Poverty and Multiple Sclerosis: A Rapid Evidence Assessment

A RESEARCH REPORT FOR THE MS SOCIETY
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SOCIAL RESEARCH
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Contents

Glossary of acronyms

AA	Attendance Allowance
CA	Carers Allowance
CSA	Care and Support Alliance
CQC	Care Quality Commission
DBC	Disability Benefits Consortium
DHSC	Department for Health and Social Care
DLA	Disability Living Allowance
DLS	Disability Law Service
DWP	Department for Work and Pensions
ECC	Extra Costs Commission
EHRC	Equality and Human Rights Commission
ESA	Employment Support Allowance
GSS	Government Statistical Service
HSCIC	Health and Social Care Information Centre
JRF	Joseph Rowntree Foundation
MIS	Minimum Income Standards
NHS	National Health Service
PIP	Personal Independence Payments
SMC	Social Metrics Commission
UC	Universal Credit
WCA	Work Capability Assessment
WRAG	ESA Work-Related Activities Group

Introduction

Multiple Sclerosis (MS) is a neurological condition which can cause significant disability and be life-limiting. The MS Society has identified poverty as a problem which is both more likely in the context of an MS diagnosis and makes living with MS even harder. Moreover, they believe that more people with MS may be living in poverty in the UK than before as a result of social policy reforms.

This report synthesises the available evidence to understand the prevalence and nature of the experience of poverty among people with MS, the role policy has played in this landscape and the further implications it has for the lives of people affected by MS (as individuals with MS, their families or their carers) as well as the costs to the NHS and wider society.

This report also considers the implications of the way in which poverty is measured on how we understand the exposure and experiences of poverty among people affected by MS and makes recommendations for how best 'poverty' should be measured in this context in the future.

What is Multiple Sclerosis (MS)

MS is a neurological condition which can affect the brain and spinal cord. Its symptoms may include difficulties with balance, coordination, sensation and cognition, stiffness in or difficulties controlling the muscles of the body, and often problems with vision. MS can be mild, but for many people with MS its symptoms can be severe; symptoms can persist or get worse over time (progressive); and they can come and go in phases (relapsing and remitting). MS is often, but not always, life-limiting and it can cause significant disability. Although it occurs in men and women, about three times as many women are diagnosed with MS than men. It can develop at any age but is often diagnosed in people in their 20s and 30s.[1] It is one of the most common neurological conditions affecting young adults in the UK (HSCIC 2012).

No National Statistics have been published on the prevalence of MS in the UK population. In their absence, the MS Society estimates that around 130,000 people have MS in the UK in 2020, with 7,000 being newly diagnosed each year.[2] Many others may be living with symptoms without having sought or received a diagnosis.

The characteristics of MS as a health condition can leave people affected by MS at even greater risk of living in poverty, compared with other groups in society. It appears that this includes the intermediary impacts of MS on someone's ability to work (and to work in gainful, full-time employment) and the extra costs they incur through their increased health or social care needs. In turn, this could put people affected by MS at potentially greater risk of experiencing detrimental knock-on effects of poverty; and potentially doing so for long periods of their lives.

What is poverty

Although the concept of poverty is meaningful and widely understood, both in this country and internationally, there is no single accepted definition of it. Definitions of poverty have tended to

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[1] 'NHS 'Multiple sclerosis'

[2] 'MS in the UK'

emphasise the importance of low income. However, this is not often regarded as an adequate definition on its own. This is because short periods of low income need not affect individuals and their households negatively; and that the ability of income and other resources to meet a certain acceptable standard of living, or to be able to afford certain types of goods and services, should also be considered. There has also been a shift in policy thinking, in the UK and Europe more generally, away from definitions which emphasised subsistence towards definitions emphasising a person's capacity to participate in society; and this has tended to raise poverty thresholds (Gordon 2006), thereby including more people in the definition.

Gordon (2006) suggests that there is general agreement among academics and policy makers that:

> …poverty is defined as having an 'insufficient command of resources over time'…(p32)

and that the consequence of poverty is deprivation. This is the definition used in this report, even if operational definitions differ slightly when poverty is measured in studies.

Aims and methods

The aim of the research is to explore the landscape of poverty experiences in the UK as it affects people with or affected by MS and the role of policy in driving and/or mitigating these experiences and their societal impacts. Included within this aim, the main objectives are to:

- Determine the extent to which people affected by MS are likely to experience poverty and which groups are affected the most.
- Understand the main factors driving the experience of poverty among people affected by MS, including the role of policy and funding.
- To understand the effects of living in poverty on people affected by MS and the knock-on effects to the National Health Service (NHS) and society more broadly.
- To identify the most relevant policy solutions to tackle poverty among people affected by MS.
- To recommend how best to estimate the number of people with MS living in poverty.

To meet these aims and objectives, a rapid evidence assessment was undertaken of (primarily) UK research published since 2005.

A rapid evidence assessment differs from a traditional narrative review in that it offers a more rigorous approach to the identification, screening and summarising of literature, providing for a more robust synthesis and interpretation of the evidence. It nonetheless allows for flexibility and expediency in the reviewing process, which is commensurate with a short scoping review such as this.

Systematic searches and screening of items from a range of academic and non-academic sources, following the rapid evidence assessment approach, was undertaken. From this, 89 items relating to poverty and disability (and associated concepts) were identified. These encompassed reports of quantitative research, qualitative research, literature reviews and those using mixed-methods approaches, and they also covered think-piece and policy reviews. The items included 35 which had a specific focus on MS (27) or otherwise made specific mention of MS

(8). Even so, there are some significant and striking gaps in the evidence base.

More details about the approach to searching, screening and extracting the literature can be found in the Appendix.

In synthesising the evidence, greater focus and weight has been given to items of higher quality and greater relevance to the research questions (as a result, not all items are reported here). This included drawing out the evidence which relates explicitly to MS, and only drawing on the wider literature which relates to disability more generally where necessary or relevant. The report identifies evidence which relates to people with MS, their families and their carers. The overall quality of the evidence and its relevance to MS and key gaps in the literature are discussed in the conclusions.

