 2023]

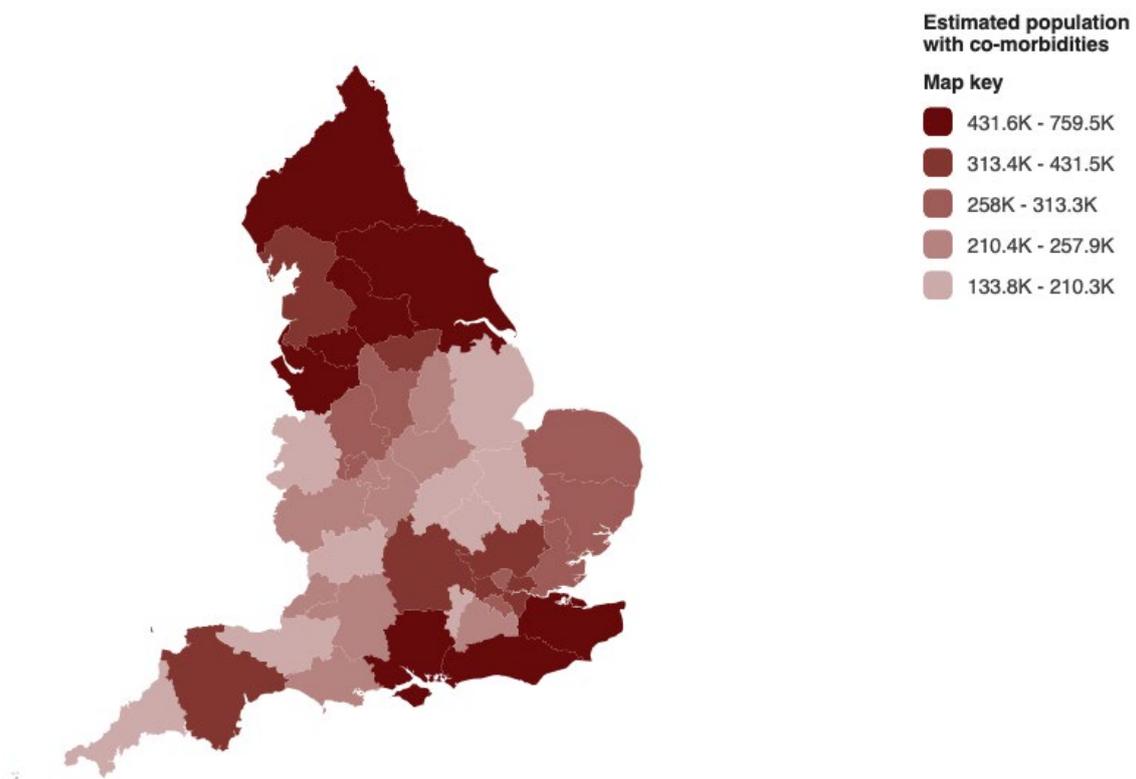
<sup>71</sup> Hewitt, P. The Hewitt Review. April 2023. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1148568/the-hewitt-review.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1148568/the-hewitt-review.pdf) [Last accessed October 2023]

- Better understanding is needed to improve risk stratification efforts, and drive advances in preventive strategies and more coherent treatment regimes
- More research is needed to understand clusters of conditions and their risk factors
- There is a greater need for more generalist medical training to support patients with multiple conditions<sup>72</sup>

A study by Barnett et al from 2012 in Scotland looked at the impact of demographic and deprivation changes on rates of multi-morbidity in the population. The study found that rates of multimorbidity increased with age and generally rose in line with increased rates of deprivation<sup>73</sup>.

By applying the age and deprivation from the Barnett et al study to the populations of ICBs in England it is possible to estimate regional levels of multi-morbidity.

Figure 14: Estimated number of people with multiple morbidities by ICB



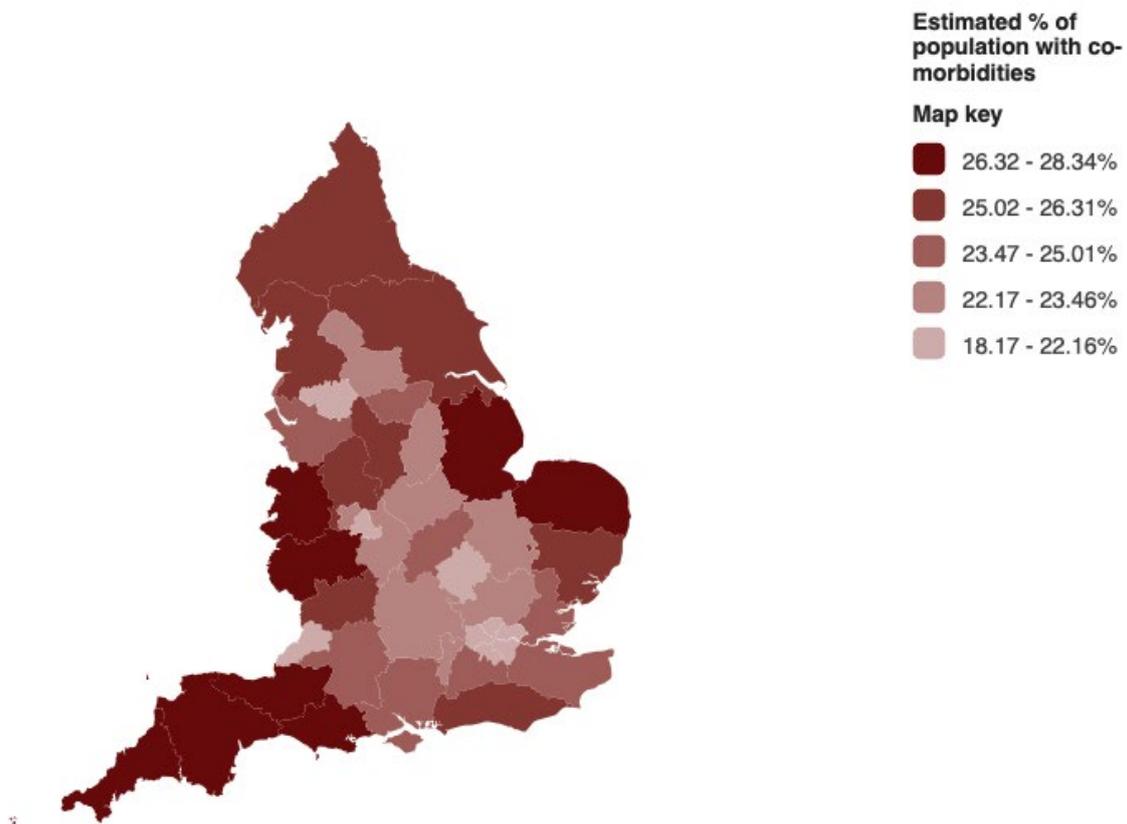
72 National Institute for Health and Care Research. Multiple long-term conditions (multimorbidity): making sense of the evidence. Available at: <https://evidence.nihr.ac.uk/collection/making-sense-of-the-evidence-multiple-long-term-conditions-multimorbidity/#:~:text=Around%20one%20in%20four%20adults,acquiring%20multiple%20conditions%20is%20falling> [Last accessed October 2023]

73 Barnett, k. et al. The Lancet. Epidemiology of multimorbidity and implications for health care, research and medical education: a cross-sectional study. July 2012. Available at: <https://www.thelancet.com/action/showPdf?pii=S0140-6736%2812%2960240-2> [Last accessed October 2023]

Nationally the analysis finds that there are an estimated 13.4 million people with co-morbidities in England. ICBs with larger populations have higher numbers. The ICB with the highest estimated number is in North East and North Cumbria ICB, 759, 434. The ICB with the lowest estimated number is Shropshire, Telford and Wrekin 133,840.

