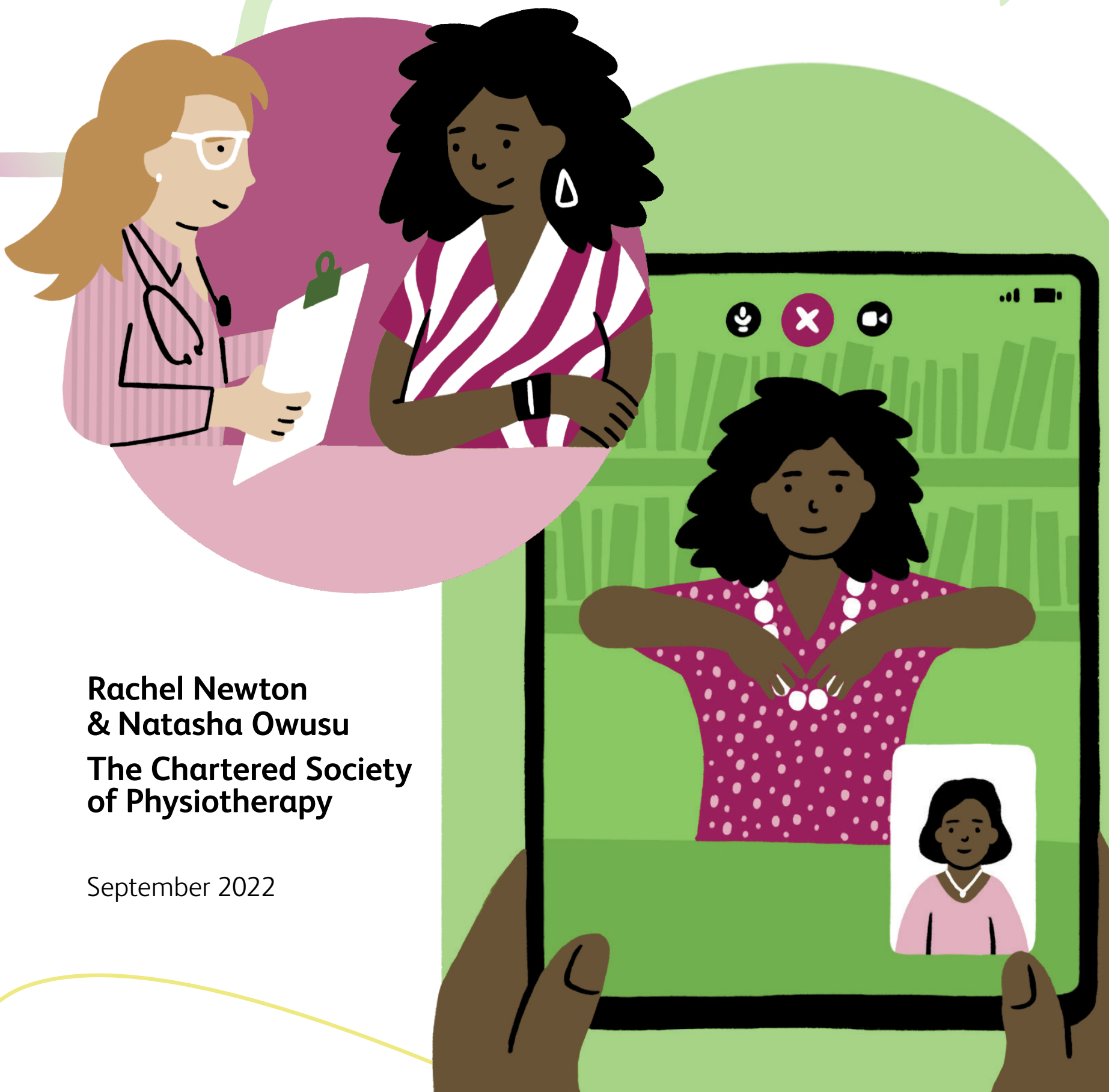


Rehabilitation, recovery  
and reducing health inequity:

# Easing the pain



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& Natasha Owusu  
The Chartered Society  
of Physiotherapy

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# Foreword

I have first-hand experience of rehabilitation services in Wales, and relied upon the multidisciplinary team both of Aneurin Bevan Health Board and subsequently in Powys tHB to help me recover from Covid-19. During my time in hospital and beyond, I experienced rehab delivered by dedicated Allied Health Professionals, who were doing their best at a time of great demand.

Across Wales patients need a similar level of care and access to rehab services. Rehab is vital to maximising outcomes for patients, and allowing people to live to their lives to full potential. The holistic approach to rehab keeps people out of hospital longer and remain independent for longer.


There is now a growing awareness that access to these services is not always equal, and work needs to be done to ensure that Wales adopts the best practice available in this field. I hope that policymakers, health board leaders, and the third sector find this guide useful in improving patient experience across Wales.

## **CIr William 'Bill' Powell**

*Former Welsh Assembly Member, and recent rehabilitation patient*

As Chair of the Community Rehabilitation Alliance in Northern Ireland I very much welcome the publication of this report. Overall people in Northern Ireland are living longer and healthier lives. However, health inequalities across Northern Ireland continues to be a persistent major issue of concern. Life expectancy for men in the most deprived areas of NI is on average 7.5 years less than their counterparts in the least deprived areas. For women, the differential is 4.3 years. In Northern Ireland there are 9 admissions to hospital for every 20 people in the most deprived areas compared to 6 admissions for





every 20 people in the least deprived areas. These inequalities continue have a detrimental impact on the entire HSC system at a time when hospital services are under extreme pressure and as we attempt to rebuild services and tackle waiting lists post COVID.

It is hoped that the new Integrated Care System, currently being developed in Northern Ireland, will bring about new ways of working and of commissioning services. It is vitally important that any new approach to commissioning should be aligned with integrated health and social care organisations on the ground and should target specific inequalities and social groups.

This report and the case studies contained within, is very timely and will make an important contribution in informing health care providers, decision makers and commissioners, across the health and care system, of the significant contribution that access to high quality community based rehabilitation services can make in addressing health inequalities in Northern Ireland.

## Neil Johnston

*Chair, Community Rehabilitation Alliance NI*





# Introduction

Progress with health care and medical science has been significant in recent years but the benefits are not equally shared because of systemic marginalisation, discrimination and inequality in income. As a result, people in marginalised groups and communities are more likely to live shorter lives, and to struggle with more health difficulties.

In the UK, deaths from stroke halved in the first decade of this century. In the last 60 years deaths from cardiovascular diseases (CVD) have declined by more than three quarters. Cancer survival has doubled in the last 40 years.<sup>(1-3)</sup> However, these major improvements in mortality rates are not enjoyed equally by different communities.

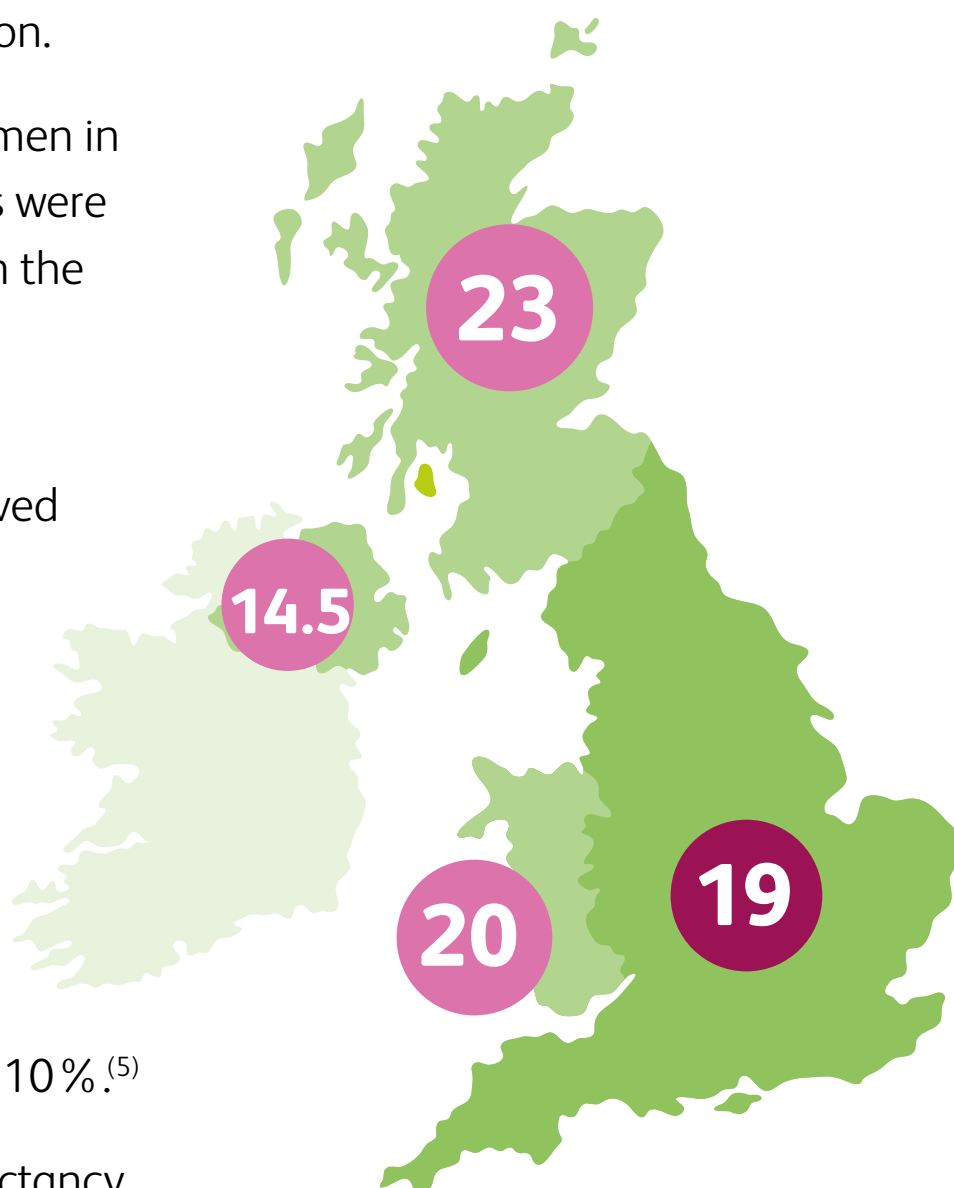
The recent COVID-19 pandemic has not only shone a harsh light on health inequalities, but it has also exacerbated these. The impact has been felt across all NHS services, including rehabilitation.

In 2019, deaths among men and women in the most deprived 10% of local areas were 176-177% times higher than those in the least deprived 10% of local areas.

This widened further in 2020, due to the pandemic. Men in the most deprived 10% of local areas were 192% and women 183% more likely to die over this period than those in the least deprived 10% of areas.<sup>(4)</sup>

While life expectancy continues to improve for the most affluent 10% of our population, it has either stalled or fallen for the most deprived 10%.<sup>(5)</sup>

Even greater than the gap in life expectancy described, are the gaps in healthy life expectancy and disability-free life expectancy. People in the most deprived communities can expect to enjoy considerably fewer years in good health than those in the most affluent. Across the UK the gap between the most deprived and least deprived communities in healthy life expectancy ranges from a 14.5 to 23 year gap (see map).