Items which have been used in the report which were identified in the rapid evidence assessment are cited in the main text, with the full citation given in the reference list. Where an item of literature taken from outside the scope of the rapid evidence assessment is referred to (e.g. because it provides useful background only), it is given instead as a footnote.[3]

The critical nature of the rapid evidence assessment approach offered the opportunity to record and assess the definitions of poverty used in the literature and note any criticisms authors have noted. This raises questions for the impact of different definitions on measurement itself and on the ability of current definitions more generally to capture the poverty experience of people affected by MS adequately. In addition to considering the definitions used in the previous literature, a targeted review of key existing national data sources (i.e. regular national surveys) was also undertaken. This enabled recommendations to be made about whether the MS Society should use existing sources or consider collecting new, bespoke data to monitor poverty in the future including to model the likely impact of future policies.

Understanding MS and poverty

Apart from poverty *per se* there were clearly other financial (and non-financial) impacts that were associated with MS (and disability more generally) that emerged from the literature. These ranged from the costs of living to someone's quality of life (see Appendix Table A2). Moreover, an initial overview of the evidence suggested that some of these are also contributory factors in the experience of poverty, while others are outcomes from poverty. Other factors still, such as the policy environment and the benefit system, were important contextual factors.

In reality, the interrelations between the different components of the poverty experience makes for a potentially complex picture. The framework below is an attempt to disentangle these relationships, to show, conceptually, the main pathways from MS to poverty and beyond (Figure 1).

It shows the primary financial impacts of MS which appear to act as drivers of poverty. Poverty in turn results in other outcomes for individuals, including secondary financial impacts and, shown in darker shading, for society more broadly.

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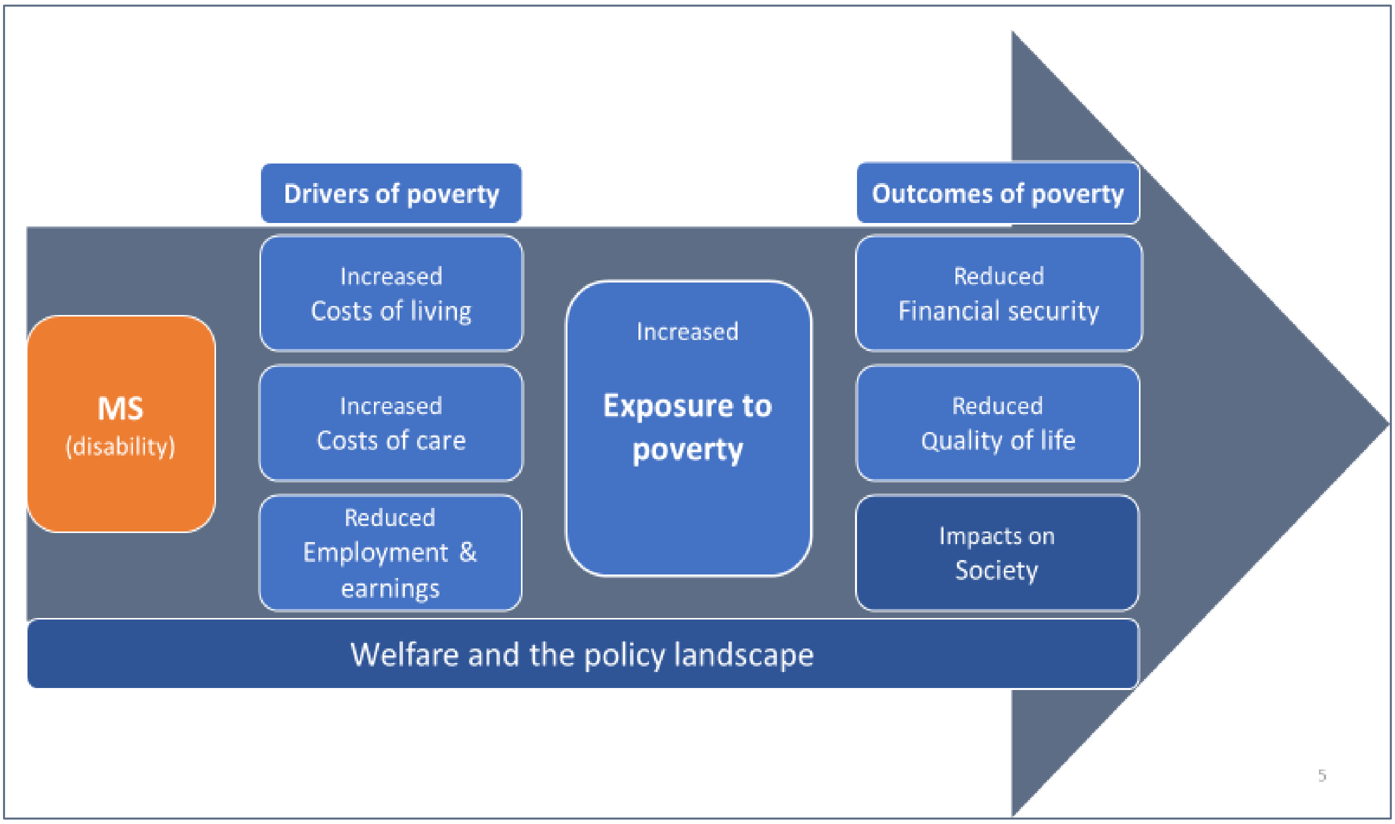
[3] Hyperlinked documents were accessed January 2020.

Figure 1: A framework for the relationships between MS and poverty



The model also highlights the influence of welfare and the policy landscape, which has the potential to aggravate or alleviate the financial impacts of MS.

Many of the impacts and outcomes of MS remain highly interrelated. Although the framework highlights the general direction of travel (from MS to intermediary impacts to poverty and other outcomes), the model does not dismiss the potential for significant feedback loops within and across each successive level.

Nonetheless, the framework is intended as a simplification and has helped to inform the structure of the rest of the report.

Exposure to poverty

This section focusses on exposure to poverty among people affected by MS. It considers poverty levels among people with MS (and their families and carers) and compares this to those without MS where possible, against people with other health conditions or none. It also explores the severity and persistence of poverty to the extent that it has been addressed in previous studies and the groups among those affected by MS to be the most affected.

The evidence discussed in this section relates to the definition of poverty which refers to having insufficient resources over time with implications for deprivation (Gordon 2006).

Included are studies which measured relative poverty (typically below 60% of contemporary national median income, accounting for household size) and also or alternatively measured material deprivation.[4] Other studies have developed more innovative measures, especially around income needs or adequacy, while some refer to 'poverty' but have not defined it clearly.

