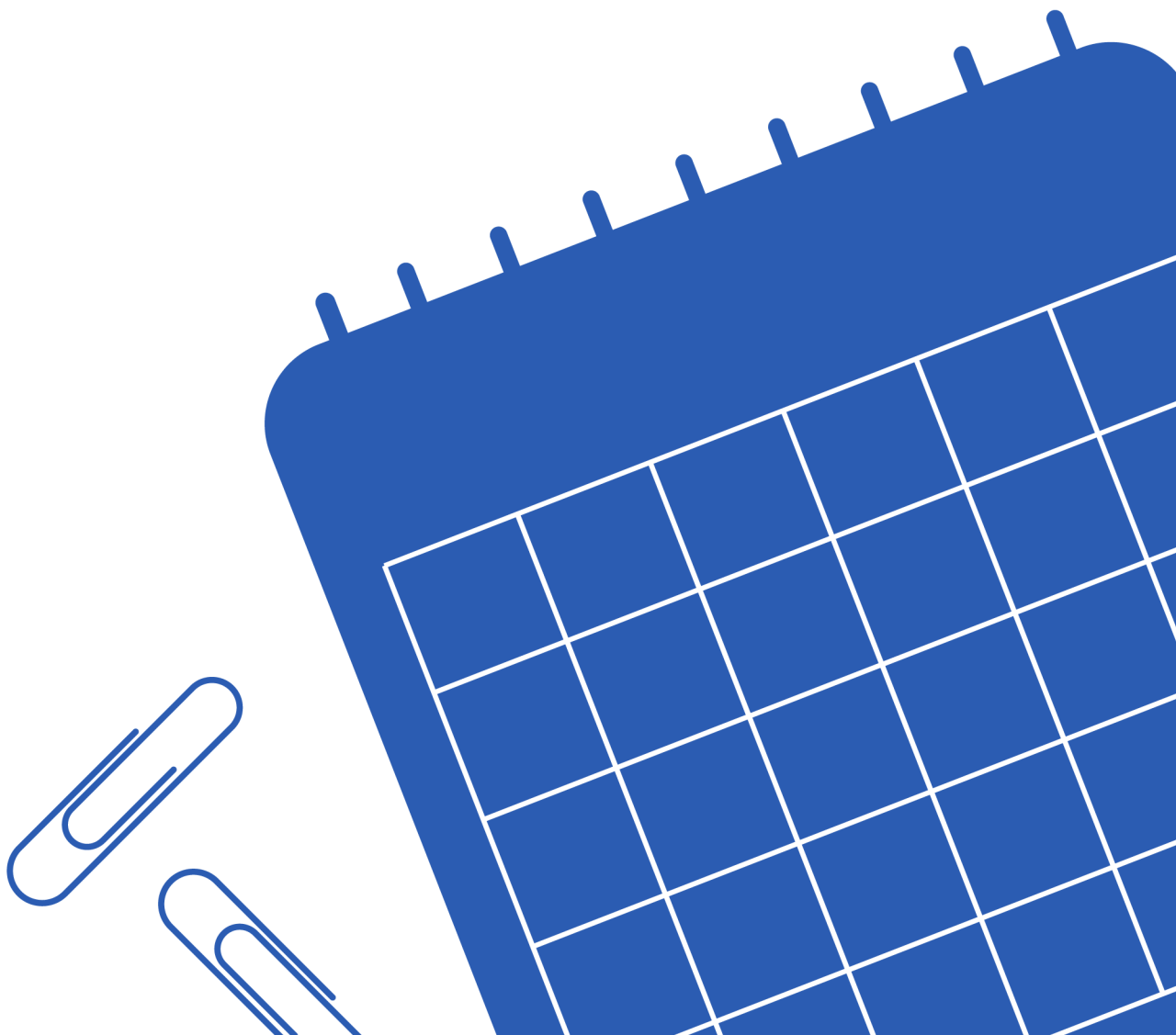


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The impact of long term conditions on employment and the wider UK economy

Zofia Bajorek
Anthony Hind
Stephen Bevan



Through its rigorous research programmes targeting organisations, cities, regions and economies, now and for future trends; The Work Foundation is a leading provider of analysis, evaluation, policy advice and know-how in the UK and beyond.

The Work Foundation addresses the fundamental question of what Good Work means: this is a complex and evolving concept. Good Work for all by necessity encapsulates the importance of productivity and skills needs, the consequences of technological innovation, and of good working practices. The impact of local economic development, of potential disrupters to work from wider-economic governmental and societal pressures, as well as the business-needs of different types of organisations can all influence our understanding of what makes work good. Central to the concept of Good Work is how these and other factors impact on the well-being of the individual whether in employment or seeking to enter the workforce.

For further details, please visit www.theworkfoundation.com.

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The infographics contained in this report were created using Piktochart.

Executive Summary

NHS England's *Five Year Forward View*, published in October 2014, highlighted that sickness absence-related costs to employers and taxpayers in the UK are currently estimated at £22 billion per year.¹ In addition, it notes that individuals collectively miss out on £4 billion a year of lost earnings.² This is in spite of the fact that there is increasing evidence that targeted health support can help keep people in employment, which in turn improves their wellbeing and preserves their livelihoods.³ For this reason, the document commits the NHS to playing its role in supporting people to both get and stay in employment.

This commitment is extremely important. The cost of long term conditions to individuals, their families and carers, the NHS, employers and the taxpayer looks set only to increase. The number of people experiencing at least one long term condition is estimated to rise above 17 million in the coming decades, affecting more individuals' participation in the labour market.⁴ With this in mind, it is important to understand how long term conditions can have an impact on the individual, the workforce and the wider economy, and how improved care and support could therefore benefit the UK as a whole.

This report highlights the problems with employment faced by people who have one of six conditions: psoriasis, diabetic macular oedema (DMO), asthma, schizophrenia, heart failure and multiple sclerosis (MS). These have been chosen as examples from six NHS programme budget areas (problems of the skin; endocrine, nutritional and metabolic problems; problems of the respiratory system; mental health disorders; problems of circulation; and, neurological conditions) in order to illustrate the importance of improving patient outcomes across the board.

The report finds that current services are not doing enough to keep people with long term conditions in employment, and the subsequent cost to the economy is significant. The six programme budget areas identified in this report collectively cost the NHS an estimated £32 billion in direct expenditure⁵, while mental health conditions alone are estimated to cost the economy between £70-100 billion.⁶ Mental illness was responsible for the loss of 70 million working days in 2007, and days lost to stress, depression and anxiety has risen by 24 per cent since 2009.⁷ Furthermore, the annual cost of worklessness and sickness absence related to working age ill-health costs the UK over £100 billion each year.⁸ This is not sustainable and the government must urgently seek to address the impact that long term conditions have on the employment prospects of individuals and carers.

The introduction of new models of care, 'vanguard' sites and 'innovation test beds', in line with the measures announced in the *Five Year Forward View*, present significant opportunities for the NHS to provide more integrated, person centred care. Given the considerable impact that long term conditions can have on the economy, it will be essential to ensure that service redesign includes a focus on: prevention; improving employment prospects through the delivery of support services; better information; and incentives for commissioners and employers.

Furthermore, the Department of Health has acknowledged that a strong NHS and social care system needs a strong economy, and simultaneously that the NHS and social care system must contribute to economic growth. However, for this to happen, we must focus on ensuring that people who have developed long term conditions are able to remain in work. The evidence set out in this report is clear that the government must

deliver targeted investment in: improving early diagnosis and prevention of long term conditions; ensuring patients are referred to specialists sooner; delivering best practice services to patients and carers; and prioritising patient access to innovative treatments and appropriate vocational support. To achieve positive work outcomes, employers need to play a greater role in making work more accessible to individuals with long term conditions, by fostering open, friendly and accessible work places in which people feel comfortable seeking help, and where reasonable adjustments are fully implemented.

Key statistics

- The average age of retirement for someone with multiple sclerosis is **42 years old**.⁹
- Over **45 per cent** of people with asthma report going to work when ill, increasing the risk of prolonged sickness and affecting their ability to perform effectively.¹⁰
- **Just 8 per cent** of people with schizophrenia are in employment¹¹, despite evidence that up to 70 per cent of people with severe mental illness express a desire to work.^{12,13}
- People with heart failure lose an average of **17.2 days of work per year** because of absenteeism caused by their condition.^a
- Over **52 per cent** of people with diabetic macular oedema are of working age.^b
- A ten per cent reduction in sickness absence for people with psoriasis would provide a **£50 million boost** to the UK economy.^c

Main findings

- The number of people in the UK with one or more long term conditions is expected to rise in the coming decades. This is as a result of the ageing population, improvements in treatments that allow people to live for longer and the rise of non-communicable risk factors, such as obesity.¹⁴
- There are substantial barriers to employment for people with long term conditions, which have an impact on individuals in a number of ways, including: lost earnings; impaired career prospects; and early exit or prolonged absence from the workforce.
- Long term conditions can also have a negative effect on an individual's quality of life, which in turn is associated with poor employment and worsening health outcomes. In addition, many people will experience more than one condition, for example depression is a common comorbidity.
- Employment rates for people with long term conditions are persistently low, despite the fact that work is often both possible and beneficial. Furthermore, the impact that long term conditions have can be life-long, and many develop during education or in the early stages of an individual's career.

^a See Appendix Two, Table 1.5, for details of assumptions and calculations.

^b See Appendix Two, Table 1.3, for details of assumptions and calculations.

^c See Appendix Two, Table 1.2, for details of assumptions and calculations.

- Long term conditions are often fluctuating, meaning symptoms can be unpredictable and difficult to manage, particularly at work. This is compounded by the fact that perceived stigma can prevent many people from seeking vital help at work.
- Indirect costs to UK society arise for a number of reasons, including: individuals having to reduce their hours; sickness absence; presenteeism (going to work when ill); early retirement; unpaid care; and, unemployment and associated welfare provision.
- Care and treatment varies across the UK, and there needs to be a greater awareness of existing best practice guidance. In addition, healthcare professionals should always ask individuals about their employment aspirations as these can have an impact on their health outcomes.
- Supporting people with chronic conditions can result in improved health, work and economic outcomes. This support can take a number of forms, such as targeted early interventions and empowering individuals to play a greater role in managing their own care in both a clinical and workplace settings.

Recommendations

Government

- The Treasury and the Department for Business, Innovation and Skills should examine the feasibility of offering tax incentives, national insurance rebates or tiered VAT charges for employers who implement policies to support employees with long term conditions.
- Consideration should be given to the commissioning of more specialist employment support programmes provided by the Department for Work and Pensions (DWP) and the voluntary sector for people with long term and mental health conditions.
- The National Institute for Health and Care Excellence (NICE) should be permitted, routinely, to take a 'societal perspective' in Health Technology Appraisal (HTA), especially where access to medicines or medical technology might reasonably be expected to enhance the labour market participation and productivity of patients and/or their carers.
- The new Health & Work Joint Unit (DWP, NHS England, Public Health England) should prioritise integrated, work-focused support for working age people with long term health conditions so that job retention and return to work are seen as key outcomes for joint DWP and NHS activity.

NHS England

- It is essential that under-prioritised disease areas like eye and skin conditions are represented by National Clinical Directors, who can provide leadership and act as a focal point for coordinating standards of care.
- Accessing and retaining employment for people with long term conditions should be a priority clinical outcome for those areas that are implementing new models of care that bring together health, social and mental care.

- NHS England should seek to measure the impact on employment outcomes that innovation can have for people with long term conditions. With the development on new ‘vanguard’ sites and innovation ‘test beds’ there is a real opportunity to better highlight the important impact that innovative technology can have on service delivery and outcomes in relation to employment.
- There should continue to be a greater focus on employment as an outcome for all long term conditions, building further on the existing NHS Outcomes Framework Indicator.
- Additional incentives are needed to drive the provision of more widespread employment support in clinical settings. This may mean more co-location of specialist employment support in some primary and secondary care settings. More investment in Nurse Specialists, who are so often key advisors for working age patients with long term conditions, would also improve job retention and return to work rates.
- There is a role for NHS England in better facilitating knowledge sharing between healthcare professionals and employers, particularly regarding information sources.
- NHS England should better promote the services and guidance offered by third sector organisations and patient groups to both employers and patients.

Employer

- Employer and business trade associations should acknowledge the significant challenge facing the UK labour market as the workforce ages and develops more chronic illness, and seek to provide leadership in partnership with the government, the NHS, businesses, trade unions and employees to implement solutions.
- All employers should seek to make reasonable adjustments for employees to support the varying needs of people with long term and fluctuating conditions.
- Workplaces should provide an open and supportive environment so that individuals feel comfortable about disclosing their condition and seeking support.
- Employers should be made aware of the specialist support available, for example how the involvement of occupational therapists, physiotherapists and the Fit for Work Service and Access to Work scheme could help to get the best work outcomes for them and their employees.