Healthy and disability-free life expectancy is further reduced dependent on an individual's ethnicity, sex, sexuality and disability. Bangladeshi men in England, for example, are expected to have 10 years less disability free life expectancy than their white counterparts.<sup>(11-16)</sup>

**The same drive for improvement and innovation that has produced medical breakthroughs now needs to be applied to recovery and rehabilitation services, to reduce the unfair inequities in health, and enable people not only to survive, but live well and active lives.**



# Glossary of terms

## Cultural competence

Cultural competence relies on a knowledge of other cultures and sensitivity and respect to these. Cultural competence is the capacity to provide effective services taking into account cultural beliefs, behaviours and needs of people. It is therefore made up of cultural awareness, sensitivity as well as the promotion of anti-oppressive and anti-discriminatory policies.

## Health inequity and health inequality

The World Health Organisation defines health inequities as differences in health status or in the distribution of health resources between different population groups, arising from the social conditions in which people are born, grow, live, work and age. Health inequities are unfair and could be reduced by the right mix of government policies.

Health inequalities refer to differences in health and is the metric by which health inequity can be assessed. Health inequities describe health differences that are unfair and unjust. Measuring and monitoring health inequalities shows objective differences in health, which can be used to evaluate and improve the state of health inequity in a population.

Given the overlap between the two terms, for consistency the term health inequity is used throughout this report.

## Long-term conditions

Long-term conditions or chronic diseases are conditions for which there is currently no cure, and which are managed with drugs and other treatment.





## Multi-morbidity

Multi-morbidity is the coexistence of 2 or more long-term conditions within an individual.

## Rehabilitation and recovery

Rehabilitation (or recovery) is a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment.


Interventions include: holistic assessment; a personalised rehabilitation treatment plan; advice and education to support self-management; structured exercise – which can be one-to-one, in groups online; support with diet; psychological support; support with communications, adaptations and assisted technology.

### Rehabilitation and Recovery services:

- empower people to successfully self-manage ongoing health conditions, with less reliance on medication
- prevent health crises: for example, reducing risks of stroke or heart attack for people with cardiovascular disease (CVD)
- prevent development of related conditions, loss of mobility, depression and pain
- enable recovery after such a health crisis or surgery – for example restoring mobility after hip and knee replacements
- optimise the effectiveness of other treatment, for example elective surgery, cancer treatment (sometimes called pre-habilitation)
- reduce or delays the impact of long-term conditions: for example, for people with neurological disorders such as Parkinson's





- 
- improve quality of life as part of palliative care
  - support people to return to work, for example after a stroke or acquired brain or spinal injury (sometimes called vocational rehabilitation).

## Statutory framework

In England the Health and Care Act 2022 updates the health equality duties of NHS England and other NHS bodies. It requires NHS England to have regard to reducing inequalities between people with respect to their ability to access services; has a duty to reduce inequalities with respect to outcomes from the provision of health services, in relation to effectiveness of services, safety and quality of experience. It requires all NHS bodies, including NHS Trusts, Foundation Trusts and health care providers must consider health inequalities when taking decisions.<sup>(17, 18)</sup>

The Equality Act 2010 applies in all parts of the UK. This includes in relation to health as a devolved matter – which means the Governments of Wales, Scotland and Northern Ireland are responsible for health and the NHS/health care systems in their respective countries. The Act provides legal protection against disadvantage and discrimination on the basis of age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation. These are termed in the legislation as ‘protected characteristics’. It also provides the Public Sector Equality Duty on public bodies, including the NHS. This includes a duty to remove or minimise disadvantages suffered due to their protected characteristics, take steps to meet the needs of people from protected groups, and monitor and publish data.<sup>(19)</sup>





# Executive summary

The gap in healthy life expectancy is being driven by the increasing numbers of people managing a long-term condition (LTC) and, increasingly more than one – known as multi-morbidity. This situation affects a higher proportion of the population facing systemic discrimination and marginalisation, and those experiencing higher levels of deprivation.<sup>(20)</sup>

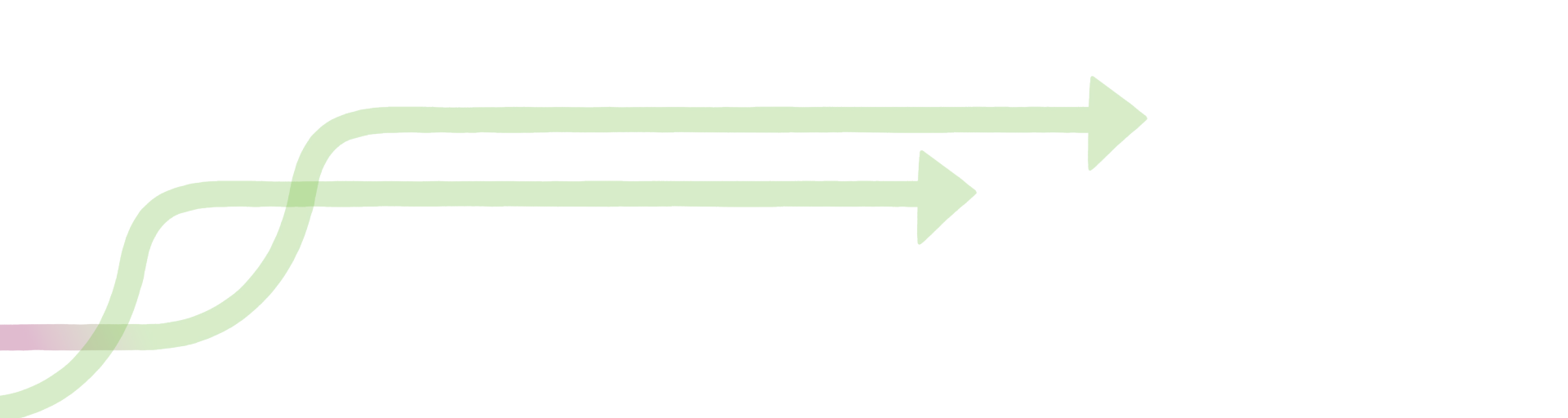
Thanks to advances in medicine, many of the conditions that previously caused death in deprived populations, such as cardiovascular disease and cancers, are now experienced as a LTC. The most common LTCs are ones where rehabilitation makes a significant difference to ongoing health and wellbeing. It should be universally available as an unmissable part of treatment. But currently millions miss out.

Whether an individual is supported through rehabilitation affects not only their health but their life chances, their earning potential, how active they are in their community, if they become socially isolated, how happy they are.

Without rehabilitation people can be stuck in a downward spiral where having one LTC leads to other health conditions, including further long-term conditions, with loss of mobility and poor mental health and multiple medication regimes (known as polypharmacy). Ensuring everyone who needs rehabilitation can access it can reverse this downward spiral.

While poor access to NHS rehabilitation services is almost ubiquitous, some communities face particular barriers which correlate to health inequity.

A new vision to transform rehabilitation is needed to drive quality improvements in order to meet the needs of all communities. This includes building from the exemplary services that already exist, co-producing services with the public that are rooted in communities, and using data to drive improvements.

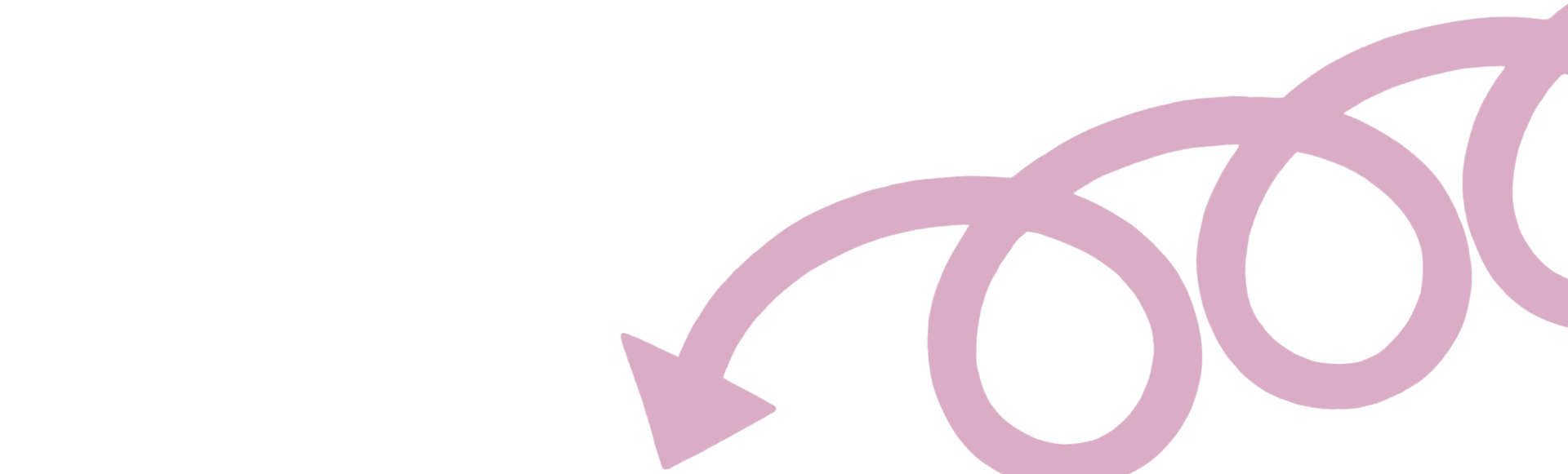


Charities and professional bodies for Allied Health Professions (AHPs), fitness professionals, geriatricians, rehabilitation doctors and nurses with a shared commitment to this have formed alliances for community rehabilitation in England, Scotland, Wales and Northern Ireland.

Using this breadth of experience and learning from the many excellent rehabilitation services that showcase modern and inclusive provision, alliance partners have developed principles and recommendations for high quality services. These include delivery models that are preventative, personalised and population focussed, with more provision outside hospitals making use of existing community assets. They are focussed on empowering individuals to self-manage, based on need rather than diagnosis and incorporate psychological support.

To raise standards, alliance members have also developed multi-professional best practice standards for community rehabilitation, underpinned by principles of inclusivity and equity. Integrated audit tools enable the standards to be monitored and reported on.

The NHS needs transforming from an illness service to a health service that meets population needs sustainably and equitably. This requires each new health intervention to have a rehabilitation component. Building rehabilitation quality and capacity as an equal pillar of healthcare is key to achieving this.





# Recommendations for action

All UK Governments have made commitments to address inadequate rehabilitation and disparities in healthy life expectancy. The latter is entirely dependent on the former.<sup>(5, 13-15)</sup>

Rehabilitation has been under-resourced and developed in an unplanned, piecemeal fashion over decades and services are not yet recovered from Covid, having been the most impacted part of the health service.<sup>(16)</sup>

The desire to do something about this has occasioned alliances in each country in the UK for community rehabilitation, bringing together national charities and professional bodies for the rehabilitation workforce.

Together we have agreed principles for quality rehabilitation – that is preventative, personalised, empowers self-management, works in partnership with patients and carers, based on need not diagnosis, incorporating psychological support, with more provision outside hospitals and making use of existing community assets.