Levels of poverty

There is, simply, a dearth of literature which has examined levels of poverty specifically among people affected by MS. We found no studies that measured levels of poverty among people living with MS as a distinct group. Instead, the most detailed analysis available is at the level of disability or long-term health conditions only.

Almost universally, studies have considered relative income poverty and deprivation among people with disabilities (or long-standing illness) as a single group. Without exception, these have found that disabled people in the UK are more likely than non-disabled people to be disadvantaged in this way, and often substantially so.

> Disabled people are more likely than non-disabled people to be in poverty

Disabled people are more likely than non-disabled people to be in income poverty, and this is true regardless of whether income is measured before housing costs (e.g. Cribb et al 2018, DWP 2013, George et al 2013,) or after housing costs (e.g. DWP 2016, EHRC 2019, Heslop 2013, Tinson et al 2016). Precise definitions, including whether individuals, families or households are considered, affects the rate of poverty identified, but the picture nonetheless remains the same. Table 1 shows a sample of estimates which have used different measures or looked at different populations.

Most recently, in 2016/7, 25.5% of adults with a disability in Great Britain were in relative income poverty after housing costs compared with 18% of those without a disability (EHRC 2019). Notably, poverty by this measure was

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[4] These reflect the main traditional official measures of poverty in the UK DWP 'Households Below Average Income', 2017/18. None of the studies reported in this section considered absolute poverty. The UK no longer has official definitions of poverty for children, working-age adults or pensioners (SMC 2019).

Table 1 Rates of poverty by different measures

Measure (population)	Disabled	Not disabled	Source
Income poverty after housing costs (adults)	25.5%	18%	EHRC 2019
Income poverty after core costs (working-age adults)	37%	18%	SMC 2019
Income poverty before housing costs (25-54 years, with 'long-standing illness')	18%	12%	Cribb et al 2018
Income poverty after core costs (families, with a disabled adult)	26%	19%	SMC 2019
Income poverty before housing costs (individuals in families with a disabled person)	20%	15%	DWP 2013

higher still among those specifically with cognitive impairment (31%; EHRC 2019), which often characterises MS symptoms.

The Social Metrics Commission (SMC) recently developed a more complex measure of relative poverty in families, which takes into account net income and liquid assets (after housing costs), and core living costs (including the costs of childcare and disability). By this measure, 37% of disabled working-age adults were in poverty compared with 18% of non-disabled working-age adults. In turn, 13% of disabled pension-age adults were in poverty, compared with 9% of non-disabled pensioners (SMC 2019). Conversely, among those in poverty in 2017/18, 47% of individuals in poverty lived in a family in which someone was disabled (compared with 35% of those not in poverty; SMC 2019).

> There is a knock-on effect of disability on poverty from individuals to their families and households

There is a knock-on effect of disability on poverty to families and households. The percentage of families in the UK with relative low income was higher when a disabled adult was present (26%) than not (16%; Heslop 2013). It was also higher among households when any disabled person (adult or child) was present (George et al 2013).

The more recent study by the SMC found that 22% of families overall were in poverty in 2017/18, rising to 26% where they included a disabled adult and 28% where they included a disabled adult or child. The recent trend in the rates for families with disabled people was slightly downwards (SMC 2019).

> People living in households with lower incomes are more likely to have a disability

Looked at another way, people in households with lower incomes are more likely to have a disability than those in better-off households (e.g. George et al 2013, EHRC 2017, SMC 2019). In 2012/13, disabled people made up 28% of people living in relative poverty, made up of 2.6m working-age adults, 0.9m pensioners and 0.3m children (Tinson et al 2016).

In 2015/16, 30% of working-age adults in families containing a disabled person were in poverty compared with 18% for those without a disabled person (DWP 2016).

> Poverty reduction among disabled people must be at the heart of attempts to reduce poverty

However poverty is measured, a recent report for the Joseph Rowntree Foundation (JRF) emphasised that poverty reduction among disabled people must be at the heart of attempts to reduce poverty in the UK overall, because rates of poverty are so high among them and because almost a half of people in poverty are disabled themselves or live with someone who is (Tinson et al 2016).

We recall that poverty is also about whether resources are sufficient to meet someone’s needs (MacInnes 2014). A 2017 UK-wide survey found that more than 1 in 4 working-age disabled adults said they had less than £50 available to spend each week after fixed expenses (income tax, council tax and housing costs; Leonard Cheshire 2017).

> Material deprivation is a significant problem for disabled people

As such, material (and social) deprivation is a significant problem among people with disabilities.

A study for Scope found that for every one of eleven deprivation measures considered, families with a disabled adult were again significantly (and substantially) more likely to be deprived. In particular, 26% of families with a disabled adult said they would like but could not afford to replace worn out clothes with new ones compared with only 8% of those without a disabled adult present, and 24% could not afford to get together with family or friends for a meal or drinks once a month (vs 9%; Touchet and Patel 2018).

Cribb et al (2018) reported an overall deprivation rate of 32% in households containing a disabled person, compared with 17% of those without. These findings are consistent with earlier research (e.g. DWP 2013) and similar finding have been observed specifically among pensioners (DWP 2013).

> Income poverty and deprivation are related

From our working definition of poverty, we expect that income poverty and deprivation are related. This is true where disability is present: families which were income-poor were more than twice as likely to be in material deprivation (59% compared with 36%; Belfield et al 2016 in EHRC 2017). And it is enhanced where disability is present: among the poorest fifth of all households by income, deprivation was more likely if someone was disabled (Tinson et al 2016).

That said, deprivation also occurred in the absence of income poverty in one study. Households with at least one disabled person and above the poverty line were still more likely than other households to be materially deprived. The likelihood of being in material deprivation in families not in income poverty was 25% if they also contained a disabled person and 9% if they did not (Belfield et al 2016 in EHRC 2017).

Persistent and severe poverty

Few studies have considered persistent or severe poverty among people with disabilities, and none we found reported estimates for people affected by MS or similar, specific conditions. Those that have, however, confirm greater exposure to both persistent and severe poverty among people with disabilities than those without.

> Disabled adults are about twice as likely as non-disabled adults to live in persistent poverty

Where defined, persistent poverty is normally counted as spending at least three in any four years below 60% of median income, before housing costs (e.g. Heslop 2013). Disabled adults in the UK are about twice as likely as non-disabled adults to live in persistent poverty (at around 10%-12%, Cribb et al 2018, DWP 2013).