When adjusted for population size, four of the top five ICBs with the estimated highest rates of co-morbidities are in the South West (Cornwall and Isles of Scilly, Somerset, Dorset and Devon) with rates of 27% or more. By contrast the five ICBs with the lowest rates are all from London with rates of 20% or less, reflecting younger populations.

Figure 15: Estimated percentage of the population with co-morbidities



However the evidence for prioritising the six ‘major’ conditions in the Strategy is more questionable.

The strategic framework itself begins with one question: *‘how should our approach to health and care delivery evolve to improve outcomes and better meet the needs of our population, which is becoming older and living with multimorbidity?’*<sup>74</sup>

74 Department for Health and Social Care. Major conditions strategy: case for change and our strategic framework. August 2023. Available at: <https://www.gov.uk/government/publications/major-conditions-strategy-case-for-change-and-our-strategic-framework--2#:~:text=In%20the%20major%20conditions%20strategy,health%20and%20the%20need%20for> [Last accessed October 2023]

A study by Stokes et al of multimorbidity amongst 8 million hospital patients identified over 60,000 unique disease combinations. The study conducted in 2017-18 found that no combination accounted for more than 3.2% of total costs for patients with multi-morbidities<sup>75</sup>. Such evidence indicates that it is difficult to target policy interventions at clear discrete disease combinations and a generalist approach is likely to be more successful<sup>76</sup>.

For patients there is a clear desire for care to be more patient centred rather than condition centred (see box below).

### The Patient View

Patients with long-term conditions consistently say:

- They want to be involved in decisions about their care – they want to be listened to
- They want access to information to help them make those decisions
- They want support to understand their condition and confidence to manage – support to self care
- They want joined up, seamless services
- They want proactive care
- They do not want to be in hospital unless it is absolutely necessary and then only as part of a planned approach
- They want to be treated as a whole person and for the NHS to act as one team<sup>77</sup>

The proposal therefore to prioritise six major conditions in the Strategy presents challenges for delivering the model of whole person care centred around the needs of the individual that the Strategy itself sets out to achieve.

There is also a danger that in adopting this approach the Strategy is not suitably future proofed for rises in particular conditions or combinations of conditions as a result of an ageing population. For example our research finds that the estimated number of people living with sight loss is expected to rise by over half a million by 2035 (an increase of 29%)<sup>78</sup>.

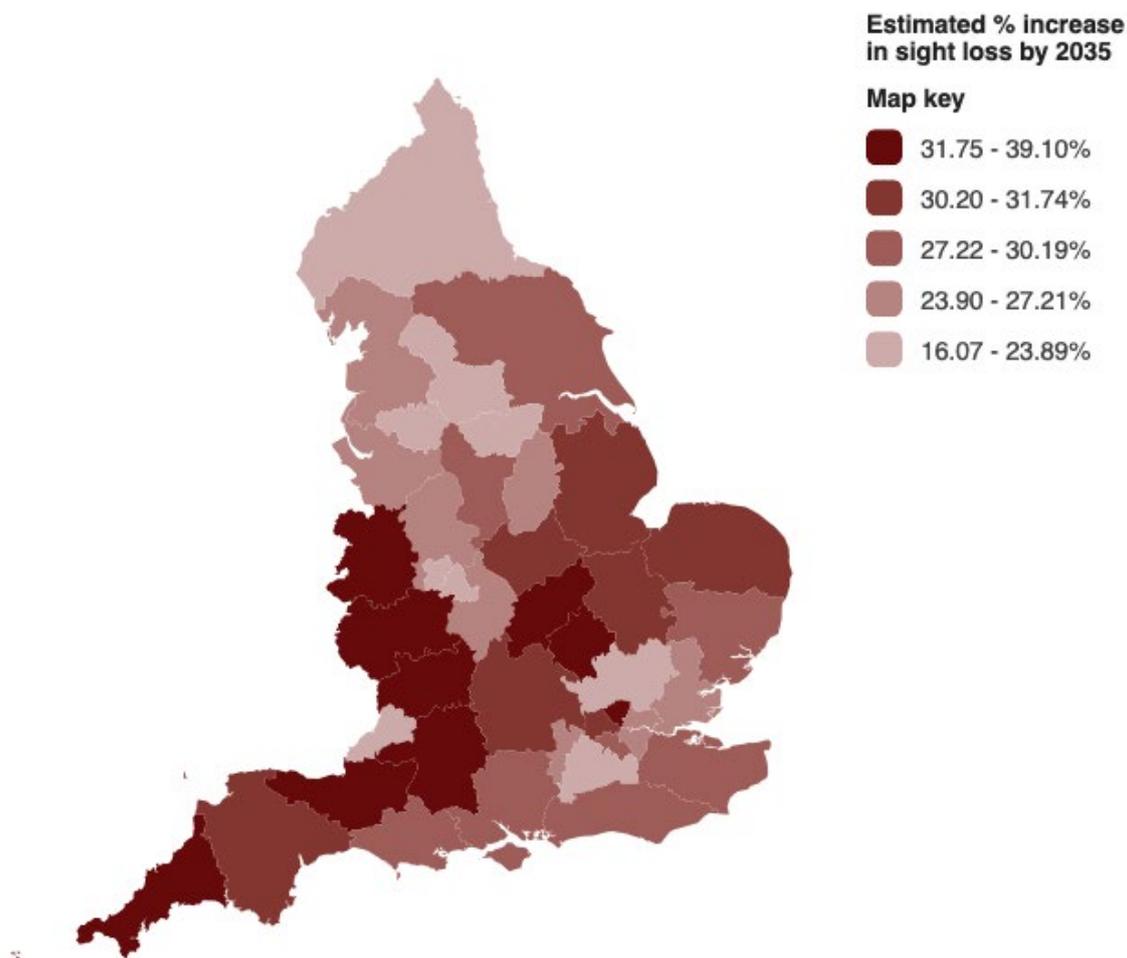
75 Stokes, J. et al PLOS Medicine. Multimorbidity combinations, costs of hospital care and potentially preventable emergency admissions in England: A cohort study. January 2021. Available at: <https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1003514> [Last accessed October 2023]

76 Stokes, J. et al PLOS Medicine. Multimorbidity combinations, costs of hospital care and potentially preventable emergency admissions in England: A cohort study. January 2021. Available at: <https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1003514> [Last accessed October 2023]

77 Department of Health. Long Term Conditions Compendium of Information. May 2012. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216528/dh\\_134486.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216528/dh_134486.pdf) [Last accessed October 2023]

78 Future Health analysis of RNIB Sight Loss Data tool. Available at: <https://www.rnib.org.uk/professionals/health-social-care-education-professionals/knowledge-and-research-hub/sight-loss-data-tool/> [Last accessed October 2023]

Figure 16: Estimated percentage increase in the number of people with sight loss in each Integrated Care Board by 2035<sup>79</sup>



Other long-term conditions not listed as major conditions are also expected to see significant growth from an ageing population – such as dermatology where an extra 1.8 million cases are forecast by 2035<sup>80</sup>.