The Chartered Society of Physiotherapy (CSP) has worked with our partners to develop Community Rehabilitation Best Practice Standards and audit tools based on these principles, underpinned by evidence; these are due to be published October 2022.

There are many excellent services showing what modern rehabilitation services should look like. But these can only be scaled up as part of joined-up efforts nationally and locally.

Redesign of rehabilitation services needs to be informed by marginalised groups, through listening and capturing data on the experience of health inequalities and barriers to accessing services. Co-produced delivery models are key. Services can only be tailored to meet the needs of all communities if there is meaningful engagement with those with lived experience to help design and implement services.

Building back and modernising our rehabilitation capacity as an equal pillar of healthcare is key to how we transform the NHS from being an illness service to a health service that can meet modern population needs sustainably and equitably.



## Recommendations for England

### Department of Health and Social Care

- Commit funding to improve access to quality rehabilitation through implementation of the NHS Long Term Plan and commitments in the Women's Health Strategy and publish the delayed Health Disparities White Paper.

### NHS England

- Hold systems to account for delivering the rehabilitation elements of the refreshed NHS Long Term Plan to address health inequity and prioritise currently under-served groups.
- Endorse the Community Rehabilitation Best Practice Standards.

### Integrated Care Boards

- Commit to measurably reducing the gap in healthy life expectancy by 2030 in line with mission 7 of the Levelling up White Paper by developing their community rehabilitation offer.
- Ensure rehabilitation is part of data improvement plans.
- Strengthen leadership and accountability for rehabilitation and health inequity<sup>(21)</sup>

### Place Boards

- Adopt outcome measures for access to community rehabilitation to reduce the gap in healthy life expectancy by 2030.
- Support local partnerships between the local NHS providers, local authorities and fitness industry.

### Rehabilitation/AHP leads

- Use Community Rehabilitation Best Practice Standards and audit tools.
- Work with service leads to identify priorities for redesigning to improve access to under-served groups identified in the Core20PLUS5 approach.
- Work with Primary Care Networks to integrate provision at neighbourhood level.



## Recommendations for Scotland

### Scottish government

- Ensure that addressing health inequalities is enshrined in the National Care Service legislation and specified in implementation plans of the Rehabilitation framework.

### Health Boards and Public Health Scotland

- Commit to extending community rehabilitation services to address health inequalities.
- Appoint rehabilitation leads to drive quality improvement.
- Endorse Community Rehabilitation Best Practice Standards.

### Health and Social Care Partnerships

- Commit to targets to reduce health inequity.
- Improve rehabilitation data systems.
- Appoint rehabilitation leads to develop services.

### Rehabilitation/AHP leaders

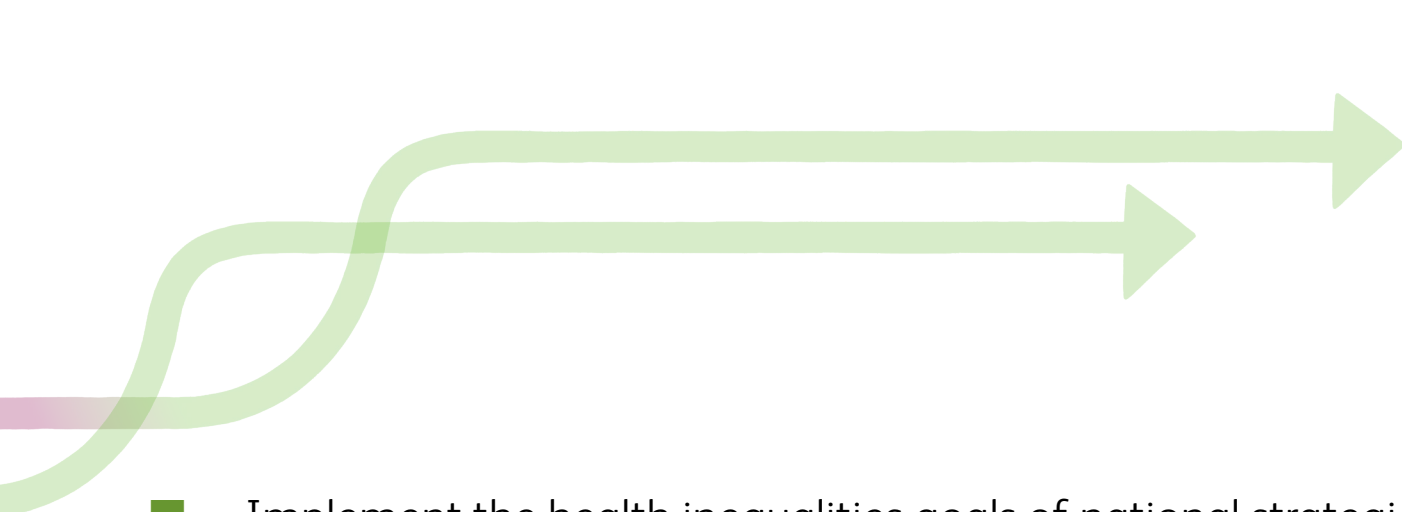
- Use Community Rehabilitation Best Practice standards to deliver on the ambitions of the rehabilitation framework and the Rehabilitation and Recovery: A Once for Scotland Person-Centred Approach to Rehabilitation in a Post-COVID Era.
- Work across primary, acute, social care and third sectors.



## Recommendations for Wales

### Welsh Government

- Consolidate commitments and measures to tackle health inequalities in one delivery plan to improve accountability.
- Introduce health impact assessment regulations.
- Commission an equality assessment of rehabilitation services.
- Ensure arrangements in place to improve data to support health equity.

- 
- Implement the health inequalities goals of national strategies including Race Equality Action Plan: An Anti-Racist Wales, LGBTQ+ Action Plan for Wales and the commitments in The Quality Statement for women and girls' health.
  - Ensure future rehabilitation quality statements and frameworks prioritise equity.
  - Work with external stakeholders to deliver the recommendations of Mind the gap.

### **Health Boards**

- Endorse Community Rehabilitation Best Practice Standards.
- Implement the standards and the principles of Healthier Wales to ensure that appropriate rehabilitation space is available across primary, secondary, and community settings, making rehabilitation as accessible as possible to all communities.

### **Regional partnership boards and public service boards**

- Use integrated care funding to encourage collaboration and tackle health inequalities.

## **Recommendations for Northern Ireland**

### **NI Executive**

- Ensure that a Right to Rehabilitation is included in the Assembly Programme for Government and is part the outcome framework for tackling inequality and discrimination in Northern Ireland.

### **Department of Health**

- Ensure the ongoing implementation of Health and Wellbeing 2026: delivering together, including the commitment to invest in HSC community development resources to enable social inclusion and tackle health inequalities.

### **Integrated Care System**

- As Integrated Care Systems are established they must ensure that at all levels of planning rehabilitation services are developed to address the specific needs of under-served groups in the population and address health inequity, with outcome measures relating to this.





# The health inequity gap

43% of people are managing a LTC in the UK and this is a primary factor in the health inequality between communities. People in the poorest communities have a 60% higher chance of being diagnosed with a LTC than those in the richest. They also have a 30% higher chance that their condition will be more severe.<sup>(22, 23)</sup>

Even after accounting for deprivation, prevalence of LTCs is higher amongst people aged 60+ who are from a black or minority ethnic group.<sup>(20, 24, 25)</sup>

People with a single LTC are at higher risk of developing further LTCs. This often contributes to a loss of mobility, pain, depression, anxiety and shrinking social networks. The prevalence of having multiple conditions, chronic pain and depression are linked to deprivation, being female and being from particular ethnic groups. Pain killers and anti-depressants are more likely to be prescribed, and for longer, for women and people living in poorer areas.<sup>(23, 26-29)</sup>

Conditions are often clustered, for example, more than a third of patients with chronic obstructive pulmonary disease (COPD) also have osteoporosis and depression. People with osteoarthritis have a 24% higher risk of cardiovascular disease and for people with rheumatoid arthritis this risk is 50-70% greater than for the general population.<sup>(26, 30-33)</sup>

People with learning disabilities, autism and serious mental health conditions experience much higher rates of many common LTCs including respiratory diseases, circulatory problems, heart failure and diabetes. This results in a shorter life expectancy of 13 to 20 years.<sup>(34)</sup>

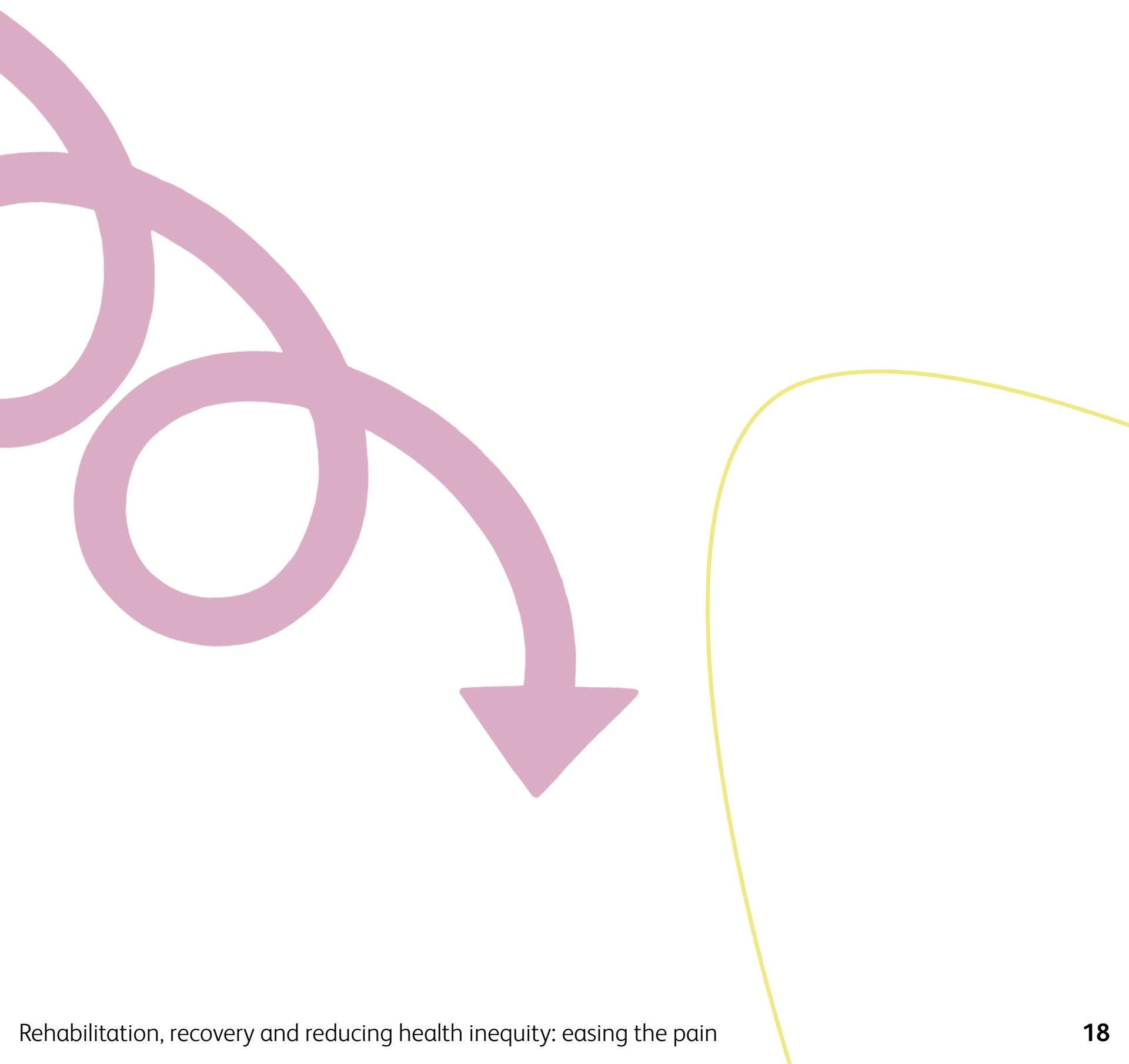
**People in the bottom fifth of deprivation levels are nearly twice as likely to have musculoskeletal and /or respiratory conditions and four times as likely to have mental health issues.**<sup>(22)</sup>





Refugees and migrants are at risk of long term conditions, such as cardiovascular diseases, COPD, diabetes and mental health issues. This results from stress and trauma, interrupted health care and poor living conditions, and from barriers to accessing healthcare in the UK – including recourse to public funds and fear of asking for help - and experiences of discrimination.<sup>(35)</sup>

All of the common long-term conditions mentioned here are ones where rehabilitation is a key part of treatment that is routinely being missed. (see box 2).