> Disabled adults are more likely to be in deeper poverty, or deprivation

Separately, disabled adults are more likely to be in deeper poverty, or deprivation. It has been estimated that a quarter of working-age disabled people were in 'deep' poverty (with an income below 50% of the median income) in 2013/14, compared with 13% of non-disabled working-age people. In addition, 18% were severely materially deprived (lacking basic items), three times as high as the proportion of non-disabled working-age people (Tinson et al 2016).

In Britain, working-age adults with a disability in 2016/17 were far more likely to experience severe material deprivation (37% vs 13.5%). This was based on being unable to afford four out of nine items listed (EHRC 2019). They were also more likely to live in overcrowded accommodation and less likely to be satisfied with their accommodation (EHRC 2019).[5]

Groups most affected

Among disabled people, exposure to poverty and deprivation varies by circumstance. We have already noted the paucity of evidence which identifies exposure by the nature of a disabled person's condition. Only one study has identified levels of income among people with MS, and higher incomes were more common among the newly diagnosed while the lowest incomes were more common among people living with MS for a long time (MS Society 2019a).

Another identified cognitive impairment as a particularly high-risk factor (EHRC 2019). Rates of poverty and deprivation were also higher among people reporting two long-standing illnesses and higher still where one of these was a mental health problem (Cribb et al 2018).

> A disabled person's age, living arrangements and access to resources matter

We have already noted substantially higher levels of poverty and deprivation among adults of working-age compared with pension-age adults (DWP 2013, Tinson et al 2016), and as much as three times higher (SMC 2019). One study, of people with visual impairment which used a measure of 'income need' to measure poverty, found that it was rare for people of pension-age to fall very far short of their income needs (Hill et al 2017). Among disabled people of working-age, poverty levels are higher still among younger adults, particularly the under 45s (Tinson et al 2016, EHRC 2017).

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[5] Based on data for respectively 2015/16 and for Wales only.

One study noted that ‘Black/African/Caribbean’ people had the highest deprivation scores (EHRC 2017). Rates of poverty were particularly high among adults living on their own, living in rented homes (Tinson et al 2016) and, among pensioners with visual impairment, living in rural or other areas without major amenities or good bus links (Hill et al 2017).

Rates were also higher if people were not working and if disability-related benefits were not received (DWP 2013, Tinson et al 2016). Pensioners with visual impairment were at greater risk if they were on low incomes but not receiving disability-related benefits (Hill et al 2017).

Drivers of poverty

MS has classically been reported as being responsible for high costs and other substantial economic burdens on people affected by it (Stephens 2019).

While the previous section found very little evidence relating the exposure of poverty to MS, there is nonetheless a significant body of evidence which identifies MS specifically as having other important financial impacts. Some of these act as intermediary, or primary financial impacts which, in our conceptual framework are drivers of poverty (Figure 1, above).

The main primary financial impacts of MS are identified in the literature as relating to the increased costs of living people with MS faced, increased costs of care and the capacity for employment. They are considered in relation to the individual and, wherever possible, to their families and carers.

This section considers the evidence which describes the scale and nature of these drivers, drawing mainly on the literature which has considered MS directly. First, however, we outline what it is about the nature of MS which contributes to the pathways to poverty.

The nature of MS

MS is a complex neurological condition, and each person is affected differently (Erez 2019). Moreover, symptoms can fluctuate day-to-day and even hour-to-hour, meaning symptoms can be unpredictable and difficult to manage (e.g. MS Society 2019c, Bajorek et al 2016).

Different impairment types have different implications

The nature of someone’s symptoms has been identified as an important intervening factor (MS Ireland 2016). Problems with balance, hand tremors, sight, walking and driving and requiring an aid for physical mobility appear disproportionately impactful, especially for employment (Chwastiak and Ehde 2017, MS Ireland 2016).

The complex and varied nature of the symptoms mean that some are hidden, for example pain, fatigue and cognitive issues (Erez 2019). One study found that fatigue and cognitive difficulties were reported by 95% and 71% of MS patients, respectively (Kobelt et al 2017). Pain and fatigue can translate to a need for frequent rest, while cognitive impairments cause difficulty concentrating and coping with stress (MS Ireland 2016, MS Society 2019c).

Onset timing, progression and severity of MS are important

Early onset (typically between 20 and 40 years of age) and long duration of MS typically results in ‘tremendous’ financial costs to individuals and their families (Chwastiak and Ehde 2017).

People with progressive forms of MS and more severe levels of disability typically incur greater financial impacts (e.g. MS Ireland 2016, Touchet and Patel 2018). The financial impacts of indirect and caregiving costs can be incurred even at low levels of physical disability in MS (Stephens 2019). However, moderate and severe symptoms impact significantly on employment outcomes (Stephens 2019, Kobelt et al 2017), while fatigue and cognitive difficulties impact negatively on working capacity (Kobelt et al 2017) and the capacity to manage finances (consistent with studies in people with brain injuries; Goverover et al 2018).

A tendency towards the comorbidity of MS and mental health problems

People with MS are also susceptible to mood symptoms and have a high prevalence of psychiatric symptoms and disorders, especially depression and anxiety (Chwastiak and Ehde 2017, Bajorek et al 2016). A study in Ireland found that 38.5% of people with MS (in a self-selecting sample) had experienced depression, anxiety, or both (MS Ireland 2016).

The cost of living

MS – and disability more generally – often places substantial extra costs on individuals and families as they go about their daily lives (e.g. Hancock et al 2016, Touchet and Patel 2018). Put another way, in order to have a similar standard of living as someone without a disability, someone with MS will often need to spend more (EHRC 2019). This underlines how measures of poverty and standards of living should not be viewed in isolation of the costs of living households face.

In practice, these extra costs reduce the disposable incomes people affected by MS have available, masking the true levels of exposure to poverty and hardship they experience. This is highlighted in the approach taken by Scope reported in the previous section, in which 37% of disabled working-age adults and 13% of disabled pension-age adults were in poverty when taking account of core living costs (Touchet and Patel 2018); higher than by any other income-poverty measure.

The extra costs of living people affected by MS face are around £600-£1,000 per month

Scope found that in 2016/17 that disabled adults on average faced almost £600 in extra costs each month as a result of their impairment or condition, and this was over and above any disability benefits they received to cover the extra costs. This was equivalent to about a half of their monthly income after housing costs (Touchet and Morciano 2019) and was similar to an earlier study (Scope 2014, in EHRC 2019).