Clinical

- Earlier diagnosis and interventions can help individuals to treat, manage or delay disease progression, which has a positive impact on health, education and employment outcomes.
- There needs to be less variation in awareness and understanding of evidence-based clinical guidelines across a range of conditions to ensure that patients are consistently receiving optimal care.
- Individuals requiring specialist care should be given timely appointments to avoid negative implications to their employment / educational opportunities through preventable disease progression as a result of the simple lack of treatment.

- Healthcare professionals should ask working age patients and young adults about their employment aspirations as early as possible in order to provide truly coordinated and multi-disciplinary care.
- Patients with long term conditions need equal or early access to psychological services, as depression has been found to be a common comorbidity amongst individuals with these conditions.
- Healthcare professionals should be aware that long periods of unemployment and difficulties in finding jobs can undermine individuals' self-esteem and may negatively affect their mental wellbeing.
- There should be increased clinical assessments of the impact that all comorbidities can have for an individual, as it is often an associated condition or the interaction of several conditions that results in poor employment outcomes.
- Self-management should be at the heart of clinical practice. The more an individual understands their condition and their treatment, the better their health and therefore their employment outcomes. Patients should be signposted to self-management support resources, especially those which focus on employment outcomes.

Individuals with long term conditions

- Patients should proactively consult with healthcare professionals, families, carers and employers to develop an understanding of what might be achievable or desirable in both the short and long term. All possible options should be considered.
- Individuals should be self-assertive and take an active role in managing their condition. As part of this, they should feel able to disclose details of their condition to their employer.
- Individuals should feel equipped with the support of the multi-disciplinary healthcare team to highlight how specific changes to working arrangements could maximise their productivity at work.

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Introduction

Long term conditions and work

NHS England's *Five Year Forward View*, published in October 2014, highlighted that sickness absence-related costs to employers and taxpayers are estimated at £22 billion a year.¹ In addition, it notes that individuals collectively miss out on £4 billion a year of lost earnings, in spite of the fact that increasing evidence suggests targeted health support can help keep people in employment, which in turn improves their wellbeing and preserves their livelihoods.² The document therefore commits the NHS to playing its role in supporting people to both get and stay in employment.

This commitment is extremely important. Long term conditions cannot be cured but can affect individuals throughout their working life. The number of people experiencing at least one long term condition is estimated to rise above 17 million in the coming decades, affecting more individuals' participation in the labour market.³ It is also predicted that by 2018, 2.9 million people will have multiple long term conditions in the UK.⁴ Consequently, the next decade will witness a rise in the demand for the prevention and management of multi-morbidity rather than just single diseases.⁵

There are three broad trends that significantly contribute to the growing burden arising from long term conditions:

- *The ageing population.* In the UK there are almost twice as many people aged 50-69 years or more than there are aged 15-24 years.⁶ With ageing comes a greater risk of poor health and premature withdrawal from the labour market.
- *The pension crisis.* The difficulty in paying for pensions due to a difference between pension obligations and the resources set aside to fund them, means that workers will need to work for longer to fund their retirement.
- *The growing burden of chronic disease.* This means that the productive capacity of the workforce risks being compromised by ill-health.

These trends persist at a time of economic uncertainty in the NHS, with financial predictions suggesting a funding gap as large as £30 billion by 2020/21.⁷ Additionally, the link between poor health, reduced workplace productivity and the wider economy is becoming increasingly understood. A recent report from the Chief Medical Officer, Dame Sally Davies, indicated that mental illness alone was responsible for the loss of 70 million working days in 2007 in the UK, and days lost to stress, depression and anxiety has risen by 24 per cent since 2009.⁸ Furthermore, Dame Carol Black's report, *Working for a Healthier Tomorrow*, indicated that the annual cost of worklessness and sickness absence related to working age ill-health cost the UK over £100 billion each year.⁹

Individuals with long term health conditions are twice or three times as likely to experience mental health problems in comparison to the general population.¹⁰ In the NHS, at least £1 in every £8 spent on long term conditions is linked to poor mental health and wellbeing – between £8 billion and £13 billion in England each year.¹¹ The growing understanding of the interplay between physical and mental health, and the

impact this has on the wider economy, has fostered an agreement that doing more of the same in terms of healthcare is not sustainable. More is needed to support individuals and to join the dots between healthcare and employment.

The economic case for enabling individuals with long term conditions to access and remain in work is clear and could lead to a reduction in welfare expenditure, increased income tax receipts, reduced sickness absence and greater organisational productivity. At a time when UK labour productivity lags behind its European neighbours¹², the health of the workforce becomes critical.

Evidence also indicates that employment can have an important positive therapeutic and economic impact on the lives of people with long term conditions. Work can provide: financial autonomy; improved quality of life and an increased sense of self-worth, which all contribute to a reduction in the risk of long term incapacity and aid rehabilitation.¹³ Supporting individuals into suitable employment, which contributes to their wellbeing, can therefore assist in alleviating the burden on the NHS by helping people to stay healthy.¹⁴ In 2014, NHS England prioritised getting people with long term physical and mental health conditions into employment by including this priority in both the NHS Outcomes Framework and the NHS Mandate – a commitment which has been carried forward in the 2015/16 mandate.^{15,16,17} In addition, Simon Stevens, Chief Executive of NHS England, has reaffirmed the commitment to expand prevention services, particularly around obesity and diabetes¹⁸, which can cause significant disruption to employment. However, patient access to interventions and services remains variable across the country¹⁹, which could be a contributing factor to persistently low employment rates for individuals with long term conditions.

The introduction of new models of care, ‘vanguard’ sites and ‘innovation test beds’, in line with the measures announced in the *Five Year Forward View*, present significant opportunities for the NHS to provide more integrated, person centred care. Given the considerable impact that long term conditions have on the economy, it is essential to ensure that service redesign includes a focus on improving employment prospects through the delivery of support services, better information, and incentives for commissioners and employers.

The Department of Health has acknowledged that a strong NHS and social care system needs a strong economy, and simultaneously that the NHS and social care system must contribute to economic growth.²⁰ For this to happen, there must be a focus on ensuring that those who have developed long term conditions are able to remain in work. The evidence set out in this report shows that the government must deliver targeted investment in: improving early diagnosis and prevention of long term conditions; ensuring patients are referred to specialists sooner; delivering best practice services to patients and carers; and prioritising patient access to innovative treatments and appropriate vocational support. To achieve positive work outcomes, employers need to play a greater role in making work more accessible to individuals with long term conditions by fostering open, friendly and accessible work places in which people feel comfortable seeking help and where reasonable adjustments are fully implemented.

This report

This report looks at the economic implications of six long term conditions (psoriasis, diabetic macular oedema, asthma, schizophrenia, heart failure and multiple sclerosis) in the UK, focusing specifically on the effects on employment for those of working age. These conditions have been chosen as examples from each of the NHS programme budget areas (problems of the skin; endocrine, nutritional and metabolic problems; problems of the respiratory system; mental health disorders; problems of circulation; and,

neurological conditions) in order to illustrate the importance of improving patient outcomes across the board.

Evidence was gathered from the available academic and grey literature. The report presents data on the direct and indirect costs to the UK society and, where the data exists, projects the likely impact the condition will have in the future. Finally, the report looks at the available interventions in the context of their potential to improve both health and work outcomes.

Where evidence was not available on UK productivity costs, we have taken the human capital approach to our calculations, using assumptions gained from the literature review. This approach involves applying the average wage cost to the amount of time an individual was absent from work. To calculate the number of yearly days of work lost, assumptions on the average number of lost days for one individual is applied across the estimated UK population. Figures and assumptions for all calculations are provided in Appendix Two.

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PSORIASIS IS A COMMON, FLUCTUATING, INFLAMMATORY SKIN CONDITION.¹



An estimated 1.8 million people have psoriasis in the UK.¹



People with psoriasis lose up to 26 days of work due to their condition each year.²



The cost of psoriasis related presenteeism and sickness absence in the UK is estimated to be **£1.07 BILLION** per year.³

EFFECTS ON ABILITY TO WORK AND QUALITY OF LIFE



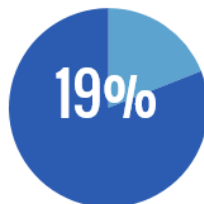
77% of people with psoriasis report their condition affects their quality of life.⁵



33% of psoriatic arthritis patients reported losing their jobs as a result of their condition.⁶

60

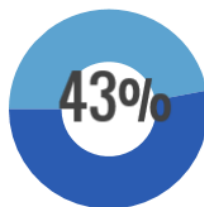
% of patients report that psoriasis on their hands and feet causes work limitations.²



19% have had to quit a job or have been dismissed as a result of their psoriasis.⁷

1/3

of workers with psoriasis have been discriminated against in the workplace because of psoriasis.⁷



43% report that psoriasis had limited their income and/or future earnings.⁷

COMMON SYMPTOMS⁴



Scales



Itching



Pain



Restricted movement

COMORBIDITIES



Depression⁵



Psoriatic Arthritis¹



Anxiety⁵

1) The Psoriasis Association. (2014). About psoriasis. Available at: <https://www.psoriasis-association.org.uk/pages/view/about-psoriasis> (last accessed 13/03/2015).

2) Ayala, et al. (2013). The impact of psoriasis on work-related problems: a multicenter cross-sectional survey. Journal of the European Academy of Dermatology and Venereology. 28(12), 1623-1632.

3) The Work Foundation analysis (see Appendix Two, Table 1.2, for assumptions and calculations).

4) National Institute for Health and Care Excellence. (2013). Psoriasis Guidelines. Available at: <https://www.nice.org.uk/guidance/CG153/chapter/introduction> (last accessed 20/08/2015).

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6) Leung, et al. (2008). Psoriatic arthritis: An update on classification, clinical features and therapies. Hong Kong Bulletin of Rheumatic Diseases, 8, 1-11.

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Psoriasis

Key statistics

- **1.8 million** people have psoriasis in the UK.¹
- On average, people with moderate to severe psoriasis take **14.1 sickness absence days per year**.²
- Across the UK population this is equal to **4 million** lost working days per year.^a
- The total estimated cost of absenteeism and presenteeism from people with psoriasis is **£1.07 billion** a year.^b

Skin conditions

Skin conditions can have a significant physical and psychological impact on a person's life. It is thought that half the UK population will have some kind of skin problem every year³, and around eight million people have a diagnosed skin condition in the UK.⁴ For many, skin conditions can have an impact on their ability to work, for example, through limiting movements and / or the development of mental health issues.⁵ The economic cost of this is likely to be substantial. In 2013/14, the government spent £61 million on out of work benefits (employment support allowance) where the main condition was a skin disease.⁶ Furthermore, recent figures suggest the NHS spent around two per cent of its budget – £2.1 billion in 2012/13 – on treating skin conditions, however the total overall cost is likely to be much higher due to the indirect costs resulting from sickness absence and reduced productivity.⁷

Psoriasis

Psoriasis is a common, chronic and inflammatory skin condition that can affect an individual's skin including their scalp and nails. Approximately 90 per cent of people with psoriasis experience plaque psoriasis which is characterised by red, demarcated, scaly patches visible on the skin.⁸ Symptoms can range from mild itching and sensitivity, to painful debilitating lesions which can affect daily functioning.⁹ When psoriasis affects an individual's hand and feet, pain and discomfort can lead to difficulties completing daily activities, including work.¹⁰ There is no cure for psoriasis and, although it is not life threatening in the majority of cases^c, it can affect an individual's ability to work and overall quality of life in the absence of appropriate treatment and support.¹¹

Psoriasis affects between two to three per cent of the population – up to 1.8 million people in the UK.¹² Individuals can be diagnosed with psoriasis at any age, although there seems to be two peaks: from the late teens to the early thirties and between the ages of 50 and 60, therefore affecting people throughout their working life.¹³

^a See Appendix Two, Table 1.2, for details of assumptions and calculations.