# Life chances and prosperity

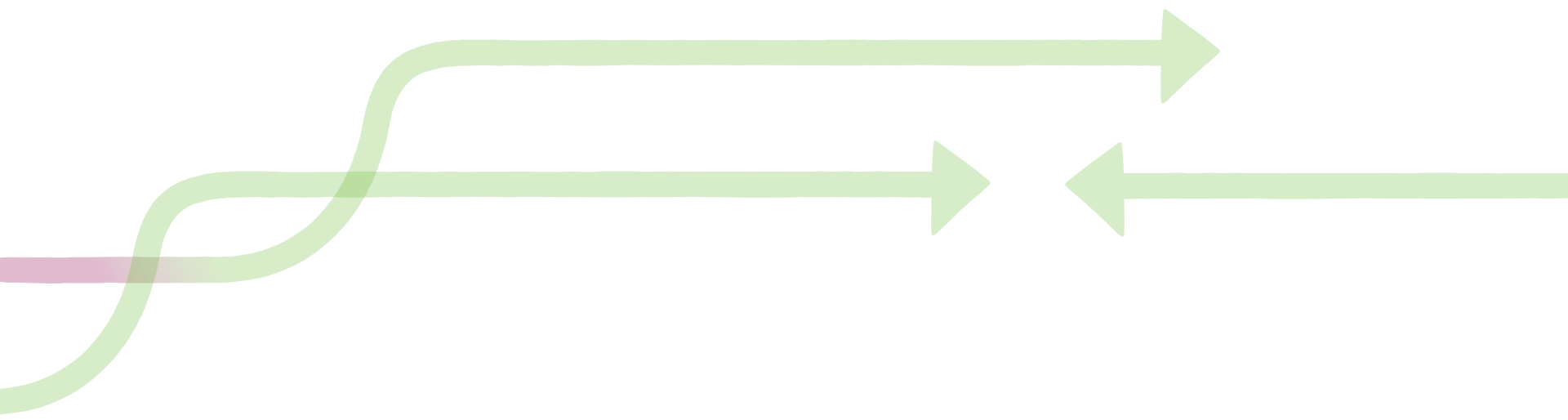
Work and health are inextricably linked. Good quality work contributes to health and wellbeing, and poor quality and insecure work, or unemployment, contributes to poor health. Someone with a LTC is more likely to be working for lower paid work or unemployed as a result of their condition. This reinforces inequity in the workplace – for example, people from black and minority ethnic communities are more likely to be in low paid and insecure work than white British communities.<sup>(36)</sup>

Nearly a third of working age people in the UK have a LTC. For many these will be conditions that limit their daily activities or the type of work that they can do, and those in this group are twice as likely to not have a job.<sup>(37, 38)</sup>

This proportion is higher in areas of deprivation and among marginalised communities. For example, people in the most deprived fifth of the population develop multiple LTCs 10 years earlier than those in the least deprived fifth. Furthermore, black Caribbean residents in their late 40s/early 50s report the equivalent levels of health as that reported by white British residents aged 61-70.<sup>(31, 39, 40)</sup>

More than half of people with a LTC see their health as a barrier to the type or amount of work that they can do, rising to more than 80% when someone has three or more conditions.<sup>(37)</sup>

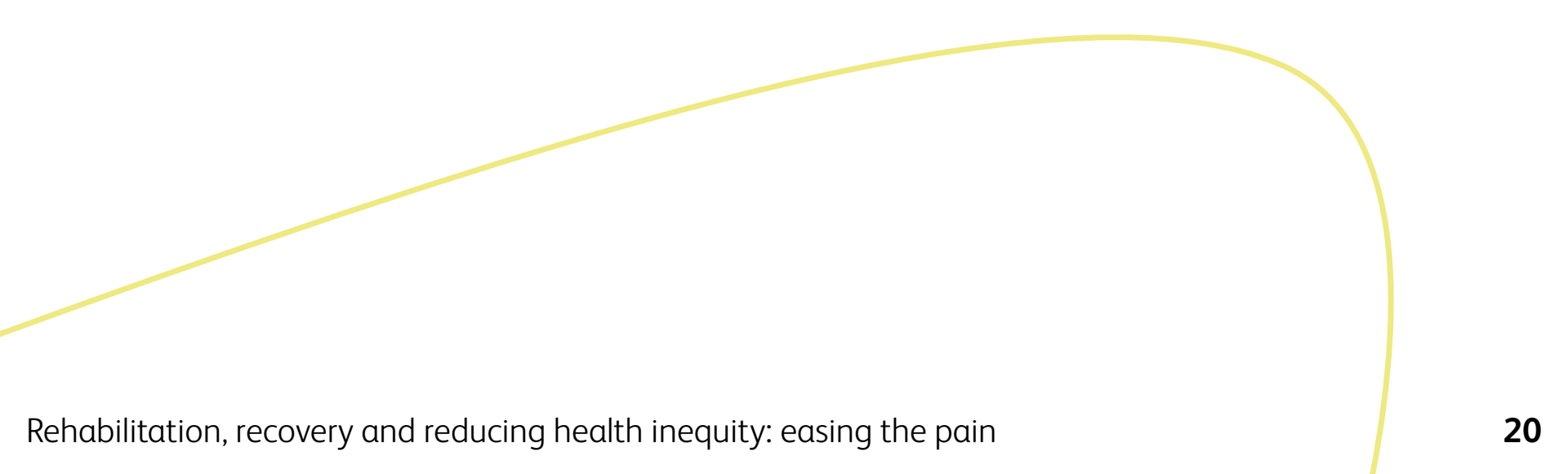




This has an additional impact on health: good-quality work has a significant contribution to an individual's physical and mental health and the contribution that poor working conditions have to health inequity.<sup>(31)</sup>

Communities living in regions with poorer performing economies are significantly (39 %) more likely to lose their job as a result of a period of ill health. If they get back into work, their wages are lower (66 %) than a similar individual in the rest of the country.<sup>(41)</sup>

Rehabilitation supports an individual to maintain or return to their usual activities, including work. It contributes to both individual prosperity and national and regional economic productivity.





# The difference rehabilitation makes

Whether Mary has timely access to rehabilitation will affect her social life, financial security and happiness, as well as her health. Without the rehabilitation she needs she can get stuck in a downward spiral. This is what drives health inequity.



Mary, 44 works full time. She loves to exercise but has been experiencing breathlessness and has smoked in the past.



Mary's GP diagnoses her with COPD. She gives Mary advice on managing her condition and how rehabilitation and exercise can benefit her. She refers Mary to a local rehabilitation service.



Mary's GP diagnoses her with COPD. She tells Mary it's irreversible, caused by her smoking. She gives her a leaflet about the condition, but says she can't refer her for rehabilitation until her condition deteriorates.



Mary stops exercising. Her COPD gets worse and eventually she needs admission to hospital. Once home she has de-conditioned and has developed back pain.





Mary continues to work and exercise, following advice from the rehabilitation service at her appointment.



Mary attends her holistic rehabilitation needs assessment at the local gym – carried out by a physio who is part of a clinical MDT.



The assessment considers Mary's needs. She agrees options for treatment that fit around her work, a mix of online and group rehabilitation at the gym.



Mary's progress is reviewed. She feels confident to manage her breathlessness and has maintained her activity levels and work. She is reassured she can self-refer to rehabilitation if she needs to in the future.



Mary's breathlessness worsens, she is depressed and her back pain is affecting her mobility. She now sees two different consultants. She has to leave work due to deteriorating health.



Mary has another COPD exacerbation. She spends five days in hospital worrying about how she will pay her rent this month.



Mary's appointment for rehabilitation has come through. She thinks it is too late to help her, so she doesn't take up the offer.





## Box 1: Long-term conditions and employment

The most common reason for time off work is musculoskeletal (MSK) issues, followed by mental health. MSK and depression are common co-morbidities of a range of physical long-term conditions, including cardiovascular disease and COPD.<sup>(42-44)</sup>

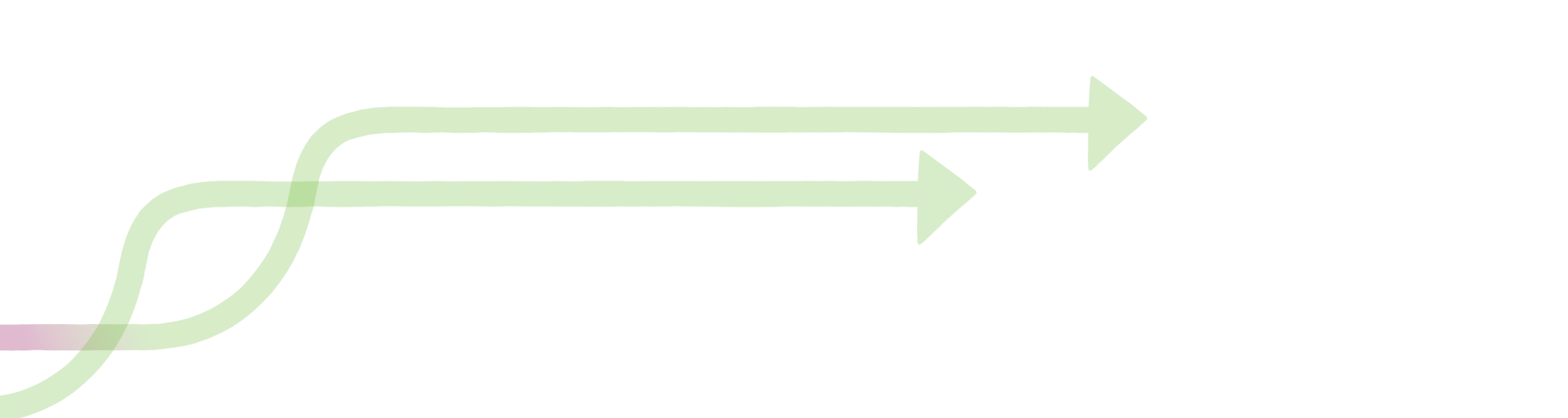
- In the UK 44% of the population with COPD are below retirement age, and around one quarter are not in work due to their COPD. People of working age are two to three times more likely to be unemployed eight years after their stroke.<sup>(45, 46)</sup>

In areas of high deprivation people are having strokes 7 years younger on average than the rest of England. It's a similar picture for heart and circulatory disease.<sup>(47, 48)</sup>

- It is not only deprivation that correlates with people having life limiting illnesses at a younger age. In some cases ethnicity is a factor. For example, people in the UK of South Asian origin are more likely to have heart disease at a younger age than the population as a whole.<sup>(49)</sup>

This in turn has an impact on an individual's working conditions, the area they can afford to live, the quality of their housing, and levels of debt, which affects their health. This is particularly an issue in the UK where access to rehabilitation is a post code lottery, and those who can't pay to make up for this are less likely to access what they need to recover.