Average costs were higher if the disabled person was single, out of work, if children were present, if both adults in a couple were disabled, or if families were in the second lowest income quintile. The impacts on income were substantial; the authors suggested that every £100 of a non-disabled person’s income was worth only £68 to a disabled person (Touchet and Morciano 2019).

A study in Norway found that the out-of-pocket cost to people with MS (and their families) specifically from everyday living costs was equivalent to around €350 per month. This also took into account government financial support (Svendsen et al 2018), which is typically more generous in Norway than the UK.

Estimates for people affected by MS in the UK are lacking. However, an earlier qualitative study estimated that extra costs amounted to around £800 per month for people with neurological conditions, rising to almost £1,200 for physical impairment (ECC 2015).

The authors note that someone with visual impairment would have to spend an extra £200 per week than a non-disabled person to achieve the same standard of living (Hill et al 2015 in ECC 2015). People with MS may spend more on keeping their homes warm in order to help manage their condition (George et al 2013, Touchet and Patel 2018), and this is true of disabilities more broadly (ECC 2015).

Disabled people generally (and by almost all impairment type) are more likely to rent their homes than own them (EHRC 2017). A rise in poverty among households that contain someone who is disabled has been attributed in research to the rising costs of rented accommodation, and they are more likely to be affected by the under-occupancy rule (in part because they find it difficult to downsize, EHRC 2017). They may also experience more wear and tear to clothing and bedding (ECC 2015).

There is also evidence – in relation to visual impairment – that comorbidity with other health conditions increases the costs (Hill et al 2017), and multiple impairment is characteristic of MS.

> Extra costs derive from a range of sources and are likely to be underestimated simply because of complexities in the individual experience of MS

The ECC's estimated financial penalty of £800 per month and £200 per week was made up of food and drink (making up £30 of the £200), household fuel (£30), other household goods and services (£20), health and personal care (£30), transport (£64) and recreation and culture (£20; ECC 2015). They also noted that clothing and bedding, specialised equipment, vehicle and parking costs, holidays and insurance were among the top cost areas identified in a consultation (ECC 2015).

The extra costs can be seen as deriving from: specialised goods and services (such as assistive technology); greater use of non-specialised goods and services (e.g. household fuel); and greater costs of non-specialised goods and services (e.g. higher travel insurance premiums; Touchet and Patel 2018).

A recent study of MS found that people with MS in the UK funded 75% of their non-medical costs, principally for aids and adaptations of the home or car, themselves. This was from estimated total non-medical costs of over £500,000 annually.[6]

Most attempts to measure the extra living costs of MS will most likely underestimate the true scale of these costs, however. This is simply because of the diversity of people's experiences of MS symptoms and the complexities of their lives and choices.

Though not offering independent empirical evidence, personal testimony of someone with MS in the US emphasises this in relation to the hidden costs of MS fatigue and cognitive 'fog' (Lynn 2017). These included the costs of food delivery, help with cleaning the bath, more expensive parking, paying more for goods because of a limited capacity to hunt for bargains, paying to stay overnight on trips that others could do in a day,

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[6] Nicholas et al (2020) 'Personal and societal costs of multiple sclerosis in the UK: A population-based MS Registry study'

missing events paid for in advance, charges or fines for missed bills and appointments, accounting errors, replacing items lost and not having the energy to challenge excessive bills or charges:

> "Yes, sometimes I just pay for things I shouldn't because I don't have the energy to make a phone call."

The standards of living that people with MS are able to maintain may deteriorate as resources are squeezed. Among people with visual impairment, serious shortfalls against minimum standards were found among people of working-age (Hill et al 2017). And it is likely that the situation will only get worse as prices, including energy prices, rise (George et al 2013) and there is greater reliance on privately rented housing (Whyley et al 2013).

Costs of care

Many people are also facing additional costs to meet their social care needs (George et al 2013).

The NHS provides for free medical healthcare at the point of use across the UK. However, social care is not currently provided for in the same way. Instead its management and funding is devolved to national governments outside of England and local authorities in England (Hancock et al 2016). Two in every three local authorities in England have introduced new or increased social care charges in the past three years (MS Society 2019b).

In 2016/17, total spending by local authorities on adult social care was £16.8bn, including the Better Care Fund (Wenzel et al 2018).[7] But clearly people affected by MS or other disability, whether those with MS themselves, families or carers, are also contributing substantial amounts; we have already seen that some of the extra costs of living from disability related to personal and social care (e.g. ECC 2015).

New analysis by the MS Society indicates that the amounts families spend on care and support could amount to £110,000 in lifetime costs for MS (2019b).

> A significant minority of people with MS pay all their care and support needs

A survey in 2019 found that 46% of people affected by MS reported they or their family paid all of their direct care and support, and a further 24% said they paid in part (MS Society 2020). This was based on a self-selecting sample; however, it represented a significant increase compared with a similar survey undertaken in 2016 and in turn in 2013 (MS Society 2017d). Only 20% in 2019 said that the government paid for all of their care needs (MS Society 2020).

The most common types of support people said they needed were with practical tasks such as cleaning and laundry, shopping and cooking. Those who only needed support with practical tasks, and not essential activities such as eating and getting in and out of bed (e.g. cooking and cleaning) were very likely to pay for all or some of the cost themselves. Moreover, those who paid for care themselves were less likely to feel their care needs were being met (MS Society 2017d).

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[7] The Better Care Fund was £5.3bn fund introduced by the UK Government in the June 2013 Spending Review.

Many people nonetheless have unmet care needs

Many people with MS and other disabilities have unmet care needs (e.g. AgeUK 2018, CSA 2018, MS Society 2017d). The Care and Support Alliance (CSA, 2018) notes that an estimated £6.3bn (49% of funding) was taken out of adult social care between 2010 and 2017 and that growing numbers are unable to access it. Some people struggle to navigate the system. The number of older and disabled people who do not receive the care they require almost doubled in that time, and the number of adults receiving it overall fell by a quarter between 2009/10 and 2013/14. The more limited support available means paid care staff are often unable to do more than the basics (CSA 2018).

In 2017, the Care Quality Commission (CQC) rated one in five providers as 'requiring improvement' or 'inadequate' (Wenzel et al 2018).