^b *ibid.*

^c Erythrodermic psoriasis is considered to be a life threatening condition (see: <https://www.psoriasis.org/about-psoriasis/types/erythrodermic>, last accessed 04/12/2015)

Comorbidities

Comorbid mental health issues are common among individuals with psoriasis and can be further negatively affected by the condition and the difficulties encountered when trying to enter or remain in employment.¹⁴ A third of people with psoriasis report clinically significant anxiety and depression, while one in ten have contemplated suicide.¹⁵ Psychological comorbidities associated with psoriasis are rated as one of the worst aspects of the disease by patients, resulting in reduced self-esteem, low career aspirations and individuals avoiding work and social situations¹⁶, which may reduce their employment opportunities. In addition, one in six people with psoriasis will develop psoriatic arthritis (PsA) which can cause restrictions in movement and act as a further barrier to employment.^{17,18}

Quality of life^d

The impact that psoriasis can have on an individual's quality of life is comparable with diabetes and cancer when assessed across eight health domains using the SF-36 (see Appendix One).¹⁹ Disruptions caused by psoriasis treatment, comorbidities, associated stigma and lack of confidence can build-up throughout a person's life time, limiting educational attainment, job skills and career prospects.²⁰ Evidence suggests that psoriasis patients believe their lives would have been considerably different, particularly with regard to employment and educational opportunities if their psoriasis had been treated effectively earlier.²¹

Psoriasis, employment and the wider economic costs

Psoriasis and its related comorbidities can affect an individual's ability to work and their employment prospects in a number of ways:

- Restrictions in movement that may result from psoriatic arthritis may cause difficulties in travelling around.²²
- Visible psoriasis and itching can cause anxiety meaning individuals avoid certain situations because of a fear of stigma and / or lack of self-esteem.²³
- Societal barriers may also prevent employment. A third of individuals with psoriasis have reported experiencing discrimination in the workplace as a result of their condition.²⁴

The implications of these barriers are wide reaching. An estimated 67 per cent of individuals with very active and extremely active psoriasis reported that their condition had affected their working life, while 43 per cent of all surveyed individuals felt that psoriasis had limited their income and/or future earnings.²⁵ Additionally, 19 per cent felt they have had to quit a job or have been dismissed as a result of their psoriasis²⁶ and 31 per cent of respondents have reported that they had suffered some degree of financial distress resulting from their psoriasis.²⁷

Evidence suggests that the average sickness absence for a worker with moderate to severe psoriasis is 14 days per year²⁸, whereas those with severe psoriasis lose up to 26 days.²⁹ This can be compared to the average UK sickness absence rate which is 4.4 days per year.³⁰ Psoriasis also has an impact on an individual's ability to perform to their full potential while at work, with one study finding sickness absence rates of 6.6 per cent of working time over a four week period and losses in productivity due to presenteeism

^d Quality of life in this report refers to the ability of individuals to physically and mentally function in day to day life. The quality of life measures chosen for all conditions are considered robust and reliable ways to quantify this.

at 7.6 per cent.³¹ Both the level of work impairment and the likelihood of being unemployed increases with disease severity.^{32,33,34}

Using assumptions based on the average sickness absence and prevalence taken from international literature, it is predicted that four million working days are lost in the UK per year due to moderate to severe psoriasis alone, at a cost of almost £0.5 billion to the economy.^e This figure increases to £1.07 billion when adding the potential cost of lost productivity due to presenteeism, equalling over a third of the NHS spend on the treatment of skin conditions as a whole in 2012/13.^f These figures are likely to be an underestimation as they are based on lower bound assumptions of adult prevalence, and do not include losses incurred through individuals exiting the labour market (i.e. through ill health or early retirement) as a result of psoriasis. Additionally, these calculations do not include the impact that comorbidities can have. For example, sickness absence and reduced work productivity as a result of mental health issues, which are particularly prevalent in people with psoriasis, are estimated to cost employers £26 billion each year.³⁵ Taking this into account, the economic cost of psoriasis is likely to be greater than currently predicted.

Treatment and care in the UK

Early diagnosis, rapid referral and access to timely and effective treatment by trained multi-disciplinary professionals is essential to the management of psoriasis, minimising the impact that the condition has on an individual's employment by controlling symptoms or disease progression. This could lead to wider economic gains through increasing worker capacity.³⁶ The NHS implements a three stage pathway in the treatment of psoriasis:

- Most patients are treated with topical treatments (applied to the body) such as corticosteroid creams or vitamin D.³⁷
- If these are unsuccessful, patients are referred to a dermatologist where common treatments are phototherapies and/or non-biological drug treatments.³⁸
- The final stage of treatment is biological therapies, which are typically reserved for individuals who have been unresponsive to other treatments.³⁹

Biological therapies can produce enhanced clinical outcomes when compared to topical and non-biological treatments for individuals with moderate and severe psoriasis, although the direct costs are estimated to be greater per person annually.⁴⁰ However, biologics may also result in a significant reduction in inpatient admissions⁴¹, which may translate into days worked for individuals who are employed. For example, if an intervention was to achieve a ten per cent reduction in sickness absence resulting from reduced need to attend hospital for treatments, the subsequent gains could equal around £50 million.⁹

Despite the significant impact that skin conditions have on a patient's life and the wider economy, evidence indicates that the NHS is currently failing to provide adequate psoriasis care.⁴² For instance, 20 per cent of dermatology units have no specialist dermatology nurse, 56 per cent have no clinical psychology services,

^e See Appendix Two, Table 1.2, for details of assumptions and calculations.

^f *ibid.*

⁹ ten per cent of total lost productivity due to absenteeism. See Appendix Two, Table 1.2, for full details of assumptions and calculations.

and 39 per cent restrict the prescribing of biologics due to a lack of funding.⁴³ As psoriasis has wide physical and psychological effects, limited access to specialist care can be detrimental to both the patient and the economy and so must be addressed.

Recommendations

In order to improve employment outcomes for individuals with psoriasis, the following should be considered:

- **NHS England needs to prioritise dermatologic conditions as long term conditions.** This would require greater levels of accountability within the NHS to ensure standards of care are consistently improved across the board.
- **There needs to be greater focus on the early diagnosis of skin conditions and rapid referral to specialists.** This will require targeted investment in GP education and an increase in the provision of specialist dermatologists.
- **Individuals with psoriasis, who require specialist care, should have timely access to a dermatologist.** Patients have expressed that their condition has had a negative impact on their employment and educational opportunities, which could be avoided if psoriasis is effectively controlled earlier.
- **The full impact that psoriasis has on an individual needs to be treated and managed by a multi-disciplinary team.** Any treatment should address the profound functional and psychological effects of psoriasis, which can result in reduced levels of employment and income.
- **There should be a greater investment in psychological services for patients with psoriasis.** This includes establishing a larger number of 'psycho-dermatology services', which integrates psychological services within hospital dermatology departments.
- **Investment in developing psychological services needs to be accompanied by improved data collection practices.** This would help measure the impact this investment has for quality of life and employment outcomes.
- **Training on dermatology for healthcare professionals (GPs, nurses and pharmacists) should include a greater emphasis on psoriasis as a long term condition, with consequent psychosocial effects.** As diagnosis can occur at any age and psoriasis can affect people throughout their working life, healthcare professionals need to recognise the potential impact that psoriasis can have on an individual's ability to work.
- **Employers need to receive improved education about the realities of psoriasis and how it can be managed successfully in the workplace.** There needs to be the creation of a 'stigma-free' work environment so individuals with psoriasis do not feel unfairly discriminated against.

Conclusion

Psoriasis and related physical and psychological comorbidities can cause significant disruptions to an individual's working life, which could result in sickness absence, underemployment and unemployment. The financial and social costs of psoriasis need to be addressed through targeted interventions and improved clinical outcomes that aim to help those with psoriasis remain in employment. Improvements in access to innovative treatments and gaps in specialist healthcare provision need to be addressed and joined up with appropriate vocational support that empowers the individual and helps them enter or remain in employment. Failure to do so will be to the detriment to a vast number of psoriasis patients across the UK and will come at a significant cost to the UK economy in the coming decades.

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DIABETIC MACULAR OEDEMA (DMO) IS THE MOST COMMON FORM OF VISUAL IMPAIRMENT FOR PEOPLE WITH DIABETES.¹

COMMON SYMPTOMS¹

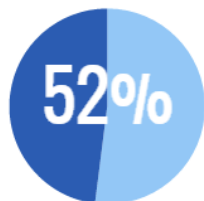


Reduced clarity of vision



An estimated 166,000 people have DMO in the UK.² Trends in the increasing levels of diabetes could see this figure rise to over 350,000 by 2025.³

COMORBIDITIES⁴



52% of people with DMO are of working age.³

An estimated 242,000 working days are lost due to DMO related sickness absence in the UK each year.³



Depression



DMO related sickness absence costs the UK £29.4 million per year.³



Cardiovascular disease

£116.3

million is estimated as the total direct health and social care cost of DMO in the UK.²

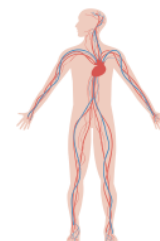
EFFECTS ON ABILITY TO WORK AND QUALITY OF LIFE



It can become increasingly difficult to read and see fine details as DMO worsens.⁵



Driving can become problematic and travelling can become difficult without help.⁵



Hypertension



DMO has a greater impact on quality of life than other eye conditions including glaucoma and cataracts.⁶



Reduced ability to perform at work because of vision loss can leave people feeling distressed.⁷



Kidney disease

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Diabetic Macular Oedema (DMO)

Key statistics

- An estimated **166,000 people** have DMO in the UK.¹ If trends persist this could rise to over **350,000** by 2025.^a
- Approximately **52 per cent** of individuals with DMO are of working age (16 – 64).^b
- **An estimated 242,000** sickness absence days are taken each year as a result of DMO.^c
- Lost productivity associated with DMO related sickness absence costs the UK **£29.3 million** a year. This could rise to over **£62.7 million** by 2025 if trends persist.^d

Sight loss and visual impairment

Around two million people in the UK are currently living with sight loss.² The number of people in the UK with sight loss is set to increase dramatically in the future as the population ages, and because there is a growing incidence in key underlying causes of sight loss, such as obesity and diabetes.³ This means that, without action, the number of people with sight loss in the UK is likely to increase dramatically during the next 35 years to over four million.⁴ The economic consequences of this are likely to be substantial as sight loss and visual impairment can have severe implications on the employment prospects of those who experience them. In 2012/13 the NHS spent £2.3 billion on treating problems related to vision⁵, however, costs resulting from unpaid care, reduced employment and other indirect costs to the UK economy as a result of sight loss were estimated to be £4.34 billion.⁶

Diabetic macular oedema

DMO is the most common cause of visual impairment for all people with diabetes.⁷ It occurs when high blood sugar affects the blood vessels in the eye causing the macula (the central part of the retina) to harden, leading to visual impairment of varying degrees.^{8,9} In the UK, an estimated 166,000 people had DMO in one or both eyes in 2010¹⁰, of which 52 per cent were of working age.^e DMO can occur at any time, but is more likely to affect those with poor diabetes control and those who have lived with diabetes for longer.¹¹

Early detection of diabetes and good disease management can prevent and / or delay the onset of DMO.¹² However, as the number of people in the UK diagnosed with diabetes is expected to rise from approximately three million to over five million by 2025¹³ (over 85 per cent of whom will have Type 2 diabetes¹⁴), it is predicted that DMO will also rise significantly to over 350,000.^f Crucially, recent evidence suggests that Type 2 diabetes is being more frequently diagnosed in younger adults than previously,

^a See Appendix Two, Table 1.3, for details of assumptions and calculations.

^b *ibid.*

^c *ibid.*

^d *ibid.*

^e *ibid.*

^f *ibid.*

meaning more people could develop DMO during their working years.¹⁵

Comorbidities

DMO cannot be considered in isolation from diabetes and diabetes related comorbidities, which often place additional strains on an individual when trying to manage their illness and employment.^{16,17} Around 85 per cent of diabetes patients have at least one physical or mental comorbidity, while 49 per cent have three or more.¹⁸ Common comorbid conditions include cardiovascular disease, hypertension, kidney disease and depression.¹⁹ Managing multiple conditions can have severe consequences for an individual's employment prospects, with studies showing that people with diabetes and another comorbid condition report higher levels of sickness absence compared to those solely with diabetes.²⁰

Quality of life

When discussing quality of life related to visual impairment (using the NEI-VFQ questionnaire: see Appendix One), individuals with DMO scored on average, lower than individuals with other eye conditions (e.g. diabetic retinopathy, glaucoma and cataracts) on scales measuring social functioning, mental health, dependency and role/work limitations.²¹ Furthermore, individuals with diabetic retinopathy⁹ have reported difficulties in completing tasks taken for granted by most (such as: household chores; shopping; reading; recognising faces; and using transport) resulting in stress, withdrawal from social situations, and feelings of isolation.^{22,23} This can have further implications on an individual's ability to work effectively.

DMO, employment and the economic cost

Vision loss associated with DMO can have an impact on an individual's capacity to work in a number of ways:

- It can make it difficult to see fine detail, which may impact on reading documents or computer screens.²⁴
- Driving can become problematic making it difficult to travel to work and get around unassisted.²⁵
- Tasks can often take longer to complete.²⁶
- A reduced ability to perform at work can leave individuals with DMO feeling distressed, fearful for their job, and may lead to individuals leaving the workforce prematurely.²⁷

As DMO is one of the most common causes of blindness and visual impairment in the working age population, it can be expected that the above factors contribute to the low employment rate observed in this population. Evidence from the UK Labour Force Survey indicates that the average employment rate for working age individuals who classify themselves as having a 'seeing difficulty' that has an impact on their daily life (used in this study as a proxy measure for 'blindness and visual impairment') is 44.9 per cent, compared to 72.8 per cent for all working age people (data from twelve quarters from October 2011 to September 2014).²⁸ The data also suggests that people with seeing difficulties are being left behind in the economic recovery. Over the period from 2010 to 2014, the employment rate for people who are classified as having a long term disability as a result of a seeing difficulty fell by 3.9 per cent, while for all people of

⁹ A diabetic eye condition which often precedes DMO

working age there was a 0.2 per cent reduction.²⁹

Evidence from Canada (where treatments are similar to those available in the UK) suggests that the average worker with DMO loses an additional 2.8 working days per year due to their condition compared to their healthy counterparts.^{h,30} Assuming the same amount of absenteeism was present across the UK would mean that DMO leads to approximately 243,000 days lost per year, resulting in a £29.3 million cost annually.ⁱ Projections suggest this could rise to over £62.7 million by 2025 fuelled by the increase in diabetes.^j These figures do not take into account sickness absence as a result of diabetes or other associated comorbidities, nor does it take into account presenteeism or early retirement, meaning the true figure is likely to be higher. Additionally, evidence indicates that family members are often called upon to provide care for individuals with DMO, with around eleven per cent foregoing paid work time to do so.³¹ The cost of this is estimated to account for around one per cent of the total societal cost of DMO.³² Overall, the cost of formal social care associated with DMO in the UK was estimated to be approximately £12 million in 2010, while the total direct health and social care cost in the UK was estimated to be £116.3 million.³³

Despite there being evidence to suggest that individuals with DMO face significant barriers to work, there has been limited research into the wider economic impact of DMO. Consequently, there is a need to overcome these knowledge gaps so the true costs resulting from the effects of DMO on employment can be measured, and appropriate interventions implemented.