Finally the Strategy also has a set objective to reduce pressures on the health system<sup>81</sup>. However a number of conditions not included as ‘major conditions’ are already significant and growing contributors to health service activity volumes.

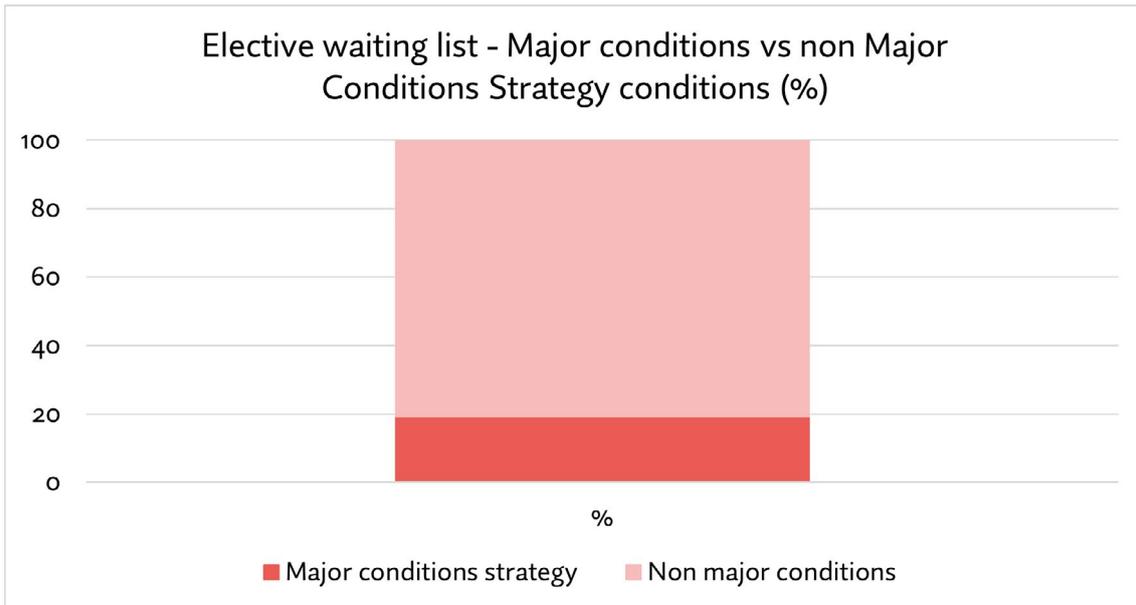
79 RNIB. Sight Loss Data Tool. Available at: <https://www.rnib.org.uk/professionals/health-social-care-education-professionals/knowledge-and-research-hub/sight-loss-data-tool/> [Last accessed October 2023]

80 Future Health projections of future ICB dermatology prevalence based on Richard et al, Prevalence of most common skin diseases in Europe: a population-based study, March 2022. Available at: <https://onlinelibrary.wiley.com/doi/full/10.1111/jdv.18050> [Last accessed October 2023]

81 UK Parliament. Written questions, answers and statements. Government Action on Major Conditions and Diseases. January 2023. Available at: <https://questions-statements.parliament.uk/written-statements/detail/2023-01-24/hcws514> [Last accessed October 2023]

For example when one analyses the elective waiting list, 80% of those waiting for treatment are for conditions not listed as ‘major’ by the ‘Major Conditions Strategy’<sup>82</sup>.

Figure 17: Analysis of elective waiting list by major condition and non-major condition as defined by the Major Conditions Strategy



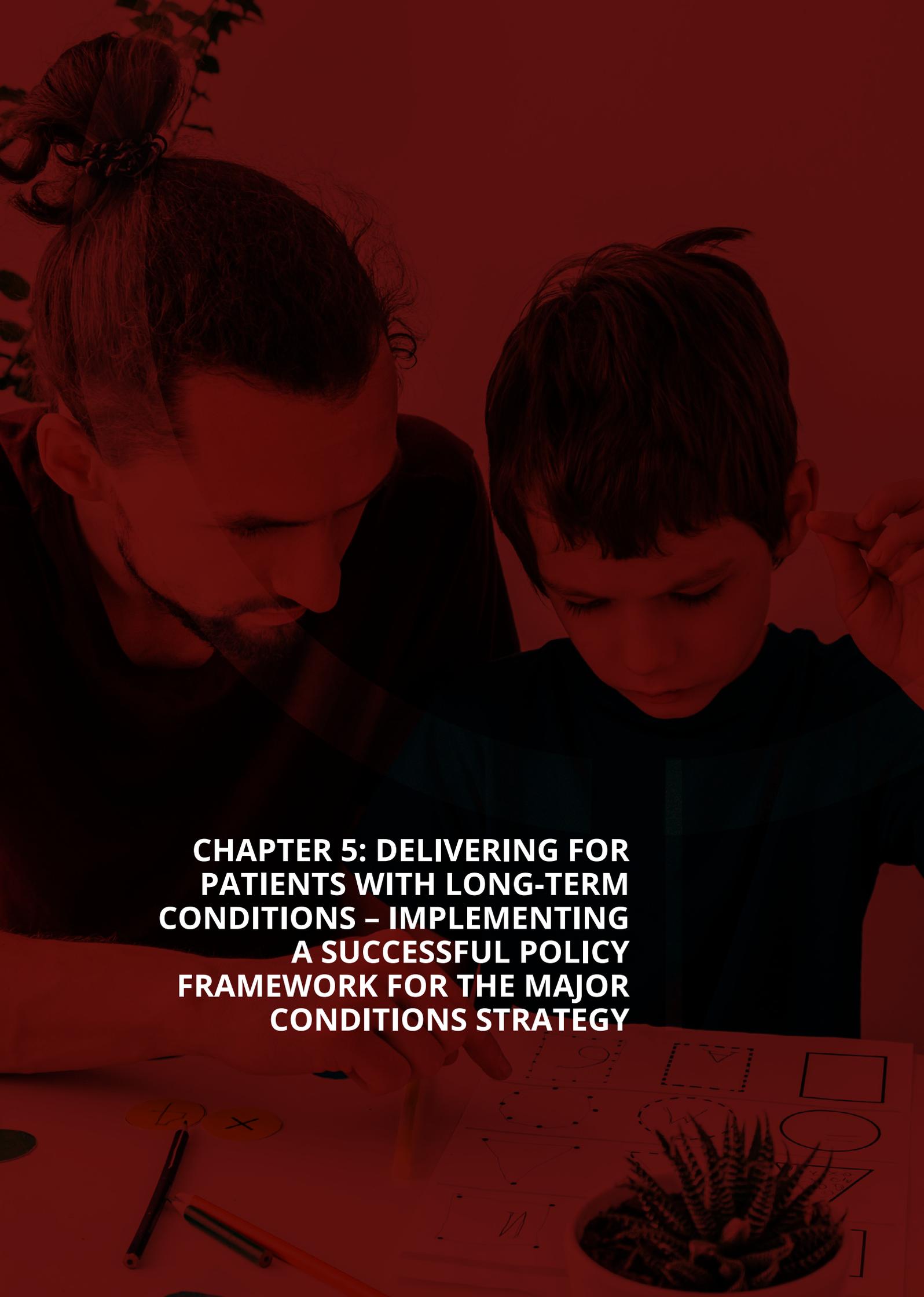
### Summary

The Major Conditions Strategy does present a welcome opportunity to improve care for people with long-term conditions and move the design of care towards a more patient centred model, particularly when looking at the growing numbers of patients with multiple conditions.