Unmet care needs impact disabled people in several ways

In a nationally representative survey of disabled adults, 39% of those saying they did not receive all of the paid care they needed to maintain social and community links felt unable to leave their house when they wanted more than once a day. They reported loss of confidence (60%) and feeling isolated or lonely (54%) and saw negative impacts on their mental and physical health (Leonard Cheshire 2017).

Unmet care needs were also linked to poverty. Those not getting the social care support they needed were more likely to report having less disposable income than their counterparts who did get support (£116 vs. £153 per week respectively; Leonard Cheshire 2017). It could also impact people's capacity to work (Leonard Cheshire 2017), for example, if the help needed to get someone ready in the morning was not there.

Moreover, there are 'costs' of MS (not of poverty) on friends, family and (other) caregivers, including through care giving, financial burdens, and stress (Trisolini 2010).

In Europe, 42% of patients with MS need assistance from their families and the intensity of help needed increases with symptom severity (Kobelt et al 2017). In the UK, the average annual cost of informal care provided by family and friends has been estimated at approximately €5,000 for mild MS-related disability to €11,000 for severe disability (Kobelt et al 2017).

The CSA reports, regardless of disability type, that cuts to care funding have increased pressures on unpaid carers – typically families and friends – who collectively provide care worth £132bn. This is almost the same as the UK's total annual spend on healthcare (2018). One of the impacts carers experience is on their own ability to work and capacity to earn. Over two-thirds of all carers say they regularly pay for further care or support, equipment or products for the person they care for from their own income or savings (Carers UK 2019).

Employment and earning

A fairly substantial amount of research has been done to assess the impact of MS on employment and, to a lesser extent, on earnings. This includes the impacts on people with MS (and research on disability more generally is used to consider the situation for carers).

Most people with MS are either in work (i.e. in employment), or out of work and not looking for work (i.e. economically inactive; All Party Parliamentary Group, APPG, for MS 2016). However, this masks some important patterns among working-age people with MS. And while the impacts of MS on employment may be varied, the financial consequences can be significant (Bajorek et al 2016).

Employment rates for people with MS are substantially lower than average

It has been noted that employment rates for people with long-term conditions as a whole are low, and persistently so (Bajorek et al 2016). In 2016/17, 35% of people with any disability were employed if they were economically active (available for work) compared with 72% of those without a disability (EHRC 2019). The gap has been steady for the last 20 years (MS Society 2017a). Conversely, people with a disability were twice as likely to be unemployed if they were economically active, and if they were working, they were more likely to be in insecure jobs and earning less per hour as employees (£10.19 vs £11.73 median).

The employment for people with MS was recently reported at 55%; this compared with an employment rate – defined here as the proportion of people aged 16 to 64 who were in work – of 75% in the general population (APPG for MS 2016). By this token, it appears that people with MS are 'somewhere in the middle'. However, more people with MS than average are working part-time (45% vs 27%; APPG for MS 2016).

Estimates do vary, however, and a very large-scale survey of people affected by MS (and which was broadly representative by key demographic characteristics and MS status and symptomology) found that only 43% of people aged 16-65 with MS were in employment in 2019, with just over half of these in full-time employment (MS Society 2020). These figures were similar to those found in 2016 (MS Society 2016).

Employment varies by MS status and the severity of symptoms.

Compared with people with relapsing remitting MS, the employment rate among those with secondary progressive MS was less than half (APPG for MS 2016). And the average employment rate for people with severe MS was a small fraction compared to those with mild MS (4% vs 37%; Naci et al 2010 in Bajorek et al 2016).

In practice many people with MS are not working, often despite work being possible and beneficial (Bajorek et al 2016). A study in 2017 found that 55% of working-age people with MS in the UK were not working due to MS (Kobelt et al 2017). The MS Society's 2016 survey found that 23% were not looking for work (MS Society 2016); although this reduced to 14% in a similar survey in 2019 (MS Society 2020). Among disabled people more generally, employment rates (defined here again as the proportion of people aged 16 to 64 who were in work) were particularly acute among young adults, aged under 26 (Leonard Cheshire 2017).

MS symptoms and status affects the range of jobs and hours people can do

As MS progresses from diagnosis, many people reduce or change their working arrangements; MS limits the range of jobs and hours people can do and symptoms such as fatigue make working increasingly difficult (APPG for MS 2016). Changes reported to the 2016 survey included reduced hours, changing roles, changing the work environment or location and ceasing work; only 13% had made no changes (MS Society 2016). Most people want to stay in employment, but many eventually go part-time or become self-employed (MS Society 2017b). In some cases, work exacerbates people's symptoms (APPG for MS 2016).

In some cases, people with MS leave employment altogether (including by retiring early) because of the difficulties they face working given their symptoms (MS Society 2017b). And once they leave it is uncommon for them to return to the workplace (APPG for MS 2016). In the 2016 survey, six in ten respondents had left work entirely or retired early as a result (MS Society 2016).

Mobility issues associated with MS appear to pose significant obstacles to working. The physical demands of work can be problematic when symptoms impair the ability of some people to work safely. Problems with fatigue, cognition, balance and eyesight problems have also been identified as common reasons for having to stop working or reducing working hours (MS Ireland 2016). The fluctuating nature of symptoms can also be problematic (MS Society 2017c).

Symptom severity has a strong influence on workforce participation among people with MS (Stephens 2019, Kobelt et al 2017, MS Society 2017c) and fatigue and cognitive difficulties have been shown to have important independent effects on difficulties and symptoms at work (Kobelt et al 2017).

The support people receive is also important

Crucially, it is not necessarily the symptoms or status of MS, in isolation, which impact on people's ability to work. Authors have noted significant problems with unhelpful employer attitudes and behaviours, trying to deal with unsupportive managers and a lack of services compounding people's difficulties in working (APPG for MS 2016, MS Ireland 2016). A significant minority of people had not received the help they wanted or needed to find to remain in employment in the previous 12 months alone (MS Society 2016). As many as three in ten people with MS who are in work have been denied promotion, had duties removed without consultation or experienced other discrimination by colleagues or managers in the last five years (MS Society 2017a). This is discussed further below.

The average number of sickness absence days taken per year by people with MS in the UK is 16.6 and people in the UK as a whole collectively miss out on £4bn per year in lost earnings through sickness absence (Bajorek et al 2016). Moreover, disabled people need to earn an estimated £10.63 per hour, or £15,500 per year, to meet minimum income standards (TimeWise Foundation in MS Society 2017a).