Treatment and care in the UK

Early diagnosis and treatment can help prevent sight loss for individuals with DMO which could minimise the impact it can have on their ability to work.³⁴ In the UK, laser therapy has been the most widely used treatment for correcting and stopping the progression of DMO.³⁵ Steroid injections and anti-vascular endothelial growth factor (VEGF) drugs, which treat the underlying causes of DMO, have recently been shown to be more effective than laser therapy in preventing the progression of DMO and restoring degrees of vision, and are increasingly replacing traditional laser treatments in the NHS.³⁶ However, fears have been expressed about future NHS capacity issues that may arise from the increasing burden of delivering such therapies for patients with DMO, meaning that optimal treatment may not be available to all who experience the condition across the UK.³⁷

Effective clinical management of diabetes plays a crucial role in preventing or slowing the progression of vision loss³⁸, and is associated with the reduction in the incidence of DMO in patients with Type 1 diabetes.³⁹ Effective self-management of diabetes requires knowledge about the condition, how it is treated, what behaviours need to be avoided and what to do if things go wrong.⁴⁰ However, a recent audit of diabetes care in the UK found that only 2.4 and 6 per cent of Type 1 and Type 2 patients, respectively, were offered structured education to help self-manage their condition.⁴¹ Such help is of particular importance for those with DMO who wish to remain in employment, as both sight loss and a strict working routine can make it difficult to undertake self-management tasks, such as taking insulin at set times or following a specific diet.⁴²

^h Based on a level of 1.4 working days per patient revealed in a six month study (Gonder, et al., 2014).

ⁱ See Appendix Two, Table 1.3, for details of assumptions and calculations.

^j *ibid.*

Recommendations

In order to improve employment outcomes for individuals with DMO, the following should be considered:

- **Individuals with diabetes need dedicated advice on good disease management in order to prevent and/or delay the onset of DMO.** Successful self-management needs to be at the heart of clinical practice and more needs to be done to increase the number of people with diabetes being offered structured education to help them cope with the complex aspects of their condition.
- **Individuals should have more support from trained professionals to enable personalised care planning and management of their diabetes.** More trained staff and greater access to personalised care planning can play a part in helping to prevent complications, such as DMO arising.
- **Improvements should be made in the early detection and diagnosis of DMO.** Early diagnosis and subsequent treatment can prevent severe sight loss in people with diabetes. More work is needed to reach the NHS target of 100 per cent screening for early signs of diabetic retinopathy before it progresses to more severe forms of DMO.
- **Individuals with DMO need quick access to safe and effective treatments to prevent avoidable sight loss.** Visual impairment has a substantive impact on an individual's quality of life through the loss of independence and can lead to higher levels of depression. It can also affect an individual's ability to self-manage their diabetes, for example checking blood sugar level. Early treatment can have an impact on an individual's success in remaining in employment.
- **Employers need more information regarding the types of reasonable adjustments that can be made to support those with visual impairment to stay in work.** This will help reduce the number of people with DMO leaving employment as a result of functional limitations and to help overcome any discrimination that may be experienced in the workplace.

Conclusion

DMO is an eye condition that causes progressive impairment to sight, which can limit an individual's ability to work and affect their quality of life. The indirect economic costs of DMO are substantial and are projected to rise as the incidence of diabetes increases over the coming decades – indeed, a near doubling of the numbers by 2025. Access to targeted treatments and early interventions are needed to help those with DMO enter and remain in employment and limit the wider financial implications of the condition. To achieve this, it is vital that healthcare services are in place to better support individuals to care for themselves through increased provision of education services that may prevent some of the health, wellbeing and economic losses associated with DMO. It is also important to ensure that patients are able to access innovative treatments that help them to achieve their care and employment goals.

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ASTHMA IS A LONG-TERM, FLUCTUATING, INFLAMMATORY CONDITION THAT AFFECTS THE AIRWAYS IN THE LUNGS.¹



An estimated 5.4 million people have asthma in the UK.¹

Approximately **2.4 MILLION** of those with asthma are of working age.²



12.7 million working days are lost each year due to asthma related sickness absence in the UK.³

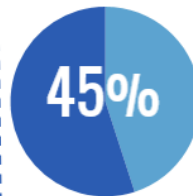


1.5 billion of indirect costs to the UK economy as a result of asthma related sickness absence each year.⁴

EFFECTS ON ABILITY TO WORK AND QUALITY OF LIFE



Roles that involve physical exertion can be difficult to maintain.⁵



45% of individuals with asthma report that they go to work when ill.⁶



Over one third feel they have been denied a promotion because of their asthma.⁷



Early onset can have an impact on education and career prospects.⁸

80

% increased risk of having a long-term period of sickness absence.⁹

43

% of patients report that asthma has some impact on their life.¹⁰

COMMON SYMPTOMS¹



Difficulties breathing



Wheezing



Coughing



Asthma attack

COMORBIDITIES¹¹



Depression



Hypertension



Chronic Obstructive Pulmonary Disease

1) Department of Health. (2011). An Outcomes Strategy for Chronic Obstructive Pulmonary Disease (COPD) and Asthma in England. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216531/dh_134001.pdf (last accessed 16/03/2015).

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Asthma

Key statistics

- An estimated **2.4 million** working age adults have asthma in the UK.¹
- It is predicted that **2.6 million** working age adults will have asthma by 2030.²
- **12.7 million working days** are reported as sickness absence as result of asthma in the UK each year.³
- The indirect cost to the UK economy associated with this asthma related sickness absence is estimated to be **£1.5 billion a year**.^a
- **45.7 per cent** of people with asthma report going to work when ill.⁴

Respiratory diseases

Respiratory diseases are extremely common in both adults and children and account for significant ill health, disability and death. Estimates suggest that over six million people in the UK have chronic obstructive pulmonary disease (COPD) or asthma⁵, the two most common respiratory diseases, of which 40 per cent are under retirement age.⁶ For many individuals, respiratory diseases can be difficult to manage without proper support and treatment, and can have a significant impact on their working lives. In addition, the economic cost of respiratory conditions is substantial. In 2012/13 the NHS spent £4.69 billion on treating problems of the respiratory system.⁷ The total cost of lost productivity as a result of all respiratory related morbidity and mortality in the UK is huge – estimated to be £1.7 and £1.9 billion respectively.⁸

Asthma

Asthma is a long term, fluctuating, inflammatory condition that affects airways in the lungs.⁹ When an individual with asthma comes into contact with something that irritates their airways, the airways become restricted causing difficulties in breathing.¹⁰ The exact causes of asthma are unknown, although genetics and environmental factors are believed to play an important role.¹¹ The most common symptoms of asthma are wheezing, coughing, shortness of breath and a tight chest.¹² These symptoms can vary in severity from day to day and can have an impact on an individual's employment if they are not managed effectively.

The UK has one of the highest recorded prevalence rates of asthma in the world, with 5.9 per cent of the population¹³ (1 in 11 children and 1 in 12 adults¹⁴) having GP diagnosed asthma. More than 2.4 million working age adults are estimated to have some form of asthma, a figure which is projected to rise to over 2.6 million by 2030.¹⁵ Asthma can develop at any age and change over time, meaning the impact it can have on an individual's working life can be diverse and long lasting if not controlled, making it important that individuals receive regular specialist care.

^a See Appendix Two, Table 1.4, for details of assumptions and calculations.

Comorbidities

Comorbidities are common in patients with asthma. Estimates suggest that 60 per cent of individuals with asthma have at least one comorbid condition, while twelve per cent have three or more.¹⁶ Common comorbidities associated with asthma are depression, hypertension, diabetes, heart disease, and COPD.¹⁷ Comorbid conditions can act as additional barriers to employment for people with asthma. For example, individuals with concurrent mental illness and asthma experience greater levels of functional disability (in terms of the number of days they feel they are limited by their condition compared to individuals with only asthma).¹⁸

Quality of life

In Europe over 43 per cent of asthma patients report that their condition affects some aspect of their life¹⁹, while 14 per cent report that they are affected when completing activities of daily living for three or more days each month.²⁰ Patients often report difficulties in walking and exercising; while night time asthma symptoms can affect sleep, leaving individuals feeling tired throughout the day and unable to perform effectively at work.²¹ Furthermore, evidence suggests that individuals with asthma on average report lower physical and mental quality of life scores across the functioning domains of the SF-36 measure (see Appendix One) in comparison to healthy individuals.²²

Asthma, employment and the economic cost

The fluctuating nature of asthma means that it can have an impact on an individual's capacity to work in a number of ways:

- Reduced fitness or more debilitating symptoms can make work that involves physical exertion, such as, prolonged walking or heavy lifting, difficult to complete without appropriate adjustments or regular rests.²³
- Severe asthma symptoms can render individuals housebound²⁴ thus creating a barrier to attending work.
- Work environments that are cold, dusty or contain fumes can exacerbate asthma, creating risks of asthma attacks.²⁵
- Stressful work situations can also exacerbate asthma and lead to asthma attacks.²⁶
- Asthma has also been highlighted as a source of stigma in the workplace.²⁷

Over 45 per cent of people with asthma report going to work when ill, which can have an impact on an individual's productivity at work.²⁸ Evidence suggests that having asthma may result in a 50 per cent increase in the risk of reduced work ability over time^b, which can have a number of negative consequences both in terms of career advancement and quality of life.²⁹ For example, one study found that 39 per cent of individuals with asthma felt they had been denied promotions and were viewed as less capable compared to other colleagues.³⁰

^b Measured as the difference on a scale of 1 to 10 between an individuals' current ability to perform physical and mental tasks and their lifetime best.

The impact of asthma on an individual's working life can begin at an early age. Younger individuals with asthma have reported that their education and career prospects have been affected as a result of missing school or lacking the confidence to do certain jobs because of their condition.³¹ Moreover, individuals with asthma have an 80 per cent increased risk of having a long term period of sickness absence.³² Crucially, we know that prolonged exit from the labour market can have detrimental effects on an individual's wider health and wellbeing and their opportunities for future employment.

These barriers contribute to an above average rate of sickness absence for individuals with asthma; in Europe, on average, one in four patients with asthma report missing at least one day of work as a result of their condition each year, whilst 14 per cent report losing over twelve working days.³³ Across the UK, estimates suggest that asthma is responsible for around 12.7 million lost working days, resulting in productivity losses of approximately £1.5 billion, which is greater than the £1.05 billion spent treating asthma by the NHS in 2012/13.^{c,34} If current population trends persist, by 2030 over a million more days will be lost as a result of asthma if no action is taken to improve patient outcomes.^d The total indirect costs of asthma are likely to be higher, as these figures do not include the cost of unemployment and early retirement. Additionally, the figure does not include days lost by caregivers, for instance, 30 per cent of parents who have a child with asthma are reported to lose work days because of their children's condition, meaning the cost of asthma for the wider economy is greater than what is currently reported.³⁵

Treatment and care in the UK

Asthma treatment aims to keep symptoms under control, allowing many people to enjoy productive working lives. Inhalers are the most frequently prescribed treatment, with three quarters of those with asthma using a reliever / controller inhaler daily, while 40 per cent of individuals intermittently use a preventer inhaler, containing steroids to control symptoms.³⁶ However, a UK audit undertaken in 2012 suggests that the NHS is failing to provide adequate asthma care. For example, 25.6 per cent of asthma patients had poor inhaler technique which can make controlling asthma symptoms more difficult, while only half had their techniques reviewed by a doctor.³⁷

Furthermore, 'Personal Asthma Action Plans', which are tailored self-management guides recommended in the National Review of Asthma Deaths, were only in place for 42 per cent of patients despite strong evidence suggesting that they improve the management of asthma and reduce the likelihood of needing emergency care.³⁸ Finally, while the British Thoracic Society Clinical Guidelines recommend yearly asthma reviews, a recent survey found that 32 per cent of asthma patients failed to attend regular reviews and only twelve per cent used Personal Asthma Action Plans.³⁹ As poor asthma control is associated with having a greater impact on employment outcomes, these findings warrant further action. For instance, the cost of an emergency admission is 23 times the cost of an annual asthma review, making the reviews far more cost effective to deliver.⁴⁰

Recommendations

In order to improve employment outcomes for individuals with asthma, the following should be considered:

- **There should be prompt and accurate diagnosis of asthma, with timely access to a specialist where needed, to ensure that correct treatment is given.** Effective early interventions can help

^c See Appendix Two, Table 1.4, for details of assumptions and calculations.