**Poor health accounts for around 30% shortfall in productivity between regions in the UK.<sup>(36)</sup>**



People with LTCs unable to access rehabilitation services are less likely to be in work. The business case for rehabilitation that actively supports an individual to remain in or return to the workplace is well established. But with access to rehabilitation services so poor, and the services that exist so overstretched, this support is commonly unavailable. This has a detrimental impact on local economies with poor health of the workforce having a direct impact on productivity. The impact is even greater in 'left behind' neighbourhoods – defined by high ranking on indices of deprivation and poor social infrastructure - in all regions.<sup>(50-52)</sup>

People with LTCs are pushed into the most expensive and overburdened parts of health and care because they are not supported in the community to manage their conditions effectively. LTCs account for half of all GP consultations, 70% of bed days in hospital and 70% of total health and social care spending. Over 60% of patients admitted to hospital as an emergency have one or more long term conditions. The patients who feel most confident in managing their long term conditions have 38% fewer emergency admissions and 32% fewer attendance at A&E than those who feel the least confident.<sup>(23, 53, 54)</sup>

The situation of poorly managed long term conditions because of inadequate support increases pressure on local health systems, with a knock-on effect for other public services in areas of greatest need.<sup>(55-57)</sup>



# Millions missing out on rehabilitation

Equitable access to rehabilitation is essential to successful management of LTCs, reducing the risk of deterioration, preventing further conditions developing, and supporting recovery after a health crisis.<sup>(58)</sup>

For decades access to rehabilitation has been poor across the UK, in spite of overwhelming evidence as to its value (see box 2). Services are inconsistently commissioned, poorly resourced and over stretched – particularly outside acute hospitals, where there is the greatest need for support.

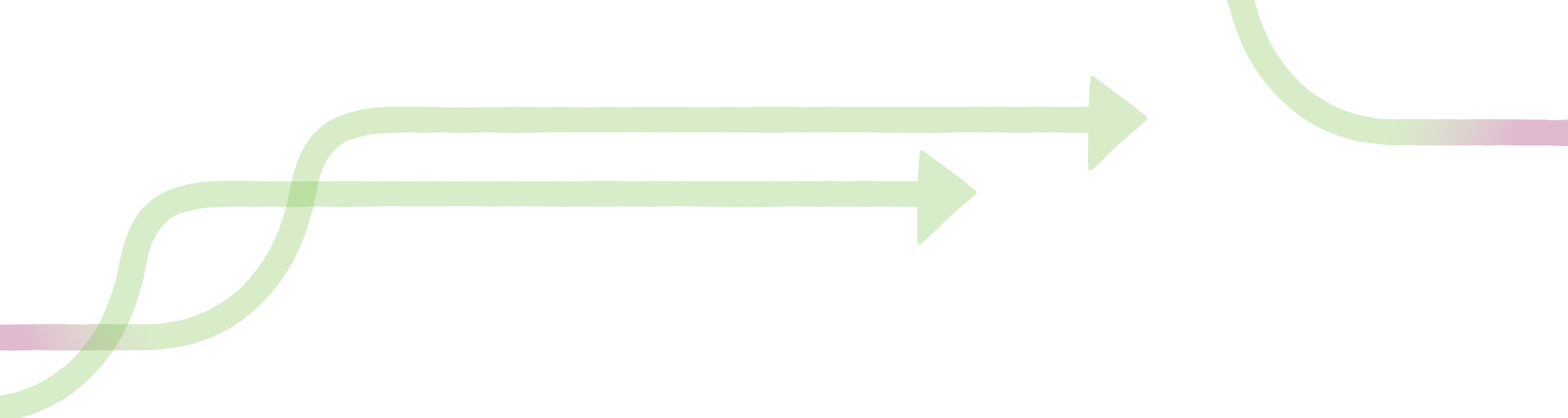
## Box 2 Some of the conditions where people routinely miss out on essential rehabilitation

Rehabilitation for people with COPD is proven to improve quality of life, reduce hospital admissions and reduce length of stay in hospital. However NHS data in England shows that even pre-pandemic, only 43% of the eligible COPD population were referred for pulmonary rehabilitation in 2019/20.<sup>(60-62)</sup>

Rehabilitation following a stroke can reduce the risk of a further stroke by 35% as well as enable people to return to previous levels of function and independence. In spite of this 20% of people who have had a stroke don't receive the minimum specialist rehabilitation required in the first 5 days and 68% do not have an assessment for rehabilitation required after discharge from hospital.<sup>(63, 64)</sup>

People with Parkinson's who complete a programme of rehabilitation to support self-management can see a 50% improvement in their health related quality of life.<sup>(65)</sup>

Thousands of people with MS rely on rehabilitation services but too many can't access this support, and this situation got worse during the pandemic. 70% of people were not able to access a rehabilitation professional when they needed it and 34% reported their MS symptoms having got worse, affecting their mobility, confidence and independence.<sup>(66)</sup>

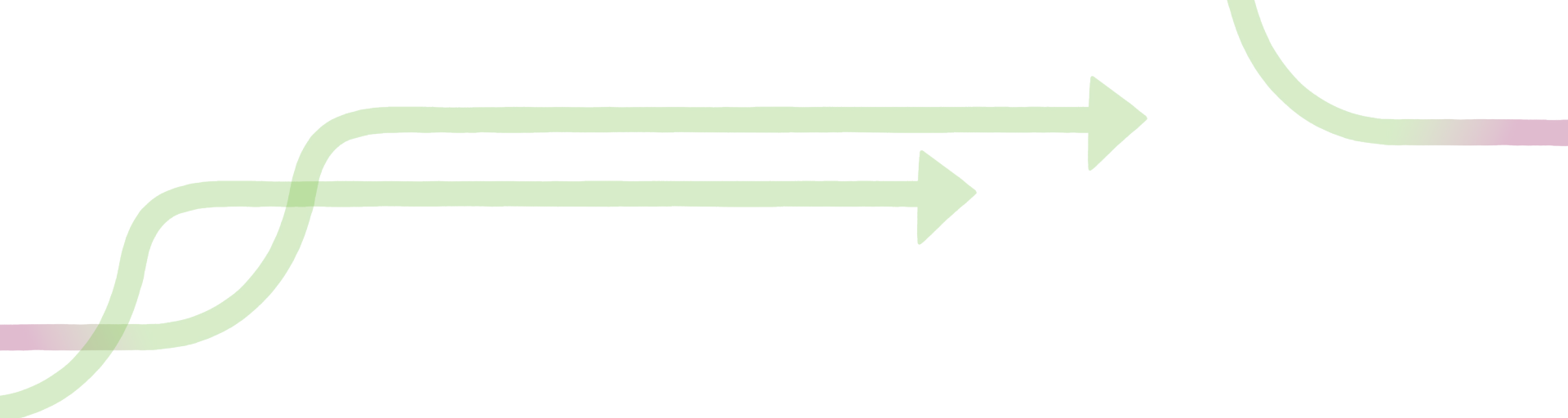


For the 1 in 6 people with a neurological condition, rehabilitation is key to managing pain, restoring function and motor skills, finding new ways to manage daily living, managing the psychological impact and support with nutrition and communication. But this is not available for many people. The Neurological Alliance Together for the 1 in 6 report of the findings of a large UK survey found that:

- over two thirds of people said their mental wellbeing needs are not being met.
- 70% said they needed more support with their diet.
- women and those living in more deprived areas with neurological conditions were more likely to report greater experience of pain, greater impacts on quality of life and greater impacts on day-to-day activities.

Referral rates and uptake of cardiac rehabilitation in England is 50%, in Wales is 61% and in NI is 49% of eligible patients. People attending cardiac rehabilitation are predominantly white British and male. Women are nearly 20% less likely to be referred and/or attend cardiac rehabilitation than men. People from deprived areas are also much less likely to have cardiac rehabilitation, and it is the same picture for people from some black and ethnic minority groups. This includes people from South Asian communities, in spite of being significantly more likely to have coronary heart disease than white communities.<sup>(70-75)</sup>

While less data on referral and take up of eligible patients are available for other areas of rehabilitation, the same patterns of low referrals and low take-up related to health inequity are evident.<sup>(67-69)</sup>