However the prioritisation of six particular specialties in the Strategic Framework does not line-up clearly with this objective and approach.

To succeed the Strategy will need to develop an operating framework that can support ICBs to effectively join-up care around the needs of patients as patients say they want.

<sup>82</sup> NHS England. Consultant-led Referral to Treatment Waiting Times Data 2023-24. Available at: <https://www.england.nhs.uk/statistics/statistical-work-areas/rtt-waiting-times/rtt-data-2023-24/> [Last accessed October 2023]

A photograph of a man and a young boy looking at a worksheet together. The man is on the left, leaning over the boy on the right. They are both looking down at the worksheet. The worksheet has various shapes and patterns on it, including a large 'X' and a large 'O'. There are also some smaller shapes and lines. The background is a solid dark red color. The text is overlaid on the bottom half of the image.

**CHAPTER 5: DELIVERING FOR  
PATIENTS WITH LONG-TERM  
CONDITIONS – IMPLEMENTING  
A SUCCESSFUL POLICY  
FRAMEWORK FOR THE MAJOR  
CONDITIONS STRATEGY**

In the 2000s the health policy operating model saw record year to year uplifts in funding. This was used to develop national strategies and frameworks for conditions or groups of conditions such as cancer, cardiovascular disease (CVD), diabetes and long-term conditions. These plans and frameworks came with targets and accountability for performance, along with levers around choice and competition, that saw a primarily top-down approach deliver some notable service improvements whilst not achieving all its goals.

In the 2010s, the model shifted. Funding was more constrained and power in the system more distributed across national, regional and local bodies. National strategies were still used for priority conditions such as cancer, CVD and mental health but they were fewer in number and a promised long-term condition strategy never materialised. Progress has been mixed.

Whilst some elements of this model have recently shifted again with the passage of the Health and Social Care Act 2022 – such as the Department of Health and Social Care having more directive power over NHS England – ambitions to empower new systems to deliver for their populations remain at the forefront of policymaking<sup>83</sup>.

As a new strategy for improving health outcomes across England is developed through the Major Conditions Strategy, the question now is what operating framework should the Strategy use to succeed?

As the current Strategic Framework notes, a top-down approach is no longer appropriate or possible and devolution must be embraced<sup>84</sup>. At the same time the Government is ultimately responsible for the performance of the health system in England.

The overarching operating model for a successful new strategy in these circumstances will need to see the Government creating an environment in which the objectives of the Strategy can be delivered and monitored and where ICBs are both empowered to deliver for their populations and held to account for doing so.

Creating the right balance to this equation is a perennial challenge for health policymakers and was a major theme of the recent Hewitt review<sup>85</sup>. There is though, a growing consensus that the new health system structures are the right partnership based approach to deliver a more balanced model<sup>86</sup>.

The following sets out ideas and thoughts on how to strike the right balance so that the Strategy delivers for patients:

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83 HM Government. Health and Care Act 2022. Available at: <https://www.legislation.gov.uk/ukpga/2022/31/contents/enacted> [Last accessed October 2023]

84 Department for Health and Social Care. Major conditions strategy: case for change and our strategic framework. August 2023. Available at: <https://www.gov.uk/government/publications/major-conditions-strategy-case-for-change-and-our-strategic-framework/major-conditions-strategy-case-for-change-and-our-strategic-framework--2> [Last accessed October 2023]

85 Hewitt, P. The Hewitt Review. April 2023. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1148568/the-hewitt-review.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1148568/the-hewitt-review.pdf) [Last accessed October 2023]

86 Hewitt, P. The Hewitt Review. April 2023. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1148568/the-hewitt-review.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1148568/the-hewitt-review.pdf) [Last accessed October 2023]

**Evolve the Major Conditions Strategy into a long-term condition and multiple conditions strategy** – The Major Conditions Strategy has already evolved since the announcement of its creation in January 2023 with a greater recognition in the summer 2023 update of the importance of tackling multi-morbidity<sup>87</sup>.

The one page strategic framework however still focuses on the six identified major conditions and places these at the top of the designed infographic<sup>88</sup>. The final strategy should move past this and instead adopt a more patient centred rather than condition centred approach. The Danish multi-morbidity strategy published earlier this year provides a model for this (see figure 18 below).

*Figure 18: Designing the Danish health system around the needs of patients with chronic disease and multimorbidity<sup>89</sup>*



87 Department for Health and Social Care. Major conditions strategy: case for change and our strategic framework. August 2023. Available at: <https://www.gov.uk/government/publications/major-conditions-strategy-case-for-change-and-our-strategic-framework/major-conditions-strategy-case-for-change-and-our-strategic-framework--2> [Last accessed October 2023]

88 Department for Health and Social Care. Major conditions strategy: case for change and our strategic framework. August 2023. Available at: <https://www.gov.uk/government/publications/major-conditions-strategy-case-for-change-and-our-strategic-framework/major-conditions-strategy-case-for-change-and-our-strategic-framework--2> [Last accessed October 2023]

89 Healthcare Denmark. Chronic diseases and multimorbidity in Denmark. Available at: <https://healthcaredenmark.dk/media/fabhotbl/3i-chronic-uk.pdf> [Last accessed October 2023]

Rather than selecting specific conditions, the Danish strategy focuses on chronic disease and multi-morbidity. The enablers for the strategy are a strengthened primary care system, greater multi-sector collaboration, improved health literacy, prevention and early detection and a coherent and patient centred approach.

The Danish strategy sits alongside wider government efforts to reduce suicide, improve mental health and reduce obesity.

As with the NHS Long Term Plan which included commitments in specific clinical areas such as cancer, stroke, COPD and others this shift in the Major Conditions Strategy would not preclude targets, ambitions and actions from being set in specific disease areas (for example setting new diagnosis targets for important conditions such as cancer and dementia). But it would ensure the primary focus for the strategy is on long-term and multiple conditions rather than on single disease care.

Aligned to this, planned reforms to the Public Health, NHS and Social Care Outcomes Framework into a Shared Outcomes Framework should be used to develop a targeted set of metrics that includes improvements in experience, outcomes and care for people with long-term conditions<sup>90</sup>.

**Strengthening the role of primary care and delivering more preventative care** – Any strategy focusing on improving the management of patients with long-term conditions and multiple conditions needs to ensure a strong and central role for primary care. Policy frameworks and levers that shape primary care will need to reflect the changing natures of patient need and also support aims to pivot care towards the improved monitoring of patients, earlier diagnosis and prevention.

The QOF was introduced in 2004 with the aim of improving the quality of primary care. There is evidence that in important areas such as diabetes, the use of quality indicators through the scheme has improved patient outcomes<sup>91</sup>. Scotland abandoned its QOF scheme in 2016. Emerging evidence has identified a significant decrease in performance in 12 of the 16 areas since<sup>92</sup>. Data from the QOF is also used for helping to identify disease prevalence and support wider efforts at clinical research.

However during the pandemic a number of QOF indicators were suspended<sup>93</sup>. There are calls from the British Medical Association to now scrap the scheme and move the funding into a core service pot<sup>94</sup>.