^d *ibid.*

patients to control their asthma, which has a positive impact on health, education and employment outcomes.

- **Increase awareness of evidence-based national guidelines/guidance, such as the British Thoracic Society Clinical Guidelines, SIGN Guidance and NICE Quality Standard.** Evidence suggests that knowledge of these guidelines is currently inconsistent, leading to variation in care practices and hospital admission rates across the country.
- **Patient education about asthma and self-management needs to be improved to reduce incidents of unscheduled healthcare.** There is a mismatch in perceived and actual asthma control. Additionally, the loss of control of asthma symptoms can lead to repeated hospitalisation/sickness absence, with consequences for an individual's education and employment outcomes.
- **All patients should receive an annual asthma review and have a Personal Asthma Action Plan.** This will ensure a reduction in the number of people with asthma that are not well controlled and therefore help to reduce sickness absence.⁴¹
- **A standard national asthma review template should be developed.** This will help to facilitate a structured and thorough review for patients, ensuring risks are understood and poor asthma control does not lead to sickness absence.⁴²
- **Employees should feel able to tell their employer about their condition in order for them to make reasonable adjustments.** These adjustments might include assessing and minimising asthma triggers in the working environment to prevent any unplanned absence.

Conclusions

Asthma can place a significant burden on an individual's working life and lead to substantial productivity losses in the wider economy. Evidence indicates that the treatment and management of asthma by healthcare professionals often falls short of best practice guidelines, which may be an influential factor to the disruption that asthma can have on employment. Focusing on improving the management of asthma by regularly reviewing treatments and developing 'Personal Asthma Action Plans' could result in improved asthma control, and increased financial and employment outcomes. Interventions that keep people out of hospital and help keep asthma under control may also translate into significant economic benefits.

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SCHIZOPHRENIA IS A SEVERE FORM OF MENTAL ILLNESS THAT CAN HAVE AN IMPACT ON HOW A PERSON THINKS AND BEHAVES.¹



It is estimated that 1% of the UK population has schizophrenia.¹



The total cost of schizophrenia in England is estimated to be **£11.8 BILLION per year.**³

Including: **£715 million in forgone tax.**³

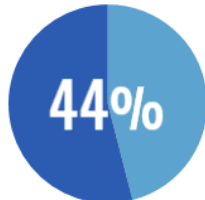
£470 million spent on social security benefits.³

EFFECTS ON ABILITY TO WORK AND QUALITY OF LIFE

JUST

8%

of people with schizophrenia are in employment.¹



report that social isolation is a major barrier to recovery.¹

The average number of sick days taken by workers with schizophrenia per year⁴



People with schizophrenia can find it difficult to develop interpersonal relationships.⁵



Onset typically occurs in late teens or early 20s and can have life long impacts on employment.⁵

LESS THAN **1/2** of those who were seeking employment were receiving help to do so.⁶

COMMON SYMPTOMS²



Changes in behaviour



Delusions



Hallucinations



Withdrawal

COMORBIDITIES



Substance and alcohol abuse⁷



Cardiovascular disease⁸



Depression⁷

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Schizophrenia

Key statistics

- Approximately **1 per cent** of the UK population have schizophrenia.¹
- **Just 8 per cent** of people with schizophrenia are in employment.²
- The average number of sickness days taken each year by employees with schizophrenia is **12.5**.³
- The yearly cost of lost and disrupted employment due to schizophrenia in England is **£3.4 billion**.⁴
- The total direct and indirect cost of schizophrenia in England is **£11.8 billion** per year.⁵

Mental health

A quarter of all people will experience poor mental health in the course of a year, while at any given time, one in six working age adults in the UK will experience symptoms associated with mental ill health (such as sleep problems, fatigue and irritability).^{6,7} It is thought that up to 50 per cent of individuals with a physical health condition will also develop a mental health condition.⁸ Despite recent developments in the treatment and diagnosis of mental health conditions, and new and more accepting attitudes towards them, they are considered to have a greater impact on a person's ability to work than any other group of disorders.⁹ This has a significant impact on the economy. Overall, mental health conditions account for 13 per cent of the NHS budget, while accounting for 28 per cent of morbidity.¹⁰ At the same time, mental illness is the leading cause of sickness absence, resulting in over 70 million days of sickness absence in 2013, and is estimated to cost the UK economy between £70 and £100 billion in lost productivity a year.¹¹

Schizophrenia

Schizophrenia is a severe form of mental illness, and is ranked as the ninth most disabling condition by the World Health Organisation (WHO) because of the impact it can have on an individual's life.¹² It is a form of psychosis, which is defined by Mind as when 'you perceive or interpret events differently from people around you'.¹³ Symptoms and behaviours are usually classified into two categories: positive and negative. Positive symptoms are characterised by a change in thoughts and behaviours, such as delusions and hallucinations. Negative symptoms are characterised by withdrawal or loss of ability to perform as one would expect a healthy person to, for example, being emotionless or flat.¹⁴ Schizophrenia is a fluctuating condition and it is common for people to have severe episodes of psychosis followed by periods of few or no symptoms.¹⁵ With assistance many individuals with schizophrenia are able and willing to work, however when the symptoms of schizophrenia become more severe, employment can become progressively more difficult if workplace adjustments and support are not received.¹⁶

Schizophrenia affects around one per cent of the UK population.¹⁷ Onset typically occurs in the late teens and early 20s when individuals are beginning to enter the labour market and become more independent.¹⁸ The condition can lead to reduced educational attainment, dependency and unemployment, which can significantly impair an individual's future prospects.¹⁹

Comorbidities

Comorbidities can often create additional barriers to entering employment for those with schizophrenia²⁰, and increase the likelihood of both morbidity and mortality.²¹ Evidence suggests that half of those diagnosed with schizophrenia will experience comorbid depression, while panic and obsessive compulsive disorders are also common.²² Individuals with schizophrenia are also more likely to experience diabetes and cardiovascular disease, largely as a result of lifestyle factors such as: poor diet; obesity; and higher levels of smoking.²³ The monitoring of lifestyle factors by healthcare professionals remains less than necessary, which may further contribute to compounding individual morbidity and increased mortality levels.²⁴ Furthermore, substance abuse is extremely common among people with schizophrenia, which can make engagement in psychological therapies difficult.²⁵ The interplay between associated comorbidities can therefore present challenges when recovering^a from schizophrenia, and make finding employment without multi-disciplinary care^b more difficult.²⁶

Quality of life

Schizophrenia and its related comorbidities have shown to dramatically affect the quality of life for those who live with them.²⁷ As symptoms of schizophrenia increase in severity, social functioning can become increasingly difficult, making it essential that appropriate and early care is received.^{28,29} Evidence suggests that individuals with schizophrenia will often withdraw from social situations in an attempt to cope with their symptoms potentially leading to social isolation, which can be detrimental to an individual's recovery.³⁰ Indeed, 44 and 46 per cent of people with schizophrenia report that the main barriers to recovery are isolation and low self-esteem (respectively), and this can hinder a willingness to engage in potentially beneficial employment.³¹ A significant contributing factor to this is stigma that persistently surrounds mental illness, which is particularly evident in the employment setting.^{32,33}

Schizophrenia, employment and the economic cost

Schizophrenia can have an impact on an individual's ability to work, and their employment prospects in a number of ways:

- Difficulties in developing interpersonal relationships can make it hard to interact with work colleagues and engage with customers.³⁴
- Schizophrenia can lead to difficulties in concentration and developing new skills.³⁵
- The side-effects of medication to treat schizophrenia can lead to individuals feeling too unwell to work.³⁶
- An individual's poor work history caused by frequent breaks in education and employment, can limit job opportunities.³⁷
- The fear of losing benefits through attempting to work can stop individuals trying to get a job.³⁸

^a In this report we are using the concept of recovery as not being only about controlling symptoms, but also about living a fulfilling life and regaining a sense of meaning (see Bevan et al., 2013)

^b Multi-disciplinary care occurs when professionals from a range of disciplines with different but complementary skills, knowledge and experience work together to deliver comprehensive healthcare aimed at providing the best possible outcome for the physical and psychosocial needs of a patient and their carers.

- Stigma and self-stigma associated with schizophrenia, caused by the misconception that those with schizophrenia lack the ability to work is a large barrier to employment.³⁹
- Individuals with mental health conditions, such as schizophrenia, may not receive or apply for training, and/or are denied promotions because of their condition.⁴⁰
- Fear of disclosure can limit access to relevant support and reasonable adjustments that could increase an individual with schizophrenia's likelihood of entering and remaining in employment.⁴¹

The interplay between the findings above, alongside evidence of substandard care⁴² (discussed below) has created a harsh working reality for many people with schizophrenia. Evidence suggests that individuals with schizophrenia face one of the lowest employment rates amongst all vocationally disadvantaged groups, with just eight per cent estimated to be in employment in the UK⁴³, compared to the national average of 73 per cent.⁴⁴ This is despite evidence that up to 70 per cent of people with severe mental illness express a desire to work.^{45,46} Additionally, even though work may not be a realistic outcome for some individuals with severe forms of schizophrenia, work is generally considered to have multiple benefits in terms of financial gain, addressing social inclusion and assisting with an individual's health and wellbeing.^{47,48}

Approximately 19 per cent of individuals employed with schizophrenia report having missed work as a result of their condition, with these individuals taking, on average, 12.5 days of sick leave per year⁴⁹, compared to the UK national average of 4.4 days per year.⁵⁰ The financial costs of this are substantial. In England alone, the total indirect cost of schizophrenia was estimated to be £11.8 billion in 2012.⁵¹ Of this, lost and disrupted employment due to schizophrenia was estimated to cost England £3.4 billion, while the knock on implications for lost tax revenues translated to £715 million in forgone tax.⁵² Additional spending on social security benefits for those with schizophrenia totalled £470 million (data for England only).⁵³

Crucially, estimates suggest that the economic gains to society from an employment rate of 50 per cent for individuals with schizophrenia (for an average of 20 hours a week at Minimum Wage) would equal £350 million in generated wages, including a saving of approximately £120 million from reduced social care costs.⁵⁴ In addition, successful gains in competitive employment by individuals who want to work also leads to improved clinical outcomes, and therefore the potential for reduced healthcare costs.⁵⁵

Treatment and care in the UK

Appropriate treatment and support can help individuals with schizophrenia find meaningful employment and lead to productivity gains for the UK economy. Current treatments in the UK include a mixture of anti-psychotic drugs, psychosocial therapy such as cognitive behavioural therapy (CBT), and rehabilitation.⁵⁶ Individuals will typically receive care and treatment from a community mental health team (CMHT), comprised of social workers, pharmacists, psychiatrists, community mental health nurses and therapists.⁵⁷

Early intervention teams (EITs) in the UK provide services for people who experience psychosis for the first time; NICE recommends that they are available to people of all ages but some limit services to those under a certain age – most often 35.⁵⁸ They have a similar make up to the CMHTs in terms of expertise and remit, but typically provide more intensive services for up to three years. EITs have been effective in reducing the likelihood of relapse after a psychotic episode and have shown a reduced frequency of positive and negative symptoms experienced by those with schizophrenia.⁵⁹ Estimates suggest that 36 per cent of individuals who receive early interventions are in employment, compared to 27 per cent of those receiving standard care.⁶⁰ The resulting benefits in terms of earnings were estimated to be £4,299 per patient.⁶¹

However, a recent audit (2014) suggests that there are not any areas of schizophrenia care currently delivering an 'excellent service', which could be limiting positive employment outcomes.⁶² The audit found that 90 per cent of health service users were unemployed, while less than half of those who were seeking employment were receiving help in doing so.⁶³ Poor treatment and management of the condition needs to be addressed through targeted investment so that the health and economic gains of work can be realised.

Recommendations

To improve employment outcomes for individuals with schizophrenia, the following should be considered:

- **More widespread use of EITs is urgently needed.** Early intervention teams have a significant impact on an individual's employment status. This is achieved by improving health outcomes, such as reducing the likelihood of a patient experiencing a relapse.
- **Increased access to CBT and tackle the current gaps in provision of this and family therapy.** CBT can help improve both health and employment outcomes. Evidence has shown that a dedicated CBT programme designed to address low self-esteem relating to employment can help patients to work more hours and retain employment for longer.⁶⁴
- **Employment should be considered to be a recovery goal for people with schizophrenia and there should be greater access to Individual Placement and Support^c schemes.** Schemes like these are essential in helping those who want to work and in supporting employers.
- **There should be more specialist employment support programmes provided by the DWP for people with schizophrenia.** Mind found that current support provided through the Work Programme and JobCentre Plus is frequently ineffective for people with mental health conditions.⁶⁵
- **Employers should create an open environment at work to tackle the problem of non-disclosure.** Fear of stigmatisation is leading many to come to work when ill. Employers need to develop an environment where people feel confident in seeking the relevant support and feel confident enough to disclose.