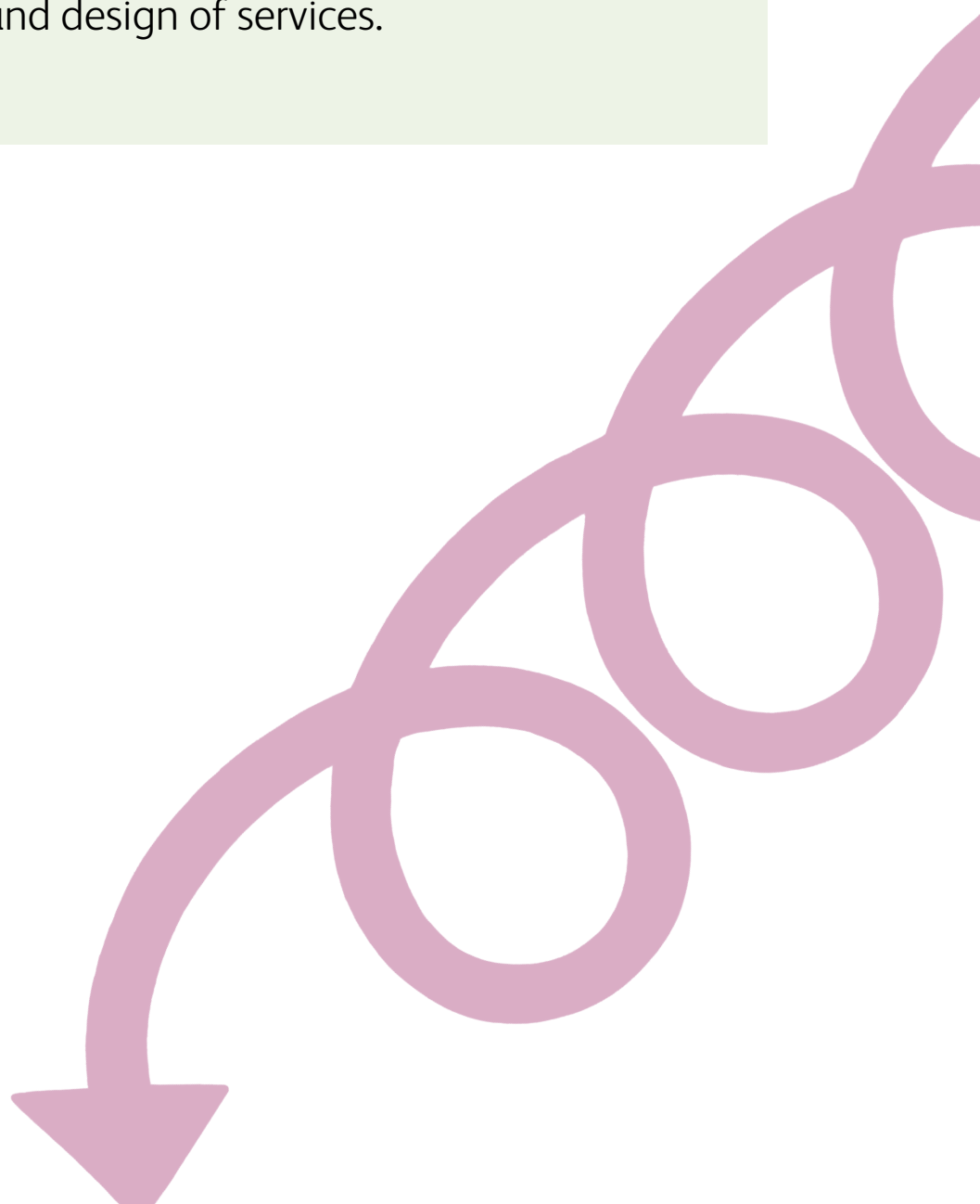


Rehabilitation services are as essential to good health outcomes as medicines and surgery. Yet are inconsistently provided – often too late or not at all.

At the same time need for rehabilitation is growing – on top of the rise of long term conditions and higher survival rates – rehabilitation needs have risen significantly as a direct and indirect consequence of the Covid pandemic.<sup>(59)</sup>

The populations who are most in need of rehabilitation, due to high prevalence of LTCs, are most challenged by poor access to rehabilitation. This includes gaps in provision, long waiting times and rationing of provision. Along with systemic inequity in income and power and structural barriers, this is a significant driver of health inequity.

But there are also notable differences between people from different communities in how likely they are to be referred for rehabilitation, and whether they take up any rehabilitation offered. This points to the need for improvements in both referrals and design of services.



# Barriers to access

## Siloed, fragmented provision

Rehabilitation services are currently delivered based on medical condition pathways and the needs of the part of the health system they are in, rather than organised around the needs of the individual. This is inefficient, often duplicates care, and does not address the needs of people living with multiple conditions, both physical and mental.



For example, a woman who has moderate frailty might benefit from strength and balance classes to prevent her from becoming extremely frail. But this will not meet her needs if her breathlessness because of a heart condition or COPD is not effectively managed.

Rehabilitation services are often fragmented and poorly networked, developed in a piecemeal way. This can make it hard for service users to navigate and for clinicians making referrals to services.

This situation can only be compounded for people unfamiliar with the health care system - which is a problem particularly challenging for refugees and migrants, who may not have recourse to public funds. It also reinforces barriers experienced by anyone less likely to ask for the support they need for reasons of language, education, class, cultural attitudes to illness or immigration status.<sup>(35, 76)</sup>

Because rehabilitation services are considered under medical conditions rather than a cross cutting and overarching need, GPs and hospital doctors are often unfamiliar with what rehabilitation is, what it can achieve, the evidence supporting this, what services exist and how to refer. As a result they often do not communicate its importance to their patients.

At the same time there is little consistency in what a 'good' level of provision and quality looks like, which makes it harder for patients and/or carers to know what to ask for or expect.

This situation both reduces the likelihood of their referring, and reduces the quality of their referrals, which results in poor take-up rates.<sup>(77)</sup>





## Discrimination

Discrimination in society causes people to experience emotional stress and distress, trauma and feelings of shame and stigma. These contribute directly to poor health.<sup>(78-80)</sup>

An analysis of the 1999 and 2004 England Health Surveys' results concluded that the relative material deprivation faced by people from black and ethnic minority communities could not account for the extent of the poorer health experienced in comparison to their white British counterparts, and that direct and indirect experience of racism in everyday life is an important contributory factor.<sup>(81)</sup>

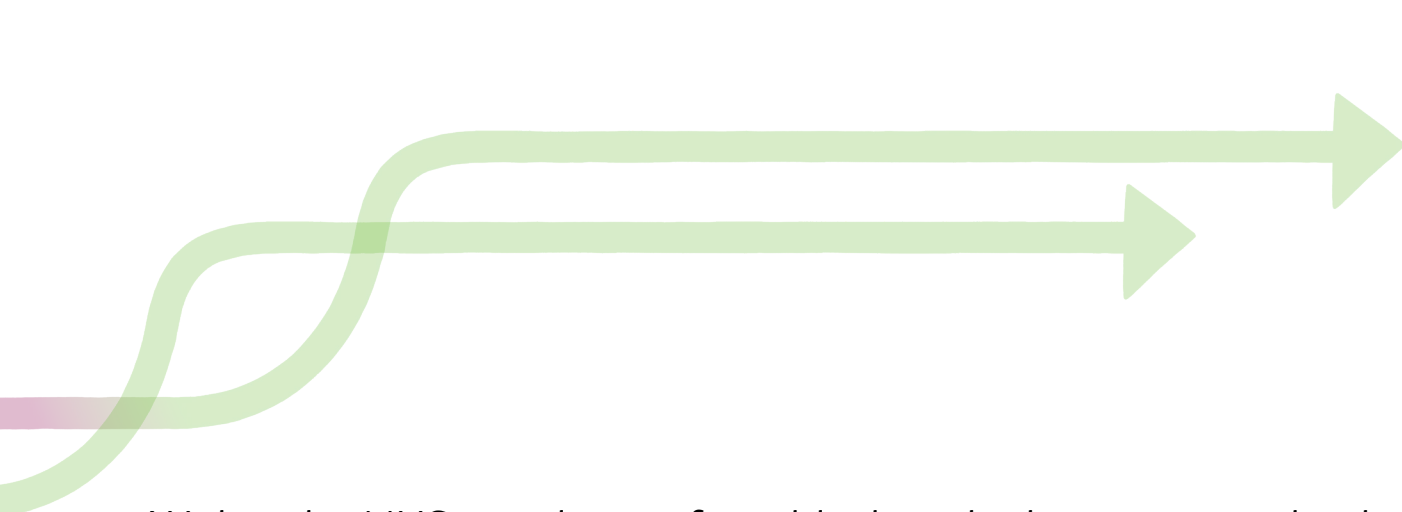
Many LTCs are more common among lesbian, gay, bisexual, transgender and queer (LGBTQ) women and men than their heterosexual peers. Deprivation levels make little difference to these inequalities in health, pointing to discrimination in society being a significant factor.<sup>(82)</sup>

Among people with disabilities (physical, cognitive, sensory) a longitudinal UK study found that those reporting an experience of discrimination were associated with poorer health and wellbeing.<sup>(83)</sup>

People's experience of discrimination is unique and intersectional. Fear of discrimination based on current and previous experiences results in low satisfaction with health services, delayed treatment seeking and poor inter-personal communication between clinicians and patients.<sup>(84, 85)</sup>

Discrimination in society can influence judgements about who would benefit most from rehabilitation, influencing decisions on referral and eligibility policies, particularly given limited availability. This can result in lower referral rates among older people, people from black and minority ethnic communities, people with chronic mental health problems, people with learning difficulties and women.<sup>(86-90)</sup>

**‘Experience of BME staff is a very good barometer of the climate of respect and care for all within NHS trusts.’<sup>(93)</sup>**



Within the NHS, employees from black and ethnic minority backgrounds are significantly more likely than white employees to experience bullying, harassment and discrimination by colleagues and by the public. They are more likely to experience poor mental health as a result and are under-represented at higher grades and in leadership positions.

Discrimination in the workplace is experienced by people with other protected characteristics under the Equality Act 2010 too. Discrimination has a negative impact on morale, wellbeing and mental health of staff and, in turn, patient care and service delivery – contributing to the unequal treatment of patients.<sup>(91, 92)</sup>

### Missed opportunities for prevention

Rehabilitation can be preventative, but for most people is not offered until late in the progression of their disease.

With COPD, for example, rehabilitation isn't considered until the patient can no longer walk for 100 feet without stopping for breath, in spite of evidence that it would be effective in earlier stages. Similarly, falls prevention services are most commonly provided after an individual has had their first fall that results in hospitalisation, not when they first seek help because of falling or being unsteady on their feet.<sup>(94-98)</sup>

This can mean people are in such poor health that it is a barrier to participation, and a missed opportunity to prevent, delay or limit declining health.

Cardiac rehabilitation is generally only available to people who have already had a heart attack, heart surgery or have congenital heart defects. But there is a wealth of evidence that rehabilitation – structured exercise, dietary support, psychological support and education – for people diagnosed with CVD or at risk of CVD reduces the risk of critical medical situations.<sup>(99, 100)</sup>





## Mental health needs are not being addressed

Depression and anxiety are particularly high in areas of deprivation and among marginalised groups in the population. Reduced symptoms of anxiety and depression are a commonly reported outcome of rehabilitation services. However, without support, having depression or anxiety can be a significant barrier to starting or persevering with rehabilitation.<sup>(101-104)</sup>

## Where, when and how services are provided

Transport can be a barrier for people who don't have a car, can't drive, can't afford taxis, can't manage public transport, or live in rural areas with limited public transport. This can be a particular problem for people with multiple conditions dealing with fragmented provision that generates multiple appointments.<sup>(105)</sup>


Services are mostly based in hospital out-patient departments. Hospitals can be hard to get to, often being on the edge of towns. More fundamentally, it medicalises rehabilitation rather than supporting self-management as part of daily life.