90 Department of Health & Social Care. Shared outcomes toolkit for integrated care systems. October 2023. Available at: <https://www.gov.uk/government/publications/shared-outcomes-toolkit-for-integrated-care-systems/shared-outcomes-toolkit-for-integrated-care-systems> [Last accessed October 2023]

91 McKay et al. Diabetes research and Clinical Practice. Associations between attainment of incentivised primary care diabetes indicators and mortality in an English cohort. April 2021. Available at: <https://pubmed.ncbi.nlm.nih.gov/33713716/> [Last accessed October 2023]

92 Morales, D, R. et al. The BMJ. Estimated impact from the withdrawal of primary care financial incentives on selected indicators of quality of care in Scotland: controlled interrupted time series analysis. March 2023. Available at: <https://www.bmj.com/content/380/bmj-2022-072098> [Last accessed October 2023]

93 British Medical Association. Quality and outcomes framework (QOF). Available at: <https://www.bma.org.uk/advice-and-support/gp-practices/funding-and-contracts/quality-and-outcomes-framework-qof#:~:text=Most%20QOF%20indicators%20have%20now,carried%20forward%20from%202020%2F21> [Last accessed October 2023]

94 Pulse Today. BMA demand QOF and PCN funding to be moved into core GP contract. June 2023. Available at: <https://www.pulsetoday.co.uk/news/breaking-news/bma-demand-qof-and-pcn-funding-to-be-moved-into-core-gp-contract/#:~:text=The%20GPC%20also%20called%20for,a%20quality%20improvement%2Dbased%20contract> [Last accessed October 2023]

Updating the QOF so that it is better aligned with delivering the goals of the Strategy and the health needs of the population is an important reform for success. Ways to do this could include incentivising<sup>95</sup>:

- **Continuity of care** – within the Quality Improvement Domain of the Framework including measures that encourage GPs to where possible provide continuity of care for people with multiple long-term conditions. This could be particularly helpful for older patients with multiple conditions who are more likely to want to see the same practitioner where possible. This is also where the greatest benefit of the policy could materialise and support wider systems efforts at delivering more preventative care<sup>96</sup>
- **Recording the prevalence of patients with multiple long-term conditions** – re-focusing the Clinical Domain so that there is a greater need to record, monitor and improve the care of people with multiple long-term conditions
- **Linking QOF payments more closely to patient feedback** – a more radical approach would be to link patient feedback of their GP experience to quality payments for GPs. A pilot scheme could be adopted to test methods and approaches for this

Alongside the QOF and as part of the introduction of Primary Care Networks, NHS England introduced a Direct Enhanced Service (DES) for improving patient satisfaction and experience of primary care. As part of this an Investment and Impact Fund (IIF) was created. In 2023-24 the number of indicators within the Fund was streamlined to five, with the majority of funding focused on improving the patient experience of contacting their practice and being assessed and/or seen within an appropriate timeframe<sup>97</sup>. As part of future updates to the DES, IIF indicators could be included focused on improving the experience and co-ordination of care for those with multiple long-term conditions.

**Investing in patient and public research into how to improve the care and treatment of people with multiple long-term conditions** – Traditionally healthcare research has been focused on single disease areas and specialties. With the increase in long-term and multiple long-term conditions there is a growing need to increase research funding to better understand the needs of these patients and how to better design services to meet this need. In its 2016 guideline for assessing and managing multi-morbidity NICE noted the gaps in research:

“The guideline committee felt that primary care was well suited to managing multimorbidity, but agreed that this was often challenging partly because of

95 NHS England. Quality and Outcomes Framework guidance for 2023/24. Available at : <https://www.england.nhs.uk/wp-content/uploads/2023/03/PRN00289-quality-and-outcomes-framework-guidance-for-2023-24.pdf> [Last accessed October 2023]

96 British Journal of General Practice. Do English patients want continuity of care, and do they receive it? 2012. Available at: <https://bjgp.org/content/62/601/e567> [Last accessed October 2023]

97 NHS England. Primary Care Networks: Network Contract Directed Enhanced Service from April 2023. March 2023. Available at: <https://www.england.nhs.uk/wp-content/uploads/2023/03/PRN00157-primary-care-networks-network-contract-directed-enhanced-service-from-april-2023-letter.pdf> [Last accessed October 2023]

how primary care is currently organised. However, there was inadequate high-quality research on alternative approaches to organising care for people with multimorbidity<sup>98</sup>.”

The NIHR has identified multiple long-term conditions as one of its strategic priorities.

### NIHR: The Multiple Long-term Conditions (Multimorbidity) Strategic Framework

Fund high quality research to provide an evidence base which:

- Identifies and maps common clusters of disease and their trajectories among the population
- Identifies the problems and outcomes that matter most to patients and carers and how they would like to see services configured to meet their needs
- Delivers research that enables the health and social care system to take a patient-centred, whole person approach to the treatment and care for people with multiple long-term conditions, including quality of life and well-being
- Supports design and delivery of interventions to prevent patients progressing from one long-term condition to multiple long-term conditions

The NIHR framework represents an opportunity to increase knowledge of how best to tackle multiple long-term conditions within the healthcare system. To succeed the framework will need to ensure it delivers in each area identified, but in particular ensure research programmes that work closely with patients and carers on their priorities.

### Case study: Understanding the priorities of patients with multiple long-term conditions in France

A study by Tran et al analysed the areas and issues patients in France with multiple long-term conditions would like to see improved. Patients' top priorities were

- (1) Transforming care to be holistic and personalised, at a consultation level
- (2) Smoothing patients' journey in the care system, increasing their knowledge of their own health and improving care coordination, at a care structure level
- (3) Training clinicians in better interpersonal skills and knowledge of specific conditions/treatments, reducing stigma and making care more affordable, at a healthcare system level

The study also asked a group of professionals in care, care quality improvement

98 NICE. Multimorbidity: clinical assessment and management. September 2016. Available at: <https://www.nice.org.uk/guidance/ng56/chapter/Recommendations-for-research> [Last accessed October 2023]

The French study above demonstrates that often the areas that patients identify as a priority for improvement are relatively easy to improve. Such understanding and insight in the NHS system could be used to deliver small but important changes in how care for people with long-term conditions and multiple long-term conditions is delivered and make care more patient centred.

**Building and digitising new guidelines of good practice care and care pathways** – As with health research, guidelines and guidance for the NHS from NICE has often focused on single care pathways. NICE’s 5-year strategy notes that there is an increasing need to build integrated guidelines across public health, the NHS and social care as a result of a rise in co-morbidities and to support ICBs in their population health efforts<sup>99</sup>.

NICE’s existing guideline for assessing and managing multi-morbidity is from 2016 and linked to a more dynamic and powerful research agenda from the NIHR above should be a priority to update<sup>100</sup>.

As set out by the Tony Blair Institute however there is a need for any such guidelines and materials to be digitised and embedded within systems to support effective implementation<sup>101</sup>. A great deal of existing NICE guidance and evidence reviews (e.g. Cochrane) is in webpage or pdf form and not easily accessible or translatable. This limits its impact. Making such guidelines easier to use, through digitisation and improved presentation, will increase their likelihood of adoption and can also be used to engage patients in what best practice care looks like and to support the uptake of it. This also extends to NHS England’s shared decision making tools which are designed to support shared decision making between clinicians and patients for a number of long-term conditions<sup>102</sup>.