Conclusion

Individuals with schizophrenia face multiple and complex barriers when entering the workforce. The social and economic consequences of these are huge, and need to be addressed through improving clinical outcomes. To achieve this, access to early diagnosis and intervention needs to be a priority, while employment as a clinical outcome needs to be further emphasised and addressed through greater provision of vocational support. The business case for doing this is strong, with the potential for large productivity gains and reduced welfare expenditure over the long term. Failure to address the existing shortcomings in care will see the societal costs of schizophrenia rise in the coming decades, placing further strain on both the NHS and the wider economy.

^c A well evidenced model of Supported Employment or "Place then Train" with the focus on getting people into competitive employment first, followed by training and support on the job. For more information see: <http://www.centreformentalhealth.org.uk/individual-placement-and-support>

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HEART FAILURE OCCURS WHEN AN INDIVIDUAL'S HEART DOES NOT PUMP BLOOD AROUND THE BODY AS IT SHOULD.¹



An estimated 750,000 people live with heart failure in the UK.²

27,000 new cases are diagnosed each year.²



The rate of incidence is 60 per cent higher in men compared to women.²



The indirect cost of heart failure in the UK is estimated to be **£0.92 BILLION**.³

The total cost of heart failure to the UK, including healthcare expenditure, is estimated to be almost **£3 BILLION**.³

COMMON SYMPTOMS¹



Breathlessness



Chronic fatigue



Fluid retention

EFFECTS ON ABILITY TO WORK AND QUALITY OF LIFE



Limited fitness and physical functioning can make manual work difficult.⁵

The average number of sickness absence days taken per year by individuals with heart failure is



Depression



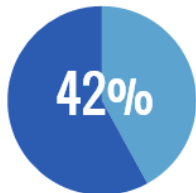
Heart failure reduces an individual's productivity while at work.⁷



The impact of heart failure on quality of life is similar to that of other chronic diseases.⁸



Renal dysfunction



42% of hospitalised patients die within 5 years of being diagnosed.⁹

ONLY 4%

of UK patients access cardiac rehabilitation which can help people return to work.¹⁰



Anaemia



Arthritis

1) The Health Foundation (2010). Bridging the quality gap: heart failure. Available at: <http://www.health.org.uk/publication/bridging-quality-gap-heart-failure> (last accessed 25/02/2015).

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Heart Failure

Key statistics

- An estimated **750,000** people are living with heart failure in the UK.¹
- Approximately **27,000** new cases of heart failure are diagnosed each year.²
- The average number of sickness absence days taken by someone with heart failure is **17.2 per year**.^a
- The total indirect cost to the UK associated with heart failure is **£0.92 billion**.^{b,3}
- The total (direct and indirect) burden of heart failure is estimated to be **£3 billion**.^{c,4}

Heart and circulatory disease

Cardiovascular disease affects approximately seven million people in the UK and is one of the largest causes of death and morbidity, resulting in over 1.6 million hospital episodes and 160,000 deaths a year.⁵ Over the last decade there have been improvements in the prevention and treatment of cardiovascular disease.⁶ However, with an ageing population, alongside the rise in levels of obesity and diabetes, it is becoming increasingly important to understand the implications of cardiovascular and related heart and circulatory conditions for employment.^{7,8} Estimates suggest that cardiovascular disease results in 69 million days of sickness absence per year in the UK, and the loss of 244,000 years of work due to premature workforce exit.^{d,9} The financial and psychological implications of early workforce exit due to cardiovascular disease can place a significant burden on individuals, families and the health and welfare systems. In 2012/13, the NHS spent £6.9 billion on treating circulatory problems in the UK (£1.6 billion of which was directed at cardiovascular disease)¹⁰ and in 2013/14 the government spent £424 million on out of work benefits for those with circulatory diseases.¹¹ The total burden, including the cost of premature death and lost productivity, is estimated to be much greater at £19 billion.¹²

Heart failure

Heart failure occurs when an individual's heart does not pump blood around the body as it should, commonly because the muscle has been damaged through heart disease, high blood pressure or a heart attack.¹³ Common symptoms of heart failure include breathlessness, limited fitness/fatigue and fluid retention, which can appear slowly and worsen over time.¹⁴ Around 750,000 people are living with heart failure in the UK and 27,000 new cases are diagnosed each year.¹⁵ Men are 60 per cent more likely to develop heart failure compared to women¹⁶, while prevalence increases with age from around one per cent of under 65's, to over six per cent of those aged 75 years and over twelve per cent for those older than 85.¹⁷ As heart failure often occurs as a result of other heart conditions it shares many of the same lifestyle

^a See Appendix Two, Table 1.5, for details of assumptions and calculations.

^b Converted from US Dollars, see Appendix Two, Table 1.5, for full details of exchange rates used and calculations.

^c *ibid.*

^d Years that would have been worked had cardiovascular disease not prevented individuals working them.

risk factors, such as: poor diet, obesity, and lack of exercise.¹⁸ These risk factors are expected to contribute to an increase in cardiovascular disease and a predicted 50 per cent rise in hospital admissions as a result of heart failure over the next 25 years.¹⁹ Importantly, the prognosis for heart failure is particularly severe, with nearly half (42 per cent) of all hospitalised patients dying within five years of being diagnosed.²⁰

One in three members of the public mistake the early symptoms of heart failure as normal signs of ageing, resulting in delays in seeking medical help and the condition worsening, making early interventions a priority.²¹ There are four stages of heart failure – asymptomatic, mild, moderate and severe – which are defined by progressive states of functional impairment.²² This means that as heart failure progresses the individual finds it increasingly more difficult to complete physical activities without strain and discomfort.²³ As functional impairment increases it can become challenging to remain in employment, particularly when roles involve physical exertion, however appropriate management (and suitable work) can help those with heart failure remain in employment.²⁴

Comorbidities

Common comorbidities experienced by individuals with heart failure include chronic obstructive pulmonary disease (COPD), renal dysfunction, anaemia, arthritis, cognitive dysfunction and depression.²⁵ Depression can contribute to the progression of heart failure, increase impairment²⁶ and result in mortality.²⁷ Living with heart failure and depression, or another condition(s), can worsen the disabling effects of heart failure and increases the likelihood of sickness absence or early workforce exit when compared to individuals who experience just one condition.²⁸ For example, individuals who experience comorbid depression and heart failure are more likely to require accident and emergency treatment, experience sickness absence from work, and to exhibit greater functional disability than those with heart failure alone.²⁹

Quality of life

Evidence suggests that heart failure has a similar impact on quality of life as other chronic conditions but, on average, patients have a significantly lower quality of life when compared to the general 'healthy' population.³⁰ A common experience for people with heart failure is social isolation, which can arise through the physical restrictions that limit an individual's ability to get around and maintain relationships.³¹ In severe cases individuals with heart failure may require a care assistant, which is often provided by friends and family members.³² The quality of life of family caregivers can also be affected when they must dedicate a proportion of their time to looking after a loved one with heart failure.³³

Heart failure, employment and the economic cost

Heart failure can have an impact on an individual's ability to work in a number of ways:

- Limited fitness and physical functioning can make it hard to complete physically demanding tasks.^{34,35}
- Heart failure can also affect individuals' ability to travel around without help and make jobs, like driving, difficult.³⁶
- Impaired cognitive performance can lead to difficulties such remembering important information or problem solving.^{37,38}

- Side effects from diuretic medications can lead individuals to need to use the toilet more frequently, which can disrupt work flow and make it difficult to complete tasks that involve being away from a toilet.³⁹

Evidence indicates that, on average, an individual with heart failure loses between 18.8 and 22.7 per cent of their working time due to their condition.^{40,41} This reduced productivity was greater than the average experienced by individuals with asthma, coronary heart disease, osteoarthritis, diabetes, and those who have experienced a heart attack without subsequent heart failure, however lower than COPD and depression.^{42,43} Moreover, employees with heart failure also, on average, have reported losing 17.2 working days per year through absenteeism as a result of their condition.^e

Physical limitations associated with heart failure often require a change in job level, function or activity. The loss of income associated with a premature workforce exit can lead to a loss of financial security and place a significant burden on families.⁴⁴ The interplay between these factors results in considerable productivity losses in the UK, with the indirect burden estimated to account for around a third – £0.92 billion^f – of the total cost of heart failure in the UK.⁴⁵ With projected rises in obesity (and an increasing number of younger people experiencing it and other risk factors) the productivity burden of heart failure is at risk of rapidly increasing, making early and preventive treatment a priority.⁴⁶

Treatment and care in the UK

Making individual lifestyle changes, such as stopping smoking, eating a healthy diet and undertaking appropriate exercise are a crucial part of controlling the progression of heart failure.⁴⁷ However, making and maintaining changes of lifestyle, including while at work, is not always easy.⁴⁸ Insufficient knowledge of self-management among heart failure patients results in poor care outcomes and unrealistic patient expectations; this is coupled with feelings of fear around the uncertainty of the condition and potential work limitations.⁴⁹ Functional decline after heart failure can also be associated with lower self-efficacy (a belief that one can achieve tasks), making psychological support an essential part of recovery, particularly when employment is an end goal.⁵⁰

Finding the right balance of medication is essential to effectively limit the impact heart failure has on a patient's life. Treatments can help make the heart stronger, improve symptoms, and reduce the risk of disease progression.⁵¹ Some research studies have suggested that specialist cardiologists provide care that is most consistent with the recommended heart failure guidelines, and have better patient outcomes compared to GPs.⁵² However, as GPs treat the majority of patients with heart failure, they have a key role when it comes to accessing more specialist provision and for upholding standards of care.⁵³

Cardiac rehabilitation has been shown to improve functional ability and quality of life.⁵⁴ Such programmes include the provision of information about the condition; advice and support on exercise; nutritional help; assistance in modifying lifestyle factors; and vocational support⁵⁵, and can support a faster return to work.⁵⁶ However there is a dearth of high quality evidence about the effect of these programmes on occupational outcomes.⁵⁷ Further to this, only four per cent of heart failure patients access cardiac rehabilitation⁵⁸, and less than one per cent of all cardiac rehabilitation patients receive a vocational assessment⁵⁹, which may limit an individual's participation in the workforce and the subsequent wider economic benefits.

^e See Appendix Two, Table 1.5, for details of assumptions and calculations.

^f Converted from US Dollars, see Appendix Two, Table 1.5, for full details of exchange rates used and calculations.

Recommendations

In order to improve employment outcomes for individuals with heart failure, the following should be considered:

- **A public information campaign is needed about the early symptoms of heart failure.** Some patients mistake the early symptoms as normal signs of ageing, resulting in delays to seeking medical help and a worsening in the condition. This has an impact on both longer term health and employment outcomes.
- **Prompt and accurate diagnosis of heart failure is needed, with timely access to the correct treatment.** Finding the right balance of medication quickly is essential for effective treatment, which can help make the heart stronger, improve symptoms, and reduce the risk of disease progression. Improved health outcomes can also help support improved employment outcomes.
- **Reduce inequalities in access to high-quality specialist heart failure care in hospital.** At present, evidence shows that access to specialist care varies between hospitals, including access to specialist nurses.
- **Ensure that heart failure care is offered by a multi-disciplinary team of healthcare professionals including GPs, specialists and nurses.** This will help to take into account the holistic needs of patients, including psychological and social needs (depression is a comorbidity commonly experienced).
- **More could be done to ensure that all patients have a discharge plan to guarantee the safety and appropriateness of hospital discharge.** Heart failure can have a significant impact on an individual's ability to work and this will be made worse by any further rehospitalisation. For this reason, good discharge planning is essential to avoid emergency readmissions.
- **Employers need to know more about heart failure.** The condition can have a significant impact on an individual's ability to work. For those remaining in employment, a change in job level or function may be required. Adjusting to this can be difficult for both employees and employers.

Conclusion

Heart failure creates a significant burden on individuals, families, organisations and society. It is detrimental to the employment prospects of those who experience it and to those who care for them. As the UK population ages, becomes more obese, and survival rates for heart disease improve (leading to the possibility that more people could develop heart failure), it is important to develop healthcare services to care for those with heart failure. Greater access to specialist care, early diagnosis and timely interventions (especially cardiac rehabilitation, including vocational assessment) are needed to improve the employment prospects of individuals with heart failure.

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MULTIPLE SCLEROSIS (MS) IS A COMPLEX, FLUCTUATING NEUROLOGICAL CONDITION¹



An estimated 100,000 people have MS in the UK.¹

Almost...