If rehabilitation sessions are all during the day and in-person this can exclude people who can't manage this because of work, childcare, caring responsibilities or disability. If service access or provision relies entirely on being online, this will exclude people who cannot access the internet or for whom this way of doing rehabilitation doesn't work, widening digital inequalities. When applied appropriately, as part of a personalised, hybrid approach, digital technology as part of service provision has the potential to improve access and be part of a concerted effort to reduce inequalities in access.<sup>(106)</sup>

## Communication barriers

Around half of adults say they struggle to understand health information provided to them, in spite of national initiatives to improve health literacy among patients and the quality of communication by clinicians. Written information for patients – including in their notes and copies of referral letters – is routinely inaccessible and none-inclusive. For example, using medial





terms when it isn't needed (e.g. saying ambulatory rather than able to walk about), not explaining medical or technical terms, and not using plain English. Commonly used phrases in health can also be perceived as judgemental and unsympathetic (the patient complains of.., the patient denies a history of..., the patient has failed to respond to...) and can put a barrier between clinician and patient.<sup>(107-110)</sup>


Multiple studies show that language barriers are a significant factor in poor access to rehabilitation services by people from black and ethnic minority backgrounds.<sup>(111-117)</sup>


In England, the public champion in healthcare, Healthwatch have reported that in spite of the legal responsibility of the NHS to reduce inequalities experienced by people who can't speak English, many people are not aware of their right to ask for an interpreter and aren't offered one. Evidence from the Race Observatory found that interpreters were particularly lacking in GP services – which is where most referrals for rehabilitation services in the community should come from. Healthwatch also found that translated material – including on referral letters – are often not available, or when using an interpreter or translated material medical terms are often not explained.<sup>(12, 118)</sup>

A recent report by Healthwatch as part of the Your Care, Your Way campaign, found that services are also failing in their legal duty to provide accessible information for people with communication barriers resulting from physical and learning disabilities and sensory impairments. It shows the significant implications for their access to healthcare and on their mental health and wellbeing, and how the situation has got worse during the pandemic.<sup>(119)</sup>

## Cultural competence

Cultural sensitivity and culturally competent adaptation of treatment should be built into rehabilitation services as part of a holistic assessment of need, and personalisation of what is provided. This includes understanding a person's needs in the context of their lived experience, which is informed by culture, beliefs and values. Evidence from psychotherapy research suggests that when programmes are culturally adapted their effectiveness is enhanced.<sup>(76)</sup>





However, this often isn't the case. For example, some people may need single-sex provision (e.g. exercise classes) in order to participate, but in most cases this isn't an option. In many cultures and communities family members play a large role in healthcare and this can be a significant asset in rehabilitation. But commonly services don't facilitate or seek to utilise this. <sup>(117, 120)</sup>

## Lack of data and evidence

Barriers to rehabilitation cannot be addressed without data on populations and on who is and isn't accessing services. Legally all NHS and social care services must collect data about patients protected characteristics. However there is significant variation in how consistently and accurately this is done. <sup>(121)</sup>

This sits within the context of incomplete and inconsistent data in community rehabilitation services. Without robust data covering community rehabilitation services it isn't possible to fully understand equity of access and outcomes for different parts of the population, and incomplete data risks further health inequality. How to address current data gaps is explored in the forthcoming report from the Community Rehabilitation Alliance (England) Data Task and Finish Group.

Rehabilitation staff have a critical role to play in improving the timely collection and use of data to drive necessary improvement and priorities – in particular ethnicity coding which is a particular area requiring improvement. To do this they need better data systems and infrastructure.

As well as patient data, consistent data collection on take up of services and outcomes is collected and looked at against population health data. This needs to be disaggregated and cut with a health inequity lens to ensure that services and interventions are inclusive of marginalised communities and to ensure the gap is not being inadvertently widened.

More broadly, action is needed to ensure that people from marginalised backgrounds are fully represented in research. Currently there is systematic exclusion and under-representation, as well as low levels of patient and public involvement in research and service evaluation. This can lead to rehabilitation interventions that are not tailored to specific needs or culturally competent. It is important that there is co-design and co-production of research with people with lived experience from diverse backgrounds.





# Scaling up modernised, inclusive rehabilitation services

Many services have successfully redesigned their offer to address these barriers, in order to be more accessible and inclusive, and these examples have been used to develop an emerging model of community-based rehabilitation.

## Features of modernisation include:

- Involving patients and carers in service redesign.
- Moving out of hospitals to gyms and other community facilities.
- Providing a simpler core rehabilitation service for people with all LTCs.
- To be provided in time to deliver secondary prevention and prehabilitation, rather than waiting for conditions to deteriorate.
- Incorporating psychological support within rehabilitation, building therapeutic and coaching relationships.
- Personalising treatment plans around the needs and preferences of the individual, and in partnership with that individual and carers.
- Building partnerships with voluntary and fitness sectors.
- Providing patients more options of treatment and treatment times through hybrid remote and in person provision.
- Incorporating vocational rehabilitation within provision to enable people to remain in or return to work.

## For these approaches to be scaled up they need to be supported throughout the system – through:

- New advanced clinical practice roles based in the community to lead change.
- Increased investment in workforce capacity.
- Partnerships between sectors and settings, with shared infrastructure and funding.
- Plans to improve data collection in community services and utilisation of population health data.





## Case studies

**Good Boost** – pool-based rehabilitation in Southwark.

Launched in October 2021, Good Boost is a pioneering project in Elephant and Castle (London), one of the most deprived council areas in England.

Based in a local leisure centre, rehabilitation clinicians from King's College Hospital NHS Foundation Trust deliver supported self-management water-based exercise sessions for people with chronic musculoskeletal (MSK) conditions and those recovering from joint replacement surgery.

After just five months, two out of three participants reported an improvement in their health and there were significant improvements in people's functional capacity (increased 23%) and pain levels (reduced 22%).

This new community based project is one of the measures expected to cut waiting times for traditional community MSK services and help to reduce demands on other primary and secondary care services.

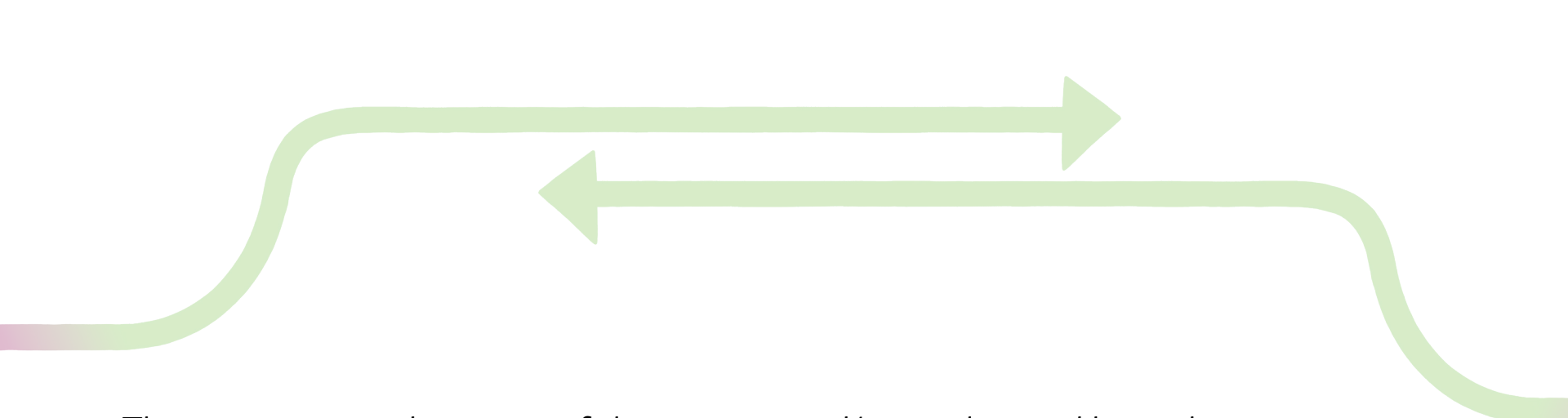
Participants include many of those who often miss out on rehabilitation. 80% are in the poorest two income quintiles, and 84% are black or Asian. Almost half live with another long term health condition. The programme is successfully appealing to people currently not involved in physical activity – 55% reported they were inactive before they started.

“I was having so much trouble with my hip keeping dislocating and just not getting any exercise. I'd got into a situation where exercise was just not something I would do, whether I'd got lazy or scared I couldn't do it. Good Boost runs in the pool just down the road from where I live, and having that structure gave me a bit more confidence, confidence that I can do it. Exercising is giving me more energy to do things and build up the strength I have lost.”

**Good Boost participant from King's College Hospital NHS Foundation Trust**

**Healthy and Active Rehabilitation Programme (HARP)** is an Ayrshire based supported self-management programme for people affected by multiple Long Term Conditions. A comprehensive extended assessment is completed for the conditions and their impact, such as angina, COPD, stroke, diabetes, atrial fibrillation, falls and cancer.

The team then supports people using options that include physical activity classes with themed facilitated self-management education sessions that utilise the power of peer support and expert therapists (physiotherapy, nursing and occupational therapists) to help participants optimise their goals whilst living with their conditions.



The project is sited in areas of deprivation and/or rurality and has robust evaluation. Among many other positive outcomes there has been a 70% reduction in bed days one year later in those that completed the programme.

**Hope in Grimsby** – In Grimsby, in the 25th most deprived ward in the country is home to an award-winning combined falls prevention and COPD rehabilitation service, run by a social enterprise, Care Group Plus.

Set up in 2005, using neighbourhood renewal funding, the service took over a derelict former medical centre. What was once a target for vandalism has become a much valued community asset – with a gym, award-winning community garden, allotment and café run by volunteers.

It has been designed and developed through a genuine co-production partnership between service users and staff. On the team are over 100 trained volunteers (buddies), mainly ex-patients or their carers, who support the design and delivery of the programme alongside a multidisciplinary team of registered clinicians (physiotherapists, OTs, nurses, a dietician) and support workers.

The service provides respiratory and falls rehabilitation programmes, with significantly higher completion and lower drop-out rates than the national average and preventing one hospital admission per patient on the respiratory programme and reducing significantly reducing the risk of falling. Volunteers are trained to deliver community education outreach on falls prevention and quit smoking classes – the latter with a success rate more than twice the national average.

Their approach has won an armful of national and regional awards.

Before the Hope Street Service there were massive gaps in treatment for COPD patients in the area, a condition well-known to be linked to deprivation. We also saw some of the problems relating to falls, could be linked to some of the experiences of COPD patients, such as inactivity and social isolation.