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99 NICE. NICE Strategy 2021 to 2026. April 2021. Available at: <https://www.nice.org.uk/Media/Default/Get-involved/Meetings-In-Public/Public-board-meetings/Mar-24-pbm-NICE-strategy-2021-2026.pdf> [Last accessed October 2023]

100 NICE. Multimorbidity: clinical assessment and management. September 2016. Available at: <https://www.nice.org.uk/guidance/ng56/chapter/Recommendations-for-research> [Last accessed October 2023]

101 Tony Blair Institute. The NHS Refounded: Delivering a Health Service Fit for the Future. June 2022. Available at: <https://www.institute.global/insights/public-services/nhs-refounded-delivering-health-service-fit-future> [Last accessed October 2023]

102 NHS England. Decision support tools. Available at: <https://www.england.nhs.uk/decision-support-tools/> [Last accessed November 2023]

### Case study: Redbridge Primary Care Team (PCT) and the uptake of COPD best practice care

Redbridge PCT sought to engage patients in the delivery of best practice care for COPD. Six indicators were selected from the NICE quality standard and developed into a patient facing scorecard. The four page scorecard was co-created with patients. Those patients participating in the study were then sent a covering letter along with the scorecard explaining the process and encouraged to take their scorecard to their GP appointment to help inform the appointment. Against each of the five final indicators used to assess the results of the study the intervention group where the scorecard was used performed better than the control group who did not receive the intervention<sup>103</sup>.

### Driving implementation and accountability of best practice outpatient models

– There were close to 100 million outpatient appointments in the NHS in 2021-22. As set out earlier some of the highest numbers of outpatient appointments are for long-term conditions such as ophthalmology, dermatology and rheumatology<sup>104</sup>.

NHS England and the Royal College of Physicians are in the process of developing a new strategy for outpatients to ensure it is delivered effectively and efficiently. One of the principles for reform identified is the increase in people with multiple conditions: “outpatient service transformation must consider the needs of patients with multiple conditions. It should be a significant element in developing more integrated care involving specialist, primary, community, and social care as well as the voluntary sector<sup>105</sup>.”

One of the early Long Term Plan priorities for ICBs was to deliver digitally enabled outpatients and primary care services<sup>106</sup>. However there will be major difficulties in delivering this programme based on experience to date. The existing *NHS Outpatient Recovery and Transformation Programme* has a series of guides on referral optimisation, the use of video consultations, personalised follow-up and reducing Do Not Attends<sup>107</sup>. However implementation of these programmes is not

103 Roberts, M, C. et al. Impact of a patient-specific co-designed COPD care Scorecard on COPD care quality: a quasi-experimental study. *Primary Care Respiratory Medicine*. March 2015. Available at: <https://www.nature.com/articles/npjpcrm201517> [Last accessed October 2023]

104 NHS England. Hospital Outpatient Activity 2021-22. September 2022. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/hospital-outpatient-activity/2021-22> [Last accessed November 2023]

105 Royal College of Physicians. Improving outpatient care. Available at: <https://www.rcplondon.ac.uk/projects/improving-outpatient-care> [Last accessed October 2023]

106 NHS England. Designing integrated care systems (ICs) in England. June 2019. Available at: <https://www.england.nhs.uk/wp-content/uploads/2019/06/designing-integrated-care-systems-in-england.pdf> [Last accessed October 2023]

107 NHS England. Outpatient Recovery and Transformation Programme. Available at: <https://www.england.nhs.uk/outpatient-transformation-programme/> [Last accessed October 2023]

mandated and there is a lack of transparency in tracking improvements. This is particularly important given the size of the challenge and its impact on patients. Reform has estimated that there are 11 million people on the follow-up waitlist in acute trusts, many of whom are needing care and management for long-term conditions<sup>108</sup>.

Currently the NHS Oversight Framework (OF) includes only a single indicator for ICBs on Outpatient Transformation related to follow-up activity levels against the 2019-20 baseline<sup>109</sup>. To deliver the programme a new indicator in the OF should be introduced that tracks the implementation of both the forthcoming and existing Outpatient transformation programmes. Improving the uptake of the approaches in the programme should drive improvements in care for people with long-term conditions.

Alongside this, ICBs as part of their annual report should set out how they are implementing the Outpatient Transformation Programme - or if they are not - explain their reasons for not doing so.

### **Using the NHS App to improve patient engagement and health literacy –**

The NHS App has been downloaded 30 million times<sup>110</sup>. New functionality is being added to support patients in better managing their care and booking appointments. For example people with musculoskeletal conditions will have free access to digital therapeutics through the App to help them manage their care, which can be accessed 24/7 without a GP referral<sup>111</sup>.

Studies have shown that 4 in 10 patients are unable to make use of everyday health information. When numeracy skills are added, this rises to over 6 in 10<sup>112</sup>. With the rise in multiple long-term conditions the amount and complexity of health information to be understood by patients is set to increase.

The wider use of the NHS App presents an opportunity to better engage patients in their care and care plans but to do so effectively will require a strategy for improving rates of health literacy<sup>113</sup>. The Danish Health system has identified eight paths to improving health literacy as part of a programme for ensuring greater health equity.

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108 Reform. The hidden waitlist: the growing follow-up backlog. October 2023. Available at: <https://reform.uk/wp-content/uploads/2023/10/Reform-The-Hidden-Waitlist-Embargoed.pdf> [Last accessed October 2023]

109 NHS England. NHS Oversight Framework. Available at: <https://www.england.nhs.uk/nhs-oversight-framework/> [Last accessed October 2023]

110 NHS Digital. NHS App hits over 30 million sign-ups. January 2023. Available at: <https://digital.nhs.uk/news/2023/nhs-app-hits-over-30-million-sign-ups> [Last accessed October 2023]

111 Department for Health and Social Care. Major conditions strategy: case for change and our strategic framework. August 2023. Available at: <https://www.gov.uk/government/publications/major-conditions-strategy-case-for-change-and-our-strategic-framework--2> [Last accessed October 2023]

112 Public Health England. Local action on health inequalities: Improving health literacy to reduce health inequalities. September 2015. Available at: [https://assets.publishing.service.gov.uk/media/5a80b62d40f0b62302695133/4b\\_Health\\_Literacy-Briefing.pdf](https://assets.publishing.service.gov.uk/media/5a80b62d40f0b62302695133/4b_Health_Literacy-Briefing.pdf) [Last accessed October 2023]

113 It is important to note that not all patients will access or be able to access the NHS App and that the Government and the NHS will need to use multiple channels and routes to effectively engage across the whole population

### Case study: Approach to improving health literacy in Denmark<sup>114</sup>

- Path No. 1 Management and culture – Health literacy is articulated and prioritised in the local management and organisational culture
- Path No. 2 Skills – Employees and managers are supported in gaining knowledge about health literacy and applying this knowledge in daily practice
- Path No. 3 Process and practice – Health literacy is integrated into all relevant work processes
- Path No. 4 Involvement – Citizens from relevant target groups are involved in the planning, implementation and evaluation of health services and programmes
- Path No. 5 Access – Information and services are visible and easy to access and navigate for citizens and health professionals
- Path No. 6 Communication – Oral, written, and digital communication is easy to understand and adapted to citizen’s needs and local levels of health literacy. Dissemination takes place on media and platforms, which are relevant to the target group
- Path No. 7 Vulnerability and high risk – A health literacy focus is emphasised in the provision of health services and information to groups with vulnerabilities and high risk of information loss
- Path No. 8 Monitoring and evaluation - Professional health literacy work processes are monitored and evaluated in the local organisation

As part of the Major Conditions Strategy the Government should include a plan, based on the ‘paths’ approach above and using the potential of the App for improving health literacy.