There is significant loss of earnings potential

Whether through sickness absence, a reduction in hours or leaving work entirely, people with MS can lose a significant amount of time from the workforce. Because people typically start to experience MS symptoms in their 20s and 30s (when people may still be in education or early in their career) the impacts on career perspectives, other benefits from participating in work and earning potential are substantial (Bajorek et al 2016, MS Society 2017b). The average age of retirement for someone with MS in the UK is 42 (Bajorek et al 2016).

We could not find a study which estimated the life-time loss of earnings to people with MS. However, an Australian study noted that 20% of people affected by MS (the individual, their family members and carers) reported having foregone income as a result (De Judicibus and McCabe 2007).

Carers also often lose income in order to provide care, by reducing or leaving work (Carers UK 2019). The CSA reports that 2 million people overall have given up work to provide informal care, while others are reducing their working hours or missing out on volunteering and other community activities (CSA 2018):

> "I have reduced my working hours and eventually my husband will need to be my carer so he will need to stop work too."

In a recent study, of 132 carers, about half had applied to employers to work flexibly, and half of these had had their applications rejected. About half overall were not working but would work if they could work flexible hours, while around a quarter again were working but would work more if flexible working was possible (DLS 2018).

Outcomes of poverty

Although the impacts of MS on poverty are poorly delineated, the previous section saw clear evidence of the impacts of MS on intermediary financial impacts: the drivers of poverty. The literature also evidences further impacts, which appear to act as secondary impacts of poverty. We have conceptualised these as outcomes of poverty in our framework (Figure 1).

These outcomes relate to people (mostly individuals, but also their families and potentially their carers) and society.

Outcomes for people affected

The outcomes of poverty among people affected by MS encompass both financial and non-financial outcomes. Financial outcomes are characterised by a reduced financial security among individuals and their families. Non-financial outcomes are captured by concepts of quality of life.

> Financial insecurity is common among people affected by MS

The impacts of MS and of poverty and MS on financial security have been considered in the literature in relation to the ability of households to make ends meet, the burden of debt, and their savings and wealth. In Ireland, 30% of people with MS reported that they were either struggling or really struggling on their current income (MS Ireland 2016). In the UK, people who are newly diagnosed with MS and, at the other end of the spectrum, those living with MS for a long period of time were especially likely to report struggling or really struggling on their current income (MS Society 2019a). Those with an unmet need for care were more likely to be struggling financially (MS Society 2017d).

> For people with disability generally, there are increased risks of food and fuel poverty

We noted earlier that one in four working-age disabled adults in the UK reported having less than £50 disposable each week after income and council tax and housing costs were paid (Leonard Cheshire 2017). Two in five carers were struggling to make ends meet, rising to over half if they were receiving Carers Allowance (Carers UK2019).

Moreover, food and fuel poverty are implicated. About a quarter of all disabled people missed at least one meal each week and one in five had not been able to afford to keep their home warm (Leonard Cheshire 2017). The problem appears to be more acute among people who had been moved onto Universal Credit (UC) from previous benefits and who were receiving less generous benefits as a result (DBC 2019a).

In national data, households containing disabled people were more likely to be fuel poor compared with households not containing disabled people (20% vs 15%; in Heslop 2013), and this was true regardless of which measure is used (Snell et al 2014). The rate increased when disability related benefits such as DLA and AA were removed from the calculation of income (Snell et al 2014).

Similarly, concerns have been expressed about the heightened tendency for the accrual of unmanageable rent arrears among disabled people affected by the under-occupancy rule (EHRC 2017).

For people with MS, the potential to be spending longer periods at home and requiring a constant ambient temperature adds to the potential to be fuel poor. Their carers may also be affected, especially if they also have health problems. Special dietary needs can lead to higher cooking costs (George et al 2013).

Disability is implicated in food bank use. In one study, one in five users of Trussell Trust foodbanks nationally were estimated to have a disability (Hadfield-Spoor 2018), rising to half of users in another (Loopsta and Lalor 2017). Disabled people are three times more likely to use foodbanks than others (Loopsta and Lalor 2017).

In addition, families with a disabled person have more difficulty managing their finances (Heslop 2013). Fluctuating and unpredictable symptoms can make it more difficult to manage consumption and budgets well (George et al 2013). And where people are struggling to make ends meet their confidence managing money is low (Ipsos MORI 2013).

The burden of debt is a problem for some people with disabilities

MS increased the likelihood that people owed debts on household bills in the US (Goverover et al 2008) and crises in paying bills were more common in the early days of MS in Australia (De Judicibus and McCabe, 2007). Higher use of prepayment meters among disabled people than non-disabled people in Scotland (Citizens Advice Scotland 2009) may tend to indicate prior arrears. In the US study, needing to borrow was also more likely among those with MS than those without (Goverover et al 2008).

Households with disabled people are twice as likely (as those without) to have consumer borrowing totalling more than half their household income (16% vs 8%; in Touchet and Patel 2018). Having a legacy of (previously manageable) borrowing before becoming ill is a common reason why people of working-age get into problem debt.[8] There is a high incidence of debt advice clients who are disabled and their debts tend to be higher (e.g. Tutton et al, 2011).

Disabled people tend to have fewer savings and lower wealth

Disabled people also have significantly fewer savings than non-disabled people, estimated at £108,000 less (McNight 2014 in Touchet and Patel 2018). People who had had high incomes before MS impacted their ability to work tended to have more resources which saw them through for longer (De Judicibus and McCabe 2007).

Total household wealth was £184,000 less on average than for non-disabled people, after controlling for age, marital status and children. Differences are greater for working-age people than during retirement. This was driven partly by the greater incidence of disability in older age and the ability of people who experience disability later in life to have accumulated wealth (McNight 2014). The authors observed a 'cumulative disadvantage' related to disability longevity (McNight 2014), and

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[8] Collard et al (2012) '[Working households' experiences of debt problems](#)'

the typical early onset of MS in life will tend to reflect this.

Poverty and financial insecurity impact quality of life

Living in poverty and the financial insecurity that can be associated with it, can have a severe impact on disabled people's quality of life, including a worsening of their physical and mental health (Leonard Cheshire 2017, DBC 2019a, MS Society 2019a).