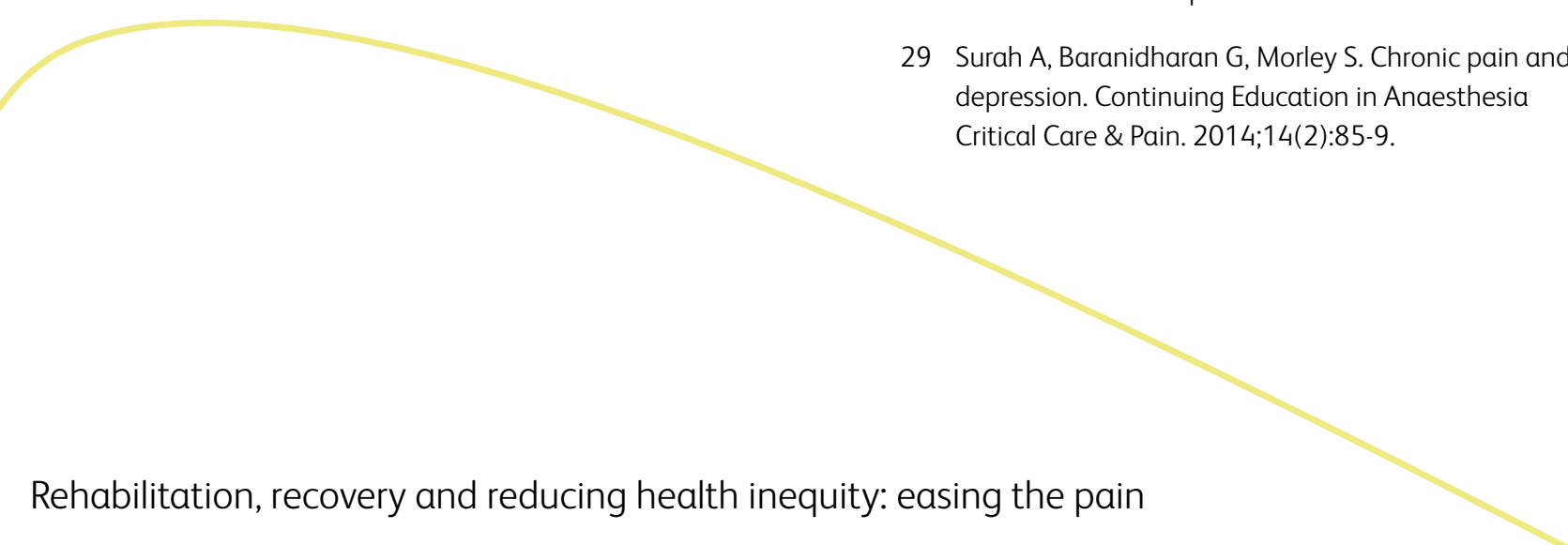
*“The service developed based on extensive consultation with patients and carers on what they wanted from a new service. We place a strong emphasis on incorporating activities into the rehabilitation programmes, and the buddies serve to create a rehabilitation community outside of the clinic, helping to forge social networks for patients.”*


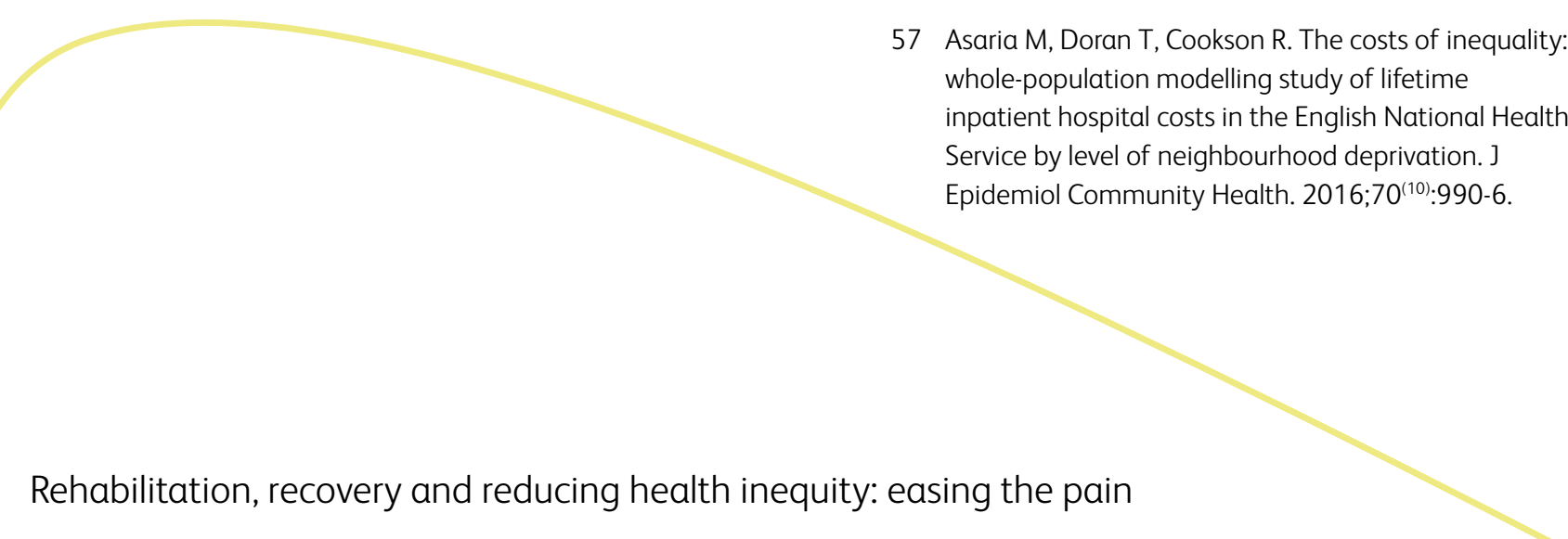
*Co-production, co-design and co-deliver has been said to be the future of health care and HOPE proved that for many years it can work well and deliver outstanding inclusive services. This is a blueprint for the rest of the NHS.*

**Leanne Capell, Head of Therapy, Hope Street Service, Care Plus Group**



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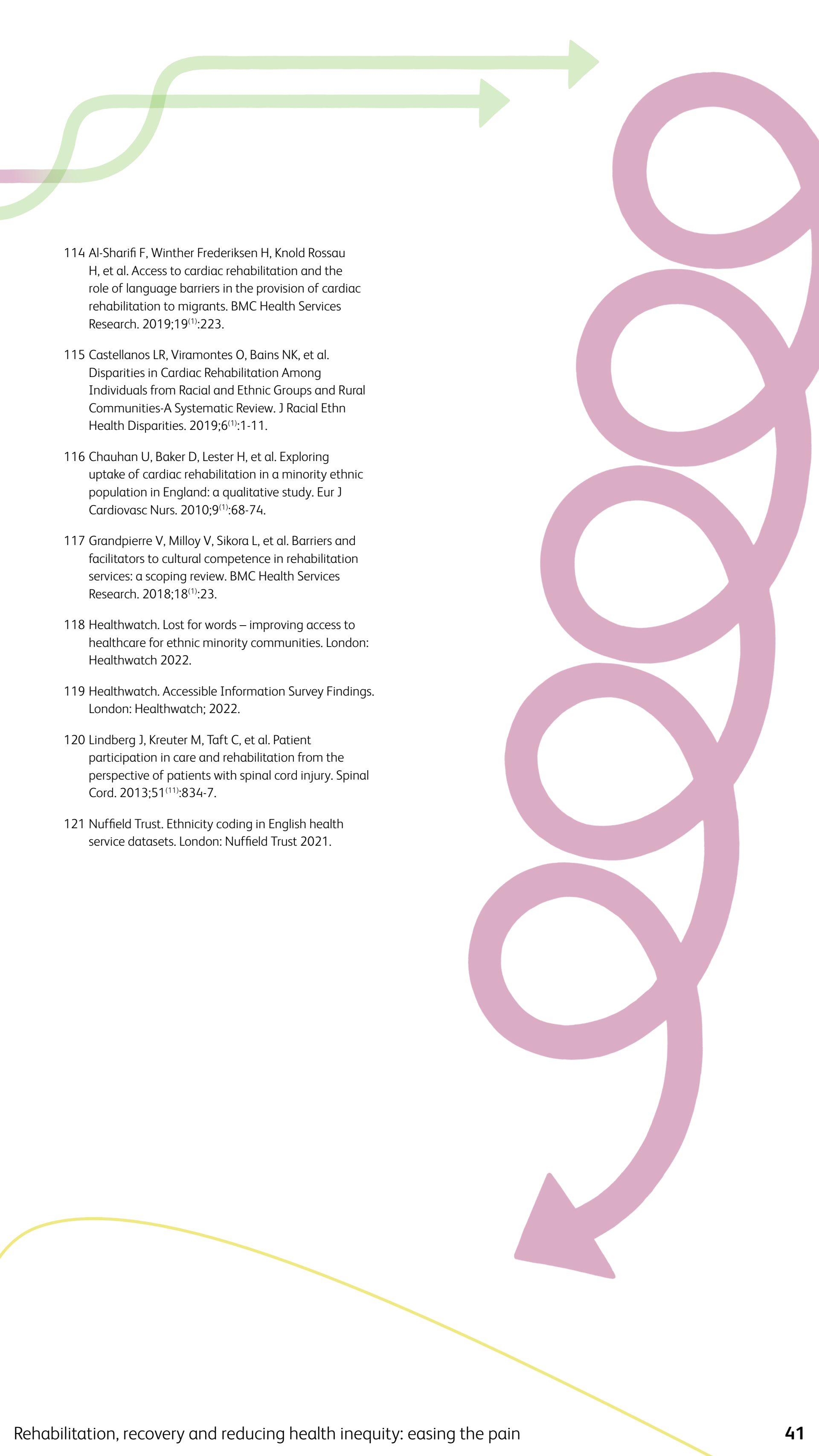
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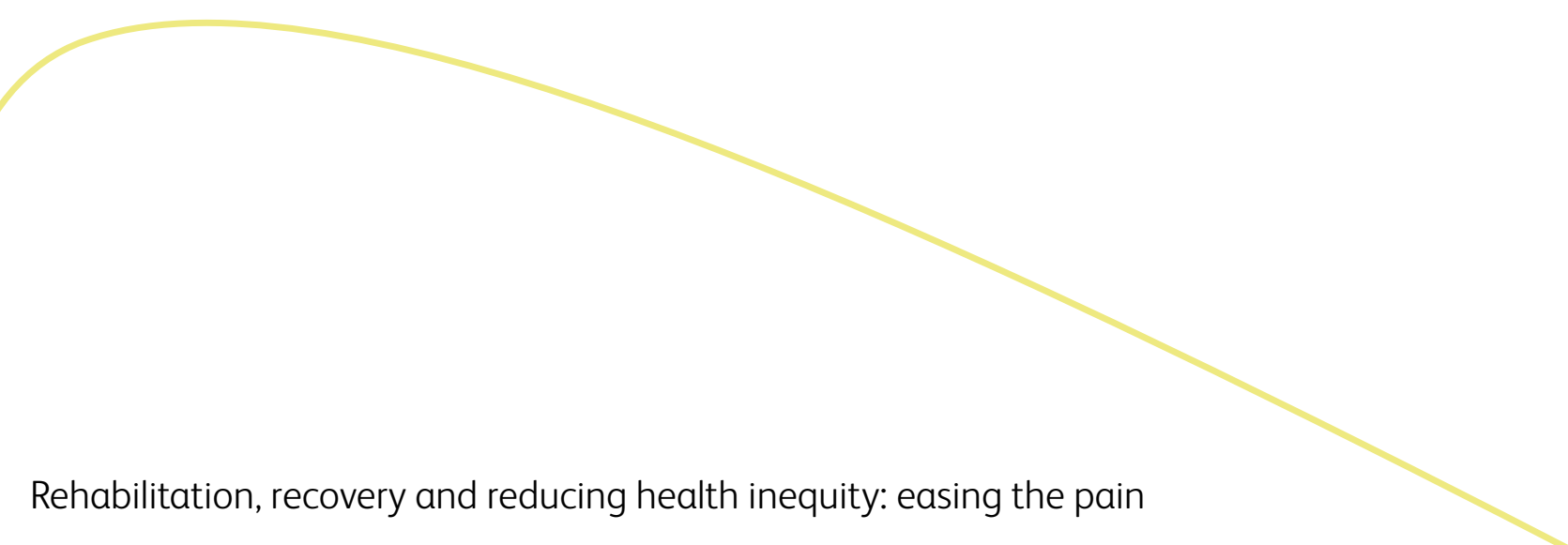


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