**National and local leadership for improving outcomes for patients with long-term conditions** – As set out above, top-down only approaches to delivering the Major Conditions Strategy will not be successful. Instead what is required is a balanced model between the centre, the regions and local health services. Leadership for implementing the strategy should be balanced across all three. Nationally the responsibility for major conditions and long-term conditions sits at Minister of State level and it will be important that this continues and that Ministerial sponsorship for the Strategy is used to secure funding, set the framework and priorities and hold the NHS to account for delivery<sup>115</sup>.

However it will be for regional and local services to lead the execution of the strategic framework based on the needs of their local populations. As the Hewitt

114 Danish Health Authority. Health Literacy in Danish Health Organisations. 2022. Available at: [https://www.sst.dk/-/media/Udgivelser/2022/Sundhedskompetence/Pixi-Sundhedskompetence-UK.ashx?sc\\_lang=da&hash=E4AF6C8774809C10EF3140415C3DA14E](https://www.sst.dk/-/media/Udgivelser/2022/Sundhedskompetence/Pixi-Sundhedskompetence-UK.ashx?sc_lang=da&hash=E4AF6C8774809C10EF3140415C3DA14E) [Last accessed November 2023]

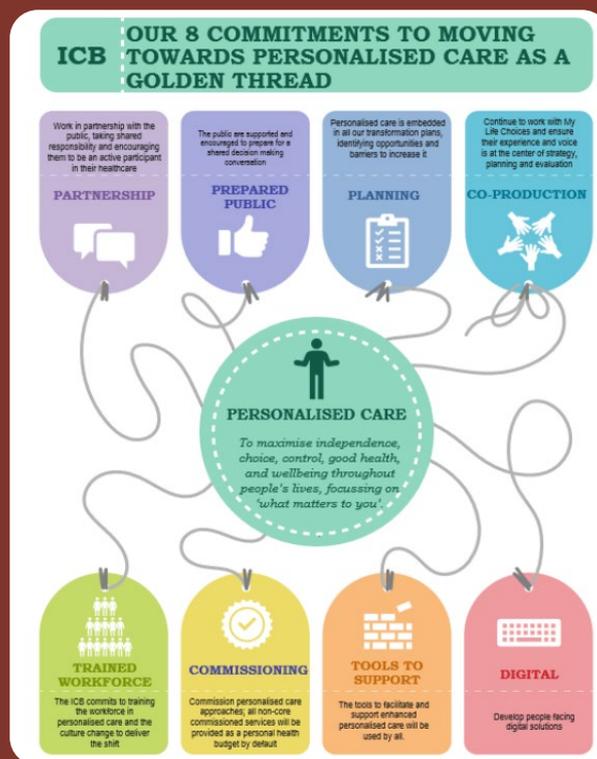
115 Department of Health & Social Care. Minister of State (Minister for Health and Secondary Care). Available at: <https://www.gov.uk/government/ministers/minister-of-state--127> [Last accessed October 2023]

review notes: “evidence-based guidance and best practice examples are, of course, invaluable to local leaders; but it is essential that those local leaders have flexibility about how they apply those lessons to their particular local circumstances<sup>116</sup>.” Locally ICBs should work with their ICPs and relevant partners across primary care, local government, social care, the voluntary and private sectors to develop their plans and make these public. An example of this is Nottingham and Nottinghamshire ICB which has developed a personalised care strategy.

**Case study: Nottingham and Nottinghamshire Personalised Care Strategy<sup>117</sup>**

Nottingham and Nottinghamshire ICB has developed a personalised care strategy that aims to make personalised care an essential driver in health and social care service improvement across all commissioned services in Nottingham and Nottinghamshire. The strategy is based on eight commitments as set out below.

Figure 19: Nottingham and Nottinghamshire ICB personalised care model



The success of the strategy will be judged on a series of metrics including staff knowledge and personalised care activity levels and people reporting improved outcomes.

116 Hewitt, P. The Hewitt Review. April 2023. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1148568/the-hewitt-review.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1148568/the-hewitt-review.pdf) [Last accessed October 2023]

117 NHS Nottingham and Nottinghamshire. Personalised Care Strategy and Key Commitments. Available at: <https://notts.icb.nhs.uk/wp-content/uploads/sites/2/2023/01/Personalised-Care-Strategy-and-Key-Commitments-1.pdf> [Last accessed October 2023]

Patient and public engagement will also be critical. The Patients Association has developed the six key principles of patient partnership to support ICBs in carrying out meaningful patient engagement.

### Patients Association – six key principles of patient partnership<sup>118</sup>

- 1. Treating patients as equals:** Patients are treated as equals, with their views recognised as equally valid and having an equal say in decisions.
- 2. Patients who are fully informed:** Services and systems make sure patients are fully informed, in a way that patients can access and understand, and patients use as much information as they wish to.
- 3. Shared decision making and patient partnership:** Shared decision making, and patient partnership approaches are used as a matter of routine.
- 4. Recognising inequalities:** Inequalities are recognised, and appropriate approaches adopted for different patient groups and communities, identifying and meeting their specific needs
- 5. Seeking patient input:** Patient input is actively sought, genuinely valued, and meaningfully acted on.
- 6. Joining services around patients:** Services join up around patients, working with them to identify their needs, and responding to them in a way that make things as easy as possible for the patient.

### Joining-up the workforce around the needs of patients with long-term

**conditions** – The NHS Long Term Workforce Plan provides welcome increases in the number of medical professionals over the next fifteen years<sup>119</sup>. However there is a need to also tackle the distribution of healthcare professionals not just the overall numbers.

New medical schools and commitments for a higher proportion of post graduates in 2024/25 to work in areas with the greatest shortages contained in the Plan will help<sup>120</sup>. Our research highlights the regional variation in the impact of multiple long-term conditions. When considering the level of workforce shortages in different parts of the country the complexity of population health need should also be factored in, so that areas with higher rates of people with multiple long-term conditions are assigned appropriate numbers of staff – particularly in primary and community care.

118 Patients Association. Six Principles of Partnership. Available at: <https://www.patients-association.org.uk/the-six-principles-of-patient-partnership> [Last accessed October 2023]

119 NHS England. NHS Long Term Workforce Plan. June 2023. Available at: <https://www.england.nhs.uk/wp-content/uploads/2023/06/nhs-long-term-workforce-plan-v1.2.pdf> [Last accessed October 2023]

120 NHS England. NHS Long Term Workforce Plan. June 2023. Available at: <https://www.england.nhs.uk/wp-content/uploads/2023/06/nhs-long-term-workforce-plan-v1.2.pdf> [Last accessed October 2023]

Ways of working also need to change to account not only for evolving population health needs but also the scale of pressures on the system. Earlier this year Sussex MSk partnership held innovative sessions with musculoskeletal patients out of hospital where patients were provided with physio and wider health and wellbeing support. 50% of those who attended were discharged and 30% directed to other services<sup>121</sup>.

**Funding the adoption and spread of innovation to improve patient care and outcomes for people with long-term conditions** – A number of reports have noted that the NHS struggles to spread and adopt innovation and good practice<sup>122</sup>. Spreading and adopting innovation is complex and requires understanding of local context and capacity to implement change<sup>123</sup>. The Health Foundation also note that the adoption of innovation requires (i) acceptance of the problem and the proposed solution and (ii) the motivation to put the solution into practice<sup>124</sup>.

One of the main issues (though not the only issue) with innovation adoption is funding the change that is required to be made. Funding is needed to support effective implementation. An example is the New Models of Care programme which was integral to the 2014 Five Year Forward View and development of ICBs which came with £329m of investment to deliver<sup>125</sup>.