3

times more women are diagnosed with MS compared to men.²



482,000 days of MS related sickness absence are reported each year.³

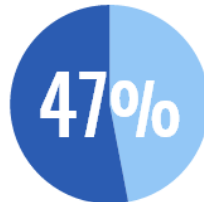


The total indirect cost of MS to the UK is estimated to be **£0.65 BILLION**.³

The total cost of MS, including direct healthcare expenditure and indirect costs, has been estimated to be **£2.33 BILLION**.²

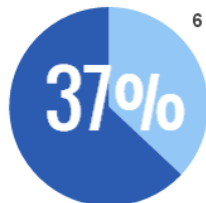
EFFECTS ON ABILITY TO WORK AND QUALITY OF LIFE

The average number of sick days taken by employees with MS per year is



of workers with MS report that it has an impact on their productivity.⁵

The average employment rate for someone with mild MS is just



The average age of retirement for someone with MS is

42⁷

46% of individuals with MS retire early in the UK.⁷



On average, people with MS report a lower quality of life compared to the general population.⁸

COMMON SYMPTOMS¹



Spasms & stiffness



Problems with balance, walking & dizziness



Problems with speech



Problems with vision

COMORBIDITIES²



Impaired cognition



Insomnia & fatigue



Depression

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Multiple Sclerosis (MS)

Key statistics

- **100,000 people** living with MS in the UK.¹
- **6,000 people** are newly diagnosed each year.²
- The average employment rate for people with mild MS is **37 per cent** and **just 4 per cent** for individuals with severe MS.³
- The average number of sickness absence days taken per year by people with MS in the UK is **16.6**.⁴
- The average age of retirement for someone with MS is **42 years old**.⁵
- The total indirect cost of MS among the working age population is approximately **£0.65 billion a year**.^a

Neurological conditions

Neurological conditions affect the brain, spinal column or nervous system and can develop through both illness and injury at any age.⁶ There are currently two million people living with a neurological condition in the UK, although this figure is expected to rise, as many of the conditions (such as Parkinson's disease and dementia) are associated with ageing.⁷ Neurological conditions can cause complex and fluctuating physical and mental impairments that can affect an individual's quality of life and their ability to live independently, for example in maintaining employment.⁸ The direct cost of neurological conditions to the NHS was £4.44 billion in 2012/13⁹, although estimates suggest that indirect costs, including those associated with unpaid care, sickness absence and reduced productivity at work, account for as much as 50 per cent of the true cost to society.¹⁰

Multiple sclerosis

MS is a chronic disease that causes damage to the nerve axons in the brain and spinal chord; this causes a variety of neurological symptoms which result from a weakening ability of the cells to conduct nerve signals, which causes disability progressively over time.¹¹ MS affects people in varied ways, although common experiences include: difficulties with balance, walking and dizziness; speech; eyes and sight; memory and thinking; and problems with the bladder and bowel.¹² There are four subtypes of MS, which are defined by the progression of the disease and frequency of disease flare ups. They are: *primary progressive*, which affects up to 15 per cent of those diagnosed with MS and occurs when progression is more gradual and sustained; *relapsing remitting*, which affects 85 per cent of people with MS and is characterised by periodic disease exacerbations; *secondary progressive*, which results from relapsing remitting MS and affects 65 per cent of people with that diagnosis, it is characterised by more frequent and longer lasting symptom exacerbations; and finally *benign MS*, which is when an individual experiences a

^a See Appendix Two, Table 1.6, for details of assumptions and calculations.

small number of relapses followed by a complete recovery.^{13,14} Evidence indicates that as MS becomes more severe, employment can become progressively more difficult to maintain without suitable adjustments and support.^{15,16}

MS affects around 100,000 people in the UK and approximately 6,000 people are newly diagnosed each year.^{17,18} Women are almost three times more likely than men to experience MS, with onset typically occurring for both sexes between the ages of 20 and 40, a time when individuals are at the beginning or middle of their working lives.¹⁹ As such, a diagnosis of MS can often have long lasting implications for an individual's career and lead to negative employment outcomes, despite many being capable of work.²⁰

Comorbidities

The majority of people with MS will experience associated physical and/or mental comorbidities that often act as additional barriers to employment.²¹ Individuals with MS report problems with cognition, affecting mental processing, memory and concentration.²² Processing speed and visual learning and memory seem to be most commonly affected by MS (51.9 and 54.3 per cent respectively).²³ Insomnia, and the resulting fatigue, is encountered by around 37 per cent of MS patients, and can affect quality of life with advancing disease severity.²⁴ Furthermore, evidence indicates that 50 per cent of people with MS will face an episode of depression²⁵, affecting their psychosocial functioning.²⁶ Those who have retired due to MS are more likely to report depression (53 per cent) compared with those still working (30 per cent).²⁷ Depression can affect work patterns and concentration and adherence to MS medication.^{28,29}

Quality of Life

The mean health state of individuals with MS was 59.7, compared to a UK population mean of 82.48 (measured using the EQ-5D questionnaire).³⁰ Restrictions in a person's mobility have been reported as the strongest predictor of reduced quality of life, while having the employment status 'sick/disabled' was also a major predictor.³¹ Mobility restrictions can reduce an individual's ability to perform daily tasks (such as access to the work environment), and in many MS cases (62.9 per cent) results in the need for carer assistance.³² Caring for a family member with MS can also have an impact on the carer's quality of life and their working life.³³

MS, employment and the economic cost

MS can affect an individual's ability to work in a number of ways:

- Fatigue, anxiety and depression can significantly limit a person's ability to concentrate.³⁴
- Restricted mobility can be a barrier to travelling to, from and around the workplace.³⁵
- Reduced dexterity can make it difficult to write, type and perform manual tasks.³⁶
- Slurred speech can make it difficult to communicate, for example using the phone or giving presentations.³⁷
- Visual impairment can have an impact on a person's ability to read.³⁸
- The unpredictable course of the disease with a varied timing and length of relapses, may greatly affect work outcomes.³⁹

- Fatigue can make it difficult for people with MS to balance work and home life as individuals may lack the energy to fulfil both commitments.⁴⁰
- Disclosure of MS is of particular concern in the employment environment, with the fear of losing their job following disclosure being a significant obstacle to continued employment. By disclosing their condition individuals are more likely to receive reasonable adjustments and access to other benefits.⁴¹
- Many employers lack the necessary skills and knowledge to support staff with MS.⁴²

A survey of employees with MS found the 47.8 per cent reported an overall impairment on their work.⁴³ Furthermore, many employees with MS take days off work because of their condition, with the average number of sickness absence days in the UK reported as 16.6 per year.⁴⁴ Applied across the UK working age population, this equates to 482,000 lost working days per year.^b It is therefore not surprising that individuals with MS are more likely to earn below the national average income compared to the general population.⁴⁵

The average employment rate for people with mild MS is 37 per cent and four per cent for individuals with severe MS.⁴⁶ This is almost ten per cent lower than the average employment rate for disabled working adults in the UK (46.3 per cent).⁴⁷ Around 15 years after the onset of MS, between 60-80 per cent of patients would have lost their jobs.⁴⁸

In one study of the 46 per cent of individuals had taken early retirement at the mean age of 42 years (the large majority (44 per cent) because of MS).⁴⁹ It may be assumed that for those with MS, re-entering the labour market having left it may be difficult.⁵⁰ The cost to the welfare system of premature loss of work for someone with MS who could have been supported to stay in work is substantial⁵¹

The indirect cost of MS to the UK society, including those resulting from lost employment, early retirement, decreased working hours and sickness absence is estimated to be, on average, £8,480 per person annually.⁵² When multiplied across the estimated working age population with MS, the total indirect cost is approximately £0.65 billion a year.^c This does not include losses from reduced work productivity, which if included would increase the indirect cost. The total cost of MS including direct healthcare expenditure and indirect productivity losses has been estimated to be £2.33 billion, with a greater proportion coming from individuals who experience more severe forms of the condition and greater levels of disability.⁵³

Treatment and care in the UK

Evidence suggests that in order to address all the consequences of MS, care should include both medical interventions and functional treatment.⁵⁴ This can potentially lead to health, economic and employment benefits to society. However, a recent survey has shown that people with MS still face problems receiving a timely and accurate diagnosis: more than a quarter of people were told by their GP they had a trapped nerve and about one in ten people were misdiagnosed with depression, anxiety or stress (14 per cent).⁵⁵ The survey also found that 20 per cent of individuals with MS had to wait between one and three years for a diagnosis following their first visit to their GP with symptoms, while 25 per cent of people visited their GP

^b See Appendix Two, Table 1.6, for details of assumptions and calculations.

^c *ibid.*

over four times before they were referred to a neurologist for further examination.⁵⁶

Disease modifying drugs are an important treatment which can allow individuals with MS to remain in employment; they have been shown to reduce relapses and, in some instances, slow the progression of disability.⁵⁷ However, research carried out by the MS Society has found that, in the UK six in ten people eligible for a disease modifying treatment (DMT) are not taking them and that people with MS in Northern Ireland are twice as likely to be taking a DMT than those living in Wales.⁵⁸ On an international level the UK performs poorly and is placed 25 out of 27 European countries for access to DMTs with only Poland and Romania faring worse.⁵⁹

It is important that health professionals consider work as an important outcome for individuals with MS and that care is co-ordinated, including GP support.⁶⁰ However, evidence suggests that, across the NHS, the treatment of MS is not well integrated and there are gaps in the provision of specialist care.⁶¹ For instance, fewer than half of NHS Trusts offer structured assessments for mood, cognition and daily activities to individuals with MS.⁶² This has an important effect on patient access to treatments. The MS Society found that people who see a MS nurse or neurologist are more than twice as likely to take DMTs as those who do not. DMT's can be life-changing and so it is worrying that access to these is so low across the UK.⁶³

Recommendations

In order to improve employment outcomes for individuals with MS, the following should be considered:

- **Early diagnosis and intervention is fundamental to improved job retention or successful return to work.** Productivity gains could be made by finding the right early interventions to help people with MS succeed at work.
- **Individuals need to help self-manage their condition and consider early disclosure.** In order to play an active role in the labour market, patients with MS need to think about how they manage their condition and ensure that their employers are informed as early as possible so optimal support is arranged.
- **A multi-disciplinary approach to treating MS leads to improved health, wellbeing and work outcomes.** An approach that includes physical, psychological and vocational support has been proven to be more effective than focusing on one treatment in isolation.⁶⁴
- **Healthcare professionals need to consider employment as an important outcome for individuals with MS.** Many individuals who experience MS would like to work and overcome any barriers to accessing permanent employment. In addition, employment support can lead to improved health and wellbeing.
- **Employers need to understand the fluctuating nature of MS and the assistance that occupational health professionals can provide.** Currently, an employer's limited knowledge of MS may create an additional barrier to the implementation of reasonable adjustments in the workplace.

Conclusion

The impact that MS can have on employment can be varied, while the financial consequences are great. Improving the management of MS and helping individuals to stay in work could lead to significant economic gains. It is therefore of great importance to find and invest in the right early interventions to help people with MS succeed at work. Failure to address gaps both in service provision and in supporting the wider uptake in efficacious treatment could therefore be costly to both health and the wider economy in the coming decades.

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Conclusion

This report has highlighted the significant impact that long term health conditions among working age people can have on the economy, the NHS and individuals' lives. It has demonstrated that the impact of long term conditions can also be felt by family members and, in many instances, can trigger further physical and mental health problems. The report has also shown how these conditions can represent a significant cost to the UK society, resulting in large scale and long term sickness absence from work, presenteeism, premature workforce exit, increased welfare expenditure and in some instances premature death. The resulting direct and indirect productivity losses ultimately harm the UK economy and risk exacerbating health inequalities and the problems of social exclusion.

The services currently provided by the NHS often fail to properly support working age individuals with long term conditions. This can have a significant impact on their ability to work and in part explains the increasing burden on the economy and the health service. In the *Five Year Forward View*, NHS England has recognised that the growing number of people with long term conditions and multi-morbidity and their associated financial cost, represents a significant challenge to the future sustainability of the NHS. The introduction of new models of care, vanguard sites and innovation test beds presents significant opportunities for the NHS to provide more integrated, person centred care. Yet for integrated care to have a significant impact, it will be essential to ensure that future service redesign includes a focus on improving employment prospects through the delivery of support services, better information, and incentives for commissioners and employers.

Furthermore, the Department of Health has acknowledged that a strong NHS and social care system needs a strong economy, and simultaneously that the NHS and social care system must contribute to economic growth. However, for this to happen, we must focus on ensuring that individuals who have developed long term conditions are able to remain in, or return to, work. From the evidence set out in this report, it is clear that for this to happen the government must deliver targeted investment in improving early diagnosis of long term conditions; ensuring patients are referred to specialists sooner; delivering best practice services to patients and carers and prioritising patient access to innovative treatments which can support work ability.

Recommendations

Government

- The Treasury and the Department for Business, Innovation and Skills should examine the feasibility of offering tax incentives, national insurance rebates or tiered VAT charges for employers who implement policies to support employees with long term conditions.
- Consideration should be given to the commissioning of more specialist employment support programmes provided by the Department for Work and Pensions (DWP) and the voluntary sector for people with long term and mental health conditions.
- The National Institute for Health and Care Excellence (NICE) should be permitted, routinely, to take a 'societal perspective' in Health Technology Appraisal (HTA), especially where access to medicines

or medical technology might reasonably be expected to enhance the labour market participation and productivity of patients and/or their carers.