Without funding to support adoption, access to innovation will remain highly variable and piecemeal for patients. Innovation funding across the system is primarily skewed towards testing and piloting innovation rather than supporting adoption<sup>126</sup>. As part of the work on the Major Conditions Strategy and the Sinker review into NHS innovation<sup>127</sup>, the Government and NHS should seek to re-balance funding and attention towards greater scalability for proven innovations. The trade-off for this will be that fewer innovations are tested, but that more with proven benefit are then scaled.

The NHS Adoption Fund provides a potential mechanism to further invest in, and currently focuses on digitising pathways in a number of long-term conditions:

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- 121 BBC. Sussex NHS physio team slashes their waiting list with one-day events. October 2023. Available at: <https://www.bbc.co.uk/news/uk-england-sussex-67122363> [Last accessed October 2023]
  - 122 Nuffield Trust. Falling short: Why the NHS is still struggling to make the most of new innovations. December 2017. Available at: <https://www.nuffieldtrust.org.uk/research/falling-short-why-the-nhs-is-still-struggling-to-make-the-most-of-new-innovations> [Last accessed October 2023]
  - 123 The Health Foundation. The spread challenge. September 2018. Available at: <https://www.health.org.uk/sites/default/files/upload/publications/2018/The-spread-challenge.pdf> [Last accessed October 2023]
  - 124 The Health Foundation. The spread challenge. September 2018. Available at: <https://www.health.org.uk/sites/default/files/upload/publications/2018/The-spread-challenge.pdf> [Last accessed October 2023]
  - 125 The National Audit Office. Development new care models through NHS vanguards. June 2018. Available at: <https://www.nao.org.uk/wp-content/uploads/2018/06/Developing-new-care-models-through-NHS-Vanguards.pdf> [Last accessed October 2023]
  - 126 UK Parliament. Evaluation of Government commitments made on the digitisation of the NHS. February 2023. Available at: <https://publications.parliament.uk/pa/cm5803/cmselect/cmhealth/780/report.html> [Last accessed October 2023]
  - 127 HSJ. AHSNs face cuts and uncertainty despite 'relaunch' and renaming. May 2023. Available at: <https://www.hsj.co.uk/technology-and-innovation/ahsns-face-cuts-and-uncertainty-despite-relaunch-and-renaming/7034882.article#:~:text=Cambridge%20Hospitals%20CEO%20Roland%20Sinker,proposals%20for%20the%20networks%20future> [Last accessed October 2023]

gastroenterology, musculoskeletal and respiratory<sup>128</sup>. The Government and NHS England should explore how the Adoption Fund could be expanded and used to deliver more co-ordinated care for patients with long-term conditions as part of work to implement the Major Conditions Strategy.

Some parts of the system are actively restricting access to innovation such as NICE approved therapies, which can deliver higher quality, cost effective and preventative care. Certain prescribing committees have been happy to publicly recognise that this is a direct breach of their statutory NHS constitution and mandate<sup>129</sup>. The Government and NHS England should ensure that any such moves are quickly over-turned.

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128 NHS England. Adoption Fund 2022-2023. <https://transform.england.nhs.uk/key-tools-and-info/adoption-fund/> [Last accessed October 2023]

129 NHS North of Tyne, Gateshead and North Cumbria Area Prescribing Committee. Minutes of the meeting held on Tuesday 11th October 2022. Available at: [https://www.northoftyneapc.nhs.uk/wp-content/uploads/meeting\\_files/2073\\_apc\\_minutes\\_\\_october\\_2022\\_v2.pdf](https://www.northoftyneapc.nhs.uk/wp-content/uploads/meeting_files/2073_apc_minutes__october_2022_v2.pdf) [Last accessed October 2023]

## CONCLUSION

In the 2000s national condition strategies and frameworks were developed to support improvements in health outcomes linked to record year on year increases in funding. Levers such as choice, competition and information were used to deliver reform and improvements. There is evidence that this model – which was primarily top-down in approach – was successful in improving care in some priority condition areas such as cancer and mental health<sup>130</sup>. However progress for patients with long-term conditions was more mixed. Whilst improvements were noted in patients' engagement with their condition, overall self-reported patient outcomes did not noticeably improve.

In the 2010s power in the health system was more spread. Whilst national strategies remained in some condition areas, in others – such as those with long-term conditions – commitments were downgraded and not taken forward. Action was instead more embedded within local health systems with predictably variable and mixed results.

A successful national strategy for improving health outcomes for the population needs to be rooted in the circumstances in which it is being launched. The policy environment in 2023-24 is very different from the early 2000s and even the early 2010s. Funding is constrained, the health system is still recovering from the pandemic with large backlogs of care, there are significant challenges with staff retention and power in the health system is more dispersed particularly with the establishment of ICBs. Perhaps most importantly, whilst there is a continuing need to improve outcomes for specific conditions, the rise in the numbers of people with multiple long-term conditions presents a major structural challenge for health systems.

A Major Conditions Strategy could be a real enabler for re-designing health services more around the needs of patients and joining up care. However the existing Strategic Framework on which the document is based places six conditions as priorities above others, which runs counter to the patient centred approach that is needed.

As the Government continues to evolve the Strategy following consultation, it should move to a model based on placing the patient rather than specific conditions at the centre. The final Strategy should be one focused on long-term conditions and patients with multiple conditions as seen in Denmark.

A blended national-local delivery model will be needed to succeed. This is not about more resource, but deploying existing resource more effectively. Government can use its role to set the policy framework for ICBs to deliver. Reforming primary care so greater incentives are in place to support continuity of care and the management

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130 King's Fund. Case study 2: The National Service Framework for Mental Health in England. Available at : <https://www.kingsfund.org.uk/publications/making-change-possible/national-service-framework-mental-health-england> [Last accessed October 2023]

of patients with multiple conditions, ensuring the health needs of patients are factored into the distribution of the workforce across the country and building the right monitoring and metrics, such as a Shared Outcomes Framework, to ensure implementation will all help in this regard. ICBs can then take forward the regional development and delivery of the plans and provide updates through their existing statutory reporting requirements for doing so.

Limited funding and a system under severe pressure might see people dismiss the Major Conditions Strategy as an irrelevance or distraction. However if got right it could be the basis of a new model between the centre, the regions, systems and patients. Over the proposed five year time frame it has the space and time to deliver. Getting the right design framework in place from the start though will be critical to success.

## ABOUT THE AUTHOR



Richard Sloggett is the Founder and Programme Director of Future Health. He was previously a Senior Fellow at Policy Exchange and from 2018-19 was Special Advisor to the Secretary of State for Health and Social Care. Richard is a regular commentator in the national media on health and social care and has been named as one of the top 100 people in UK healthcare policy by the Health Service Journal. During his time with the Secretary of State, Richard worked across Whitehall, the NHS and local government on major policy decisions including the NHS Long-Term Plan and the Prevention Green Paper. Alongside his work at Future Health Richard is undertaking his doctoral thesis in preventative healthcare systems at the University of Liverpool.

## ABOUT FUTURE HEALTH

Future Health is a public policy research centre focused on creating healthier, wealthier people, communities and nations. Future Health publishes regular research papers across its three policy research programmes of health prevention, health technology and the links between improvements in health and economic growth. <https://www.futurehealth-research.com/>

Future Health would like to thank all those who kindly contributed their time as part of an expert roundtable to discuss the early research findings in the summer of 2023. The views expressed in this report are solely those of Future Health.



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