- The new Health & Work Joint Unit (DWP, NHSE, PHE) should prioritise integrated, work-focused support for working age people with long term health conditions so that job retention and return to work are seen as key outcomes for joint DWP and NHS activity.

NHS England

- It is essential that under prioritised disease areas like eye and skin conditions are represented by National Clinical Directors, who can provide leadership and act as a focal point for coordinating standards of care.
- Accessing and retaining employment for people with long term conditions should be a priority clinical outcome for those areas that are implementing new models of care that bring together health, social and mental care.
- NHS England should seek to measure the impact that innovation on employment outcomes can have for people with long term conditions. With the development on new 'vanguard' sites and innovation 'test beds' there is a real opportunity to better highlight the important impact that innovative technology can have on service delivery and outcomes in relation to employment.
- There should continue to be a greater focus on employment as an outcome for all long term conditions, building further on the existing NHS Outcomes Framework Indicator.
- Additional incentives are needed to drive the provision of more widespread employment support in clinical settings. This may mean more co-location of specialist employment support in some primary and secondary care settings. More investment in Nurse Specialists, who are so often key advisors for working age patients with long term conditions, would also improve job retention and return to work rates.
- There is a role for NHS England in better facilitating knowledge sharing between healthcare professionals and employers, particularly regarding information sources.
- NHS England should better promote the services and guidance offered by third sector organisations and patient groups to both employers and patients.

Employer

- Employer and business trade associations should acknowledge the significant challenge facing the UK labour market as the workforce ages and develops more chronic illness, and seek to provide leadership in partnership with the government, the NHS, businesses, trade unions and employees to implement solutions.
- All employers should seek to make reasonable adjustments for employees to support the varying needs of people with long term and fluctuating conditions.
- Workplaces should provide an open and supportive environment so that individuals feel comfortable about disclosing their condition and seeking support.

- Employers should be made aware of the specialist support available, for example how the involvement of occupational therapists, physiotherapists and the Fit for Work service and Access to Work scheme could help to get the best work outcomes for them and their employees.

Clinical

- Earlier diagnosis and interventions can help individuals to treat, manage or delay disease progression, which has a positive impact on health, education and employment outcomes.
- There needs to be less variation in awareness and understanding of evidence-based clinical guidelines across a range of conditions to ensure that patients are consistently receiving optimal care.
- Individuals requiring specialist care should be given timely appointments to avoid negative implications to their employment / educational opportunities through preventable disease progression as a result of the simple lack of treatment.
- Healthcare professionals should ask working age patients and young adults about their employment aspirations as early as possible in order to provide truly coordinated and multi-disciplinary care.
- Patients with long term conditions need equal or early access to psychological services, as depression has been found to be a common comorbidity amongst individuals with these conditions.
- Healthcare professionals should be aware that long periods of unemployment and difficulties in finding jobs can undermine individuals' self-esteem and may negatively affect their mental wellbeing.
- There should be increased clinical assessments of the impact that all comorbidities can have for an individual, as it is often an associated condition or the interaction of several conditions that results in poor employment outcomes.
- Self-management should be at the heart of clinical practice. The more an individual understands their condition and their treatment, the better their health and therefore their employment outcomes. Patients should be signposted to self-management support resources, especially those which focus on employment outcomes.

Individuals with long term conditions

- Patients should proactively consult with healthcare professionals, families, carers and employers to develop an understanding of what might be achievable or desirable in both the short and long term. All possible options should be considered.
- Individuals should be self-assertive and take an active role in managing their condition. As part of this, they should feel able to disclose details of their condition to their employer.
- Individuals should feel equipped with the support of the multi-disciplinary healthcare team to highlight how specific changes to working arrangements could maximise their productivity at work.

Appendix One: Glossary of measures

EuroQol (EQ)-5D: This is a standardised instrument used as a measure of health outcomes. It is designed for self completion and measures the level of a problem on five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has three levels: no problems; some problems; extreme problems. It also includes a rating of health status which uses a visual scale from 0 – 100. It is frequently used in clinical studies as it can be converted into quality adjusted life years for cost effectiveness analysis.

<http://www.euroqol.org/about-eq-5d.html>

NEI-VFQ-25: The National Eye Institute (NEI) Visual Function Questionnaire is a reliable and valid self reported 25 item questionnaire, developed by RAND USA for NEI, that measures visual impairment and health related quality of life, which includes the extent to which vision impairs an individual's daily life. Areas covered include social functioning, mental health symptoms due to vision, driving difficulties, dependency on others, and ocular pain.

http://www.rand.org/content/dam/rand/www/external/health/surveys_tools/vfq/vfq25_manual.pdf

SF-36: The Short Form-36 (SF-36) Health Survey assesses eight domains of health, including physical functioning, role functioning related to physical status, bodily pain, general health, vitality, social functioning, role functioning related to emotional status, and mental health. These categories can be combined into a Physical Component Summary score and a Mental Component Summary score, with higher scores being indicative of a better quality of life.

<http://www.sf-36.org/tools/SF36.shtml>

SF-12: is a shorter version of the SF-36. It is estimated to capture 85 per cent of the variance of the longer version.

<http://www.sf-36.org/tools/sf12.shtml>

Appendix Two: Assumptions and calculations

In order to calculate UK wide productivity costs (including number of work days lost days lost) for some conditions, assumptions were taken from the relevant literature. The tables below outline the assumptions and calculations used for each condition (no calculations were made for schizophrenia).

Table 1.1 Baseline parameters

Parameter	Baseline values	Source
Population 16-64 (Apr 2014)	40,389,000	ONS (2014a) ¹
Employment rate (Apr 2014)	72.9%	ONS (2014a) ²
Number of working age adults in employment (Apr 2014)	30,535,000	ONS (2014a) ³
Hourly rate (£mean)	£15.13	ONS (2014b) ⁴
Average hours worked per year (2014)	1677	OECD (2014) ⁵
UK Population in 2030	71,400,000	ONS (2011) ⁶

Calculations

Parameter	Calculated estimate	Calculation notes
Average daily wage	£121.04	Hourly rate (£mean) * 8 [Eight hour working day assumed]
Average days worked per year	209.63	Average hours worked per year / 8 [Eight hour working day assumed]

Health Conditions

Table 1.2 Psoriasis

Parameter	Assumptions	Source	Comment
Adult prevalence	2%	The Psoriasis Association (2014) ⁷	The prevalence is estimated to be between 2 and 3 per cent. The lower level has been used.
Proportion with moderate to severe psoriasis	48.2%	Yeung, et al. (2013) ⁸	Epidemiological study using PASI scale of severity which is used in UK clinical settings.

Proportion of time lost to presenteeism	7.6%	Schmitt & Ford (2006) ⁹	Condition Specific Work Productivity Assessment Index measure taken from a reliable large scale study conducted in the US.
Average days off per year	14.1	Sohn, et al. (2006) ¹⁰	A study from Germany which found levels corresponded with the results of previously published studies

Calculations

Parameter	Calculated estimate	Calculation notes
Working age adults with psoriasis	610,700	Adult prevalence * Number of working age adults in employment [Baseline parameters]
Adults with moderate to severe psoriasis	294,357	Working age adults with psoriasis * Proportion with moderate to severe psoriasis
Average days lost due to presenteeism	15.93	Average days worked per year [Baseline parameters] * Proportion of time lost to presenteeism
Number of working days lost due to absenteeism	4,150,439	Adults with moderate to severe psoriasis * Average days off per year
Number of working days lost due to Presenteeism	4,689,555	Adults with moderate to severe psoriasis * Average days lost due to presenteeism
Costs relating to Absenteeism	£502,369,178	Number of working days lost due to psoriasis due to absenteeism * Average daily wage [Baseline parameters]
Costs relating to Presenteeism	£567,623,727	Number of working days lost due to psoriasis due to presenteeism * Average daily wage [Baseline parameters]
Cost of Absenteeism and Presenteeism	£1,069,992,905	Costs relating to Absenteeism + Costs relating to Presenteeism

Table 1.3 DMO

Parameter	Assumptions	Source	Comment
DMO in the UK 2010 (whole population)	166,325	Minassian, Owens & Reidy (2011) ¹¹	UK prevalence study and cost of illness study.
DMO in the UK 2010 (working age 16-64)	86,538	Minassian, Owens & Reidy (2011) ¹²	UK prevalence study and cost of illness study.
Prevalence of DMO in the population with diabetes	7.12%	Minassian, Owens & Reidy (2011) ¹³	UK prevalence study and cost of illness study.

Number of sickness absence days per individual pa	2.8	Gonder, et al. (2014) ¹⁴	Based on a level of 1.4 working days per patient revealed in a six month study.
Population with diabetes in 2025	5,000,000	Diabetes UK. (2015) ¹⁵	Diabetes UK states the diabetic population will rise to over five million by 2025.

Calculations

Parameter	Calculated estimate	Calculation notes
Percentage of working age population with DMO	52%	DMO in the UK 2010 (working age 16-64) / DMO in the UK 2010 (whole population) * 100%
Total sickness absence days each year as a result of DMO (2010)	242,306	DMO in the UK 2010 (working age 16-64) * Number of sickness absence days per individual pa
Total cost of sickness absence per year (2010)	£29,328,767	Total sickness absence days each year as a result of DMO * Average daily wage [Baseline parameters]
DMO in the UK 2025 (whole population)	356,000	Population with diabetes in 2025 * Prevalence of DMO in the population with diabetes
DMO in the UK 2025 (working age 16-64)	185,225	DMO in the UK 2025 (whole population) * Percentage of working age population with DMO
Total sickness absence days each year as a result of DMO (2025)	518,630	DMO in the UK 2025 (working age 16-64) * Number of sickness absence days per individual pa
Total cost of sickness absence per year (2025)	£62,774,934	Total sickness absence days each year as a result of DMO (2025) * Average daily wage [Baseline parameters]

Table 1.4 Asthma

Parameter	Assumptions	Source	Comment
Working days lost to asthma per year	12,700,000	Hall & Mindell (2011) ¹⁶	Report analysing the UK Labour Force Survey.

Working age population with asthma in 2006	2,400,000	Vaughan-Jones & Barham (2009) ¹⁷	Long term condition estimates and projections.
Estimated working age population with asthma in 2030	2,600,000	Vaughan-Jones & Barham (2009) ¹⁸	Long term condition estimates and projections.

Calculations

Parameter	Calculated estimate	Calculation notes
Cost of sickness absence due to asthma	£1,537,208,000	Working days lost to asthma per year * Average daily wage [Baseline parameters]
Expected sickness absence in 2030	13,758,333	Working days lost to asthma per year * (Estimated working age population with asthma in 2030 / Working age population with asthma in 2006)

Table 1.5 Heart failure

Parameter	Assumptions	Source	Comment
Proportion of time lost due to absenteeism in patients with heart failure	8.2%	Forlenza, et al. (2014) ¹⁹	Parameter measured using Work Productivity Assessment Index which asked patients to rate the proportion of time lost due to their illness in the last week. This is applied to the average number of worked days in the UK.
Indirect cost of heart failure	\$1,461,000,000	Cook, et al. (2014). ²⁰	Estimated value of indirect costs of HF in 2012 in US Dollars.
Direct and Indirect costs of heart failure	\$4,684,000,000	Cook, et al. (2014). ²¹	Estimated value of total costs of HF in 2012 in US Dollars.
Yearly average exchange rate 2012	0.6318	HMRC (2013) ²²	Sterling value of USD (average for the year to 31 December 2012)

Calculations

Parameter	Calculated estimate	Calculation notes
Number of working days lost due to heart failure per year	17.2	Proportion of time lost due to absenteeism in patients with heart failure * Average days worked per year (mean) [Baseline parameters]
Indirect cost of heart failure (GBP)	£923,059,800	Indirect cost of heart failure * Yearly average exchange rate 2012
Direct and Indirect costs of heart failure (GBP)	£2,959,351,200	Direct and Indirect costs of heart failure * Yearly average exchange rate 2012

Table 1.6 MS

Parameter	Assumptions	Source	Comment
Approximate working age population with MS	76,851	Kobelt & Kasteng (2009) ²³	Individuals with MS between the ages of 20-69.
Percentage of working individuals with MS losing work days	37.8%	Bevan, et al. (2011) ²⁴	Review of literature on the impact of MS in the UK.
Average number of work days lost	16.6	Karampampa, et al., (2012) ²⁵	MS cost of illness study covering the EU, including the UK.
Average indirect productivity loss	£8,480	McCrone et al., (2008) ²⁶	UK cost of illness study.

Calculations

Parameter	Calculated estimate	Calculation notes
Total number of working days lost as a result of MS	482,225	Working age population with MS * Proportion of working individuals with MS losing work days * Average number of work days lost
Total indirect cost of MS	£651,696,480	Working age population with MS * Average indirect productivity loss

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