Quality of life outcomes are also significantly poorer among people with MS than in the population as a whole (MS Ireland 2016). It is more likely to be impacted if someone's MS symptoms are severe (MS Ireland 2016) or they experience early MS onset or long duration (Chwastiak and Ehde 2017, Svendsen et al 2018). The negative impacts of MS on someone's quality of life can in turn result in poorer employment and health outcomes (Bajorek et al 2016), highlighting the cyclical nature of the effects of drivers and outcomes of poverty.

Quality of life was significantly lower among people with MS who were depressed

It was noted above that comorbidity with mental health problems is a factor in the lived experience of MS. A previous review found that quality of life was significantly lower among people with MS who were also depressed, and this was true over and above the effects on quality of life from neurological causes (neurologic disability, fatigue, and functional status; Chwastiak and Ehde 2017).

The extent to which people with MS who are also in poverty experience even worse quality of life outcomes is less clear in the literature but tends to indicate the 'double disadvantage' of MS and poverty. Surveys with people affected by MS have found that financially insecure people with MS find it more difficult to access services which they needed to manage their MS (MS Ireland 2016) and greater levels of unmet need overall for care, support information and daily activities (MS Society 2019a, De Judicibus and McCabe 2007).

Inadequate domestic assistance was raised as a quality of life issue in in-depth interviews in Australia, by MS professionals, people with MS and carers (De Judicibus and McCabe 2007). Unmet need for accessible housing also affects disabled people's ability to live independently, work, their social relationships and sense of dignity and control (EHRC 2017).

In the US, unemployment among people living with MS was associated with low levels of engagement in physical activity (it was highest among those working part-time) and greater social impairment. The unemployed also had significantly lower levels overall of health-related quality of life and life satisfaction than those who were working (Chiu 2015). The authors (p750) also noted that:

> …loss of employment and resulting poverty brings detrimental psychosocial, financial, and health consequences to individuals with MS.

In formative qualitative work in Australia, loss of income was expressed as a major cause of concern for many people affected by MS (whether individuals, families or carers). Adjusting to actual or threatened loss of income caused financial stress to, and in turn lower quality of life among, people with MS and their families. The major concerns centred on being unable to meet current or pre-existing financial commitments. Worry about future financial security and loss of aspiration could implicate other health problems and reduced social participation and hobby-making (De Judicibus and McCabe 2007).

People with MS in Australia also felt they were letting their families down and cash flow problems increased the stress on family relationships. Employment loss also led to the loss of enjoyment for work itself, loss of social contact, and changes to people's self-perception and perceptions of self-worth. For some, however, leaving full-time work could result in increases in subjective quality of life if they had more time for self-directed activities (De Judicibus and McCabe 2007).

Looking to disability more broadly, staying active and connected is important. A previous review found that disabled people are finding it increasingly difficult to establish and maintain a sense of connectedness with others and this is especially true of those on low incomes (EHRC 2019). Standards of living were also deteriorating as disabled people's organisations and other local community groups disappear from the lack of resources available (EHRC 2019). In this context online services are essential for access to information, shopping, entertainment and quality of life more generally (George et al 2013).

Outcomes for society

There have been very few studies which consider the impacts of poverty on the NHS or the wider society in the context of MS.

> There are significant healthcare costs of MS, but these are not related in the literature to the impacts of poverty

The annual direct healthcare costs of MS in the UK have been calculated at €2,000 among people with mild MS to €7,000 among those with severe MS (Kobelt et al 2017). These are costs which will be largely incumbent on the NHS. The figure rose to €40,000 for patients with severe MS respectively when the indirect costs of healthcare, which included disease modifying treatment but also informal care and other non-healthcare costs, were added (Kobelt et al 2017).[9]

There is apparently no research which has explored the role of poverty in the costs to the NHS.

> The primary indirect costs to society come from productivity losses

Kobelt et al (2017) notes that in the UK and other European countries, total costs to society are related to disease severity and dominated by productivity losses, non-healthcare costs and disease modifying treatments.

Per-patient productivity losses in the UK as a result of MS have been calculated at €4-5,000 annually for mild MS up to €14,000 (severe MS was €12,500; Kobelt et al 2017). The total indirect cost of MS among the working-age population has been estimated at £0.65 billion a year, arising from reduction in working hours, sickness absence, presenteeism, early retirement, unpaid

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[9] The figure of €40,000 is reported in GBP (2015) as £36,500 in Thompson et al (2017) 'Results for the United Kingdom'

care and unemployment and associated welfare provision (Bajorek et al 2016).

Government policy can inadvertently increase the costs of MS to society

One study predicts that the Government will spend an extra £93m between 2020 and 2023 simply as a result of removing welfare support (such as PIP) from people with MS. This comprises £22.3m on increased use of GP, A&E, and counselling services, £57.4m on lost income tax from people with MS and their carers, £11.4m on extra Employment Support Allowance and Cares Allowance payments for people who left work and £1.7m on processing extra Personal Independence Payments appeals and reassessments (Wetherly and Erez 2018). Failing to address gaps in effective treatment and wider service provision could be more costly to individuals and the wider economy in the coming decades (Bajorek et al 2016).

Welfare and the policy landscape

The welfare system should protect people (including those with disabilities) from experiencing poverty and hardship. It incorporates the role of the welfare state, including through the benefits, care and national insurance systems, but also encompasses the roles of health professionals, employers and voluntary organisations.[10] However, there is consistent evidence that it is not addressing the needs of people affected by MS.

This section considers this landscape, its limitations and potential solutions. It focusses on MS (drawing on the literature about disability more broadly only where necessary) and considers the main 'costs' of MS previously identified as relating to the costs of living, costs of care and employment and earnings.

Tackling the living-costs penalty

The UK's social security system has undergone significant changes within the last decade, including with the gradual (and continuing) roll-out of Universal Credit (UC) since 2013. Disability benefits support people with MS to live independent lives and participate in society (MS Society 2017c). However, in addition to the streamlining of means-tested benefits into UC, previous criticisms have been made of the new one-year time limit to contributions-based Employment and Support Allowance (ESA), removal of special "youth provisions" for contributions-based ESA, removal of the Disability Living Allowance (DLA) mobility component from care home residents, and the abolition of Crisis Loans and Community Care Grants as creating a 'hand-to-mouth existence' among people with disability, including MS (Wood and Grant 2011).

Changes to the welfare state since 2008 have meant disabled people have lost an estimated £1,200 per year each in benefits (compared with £300 per year for non-disabled people; DBC 2019d).

The primary benefits which support people with disabilities can be grouped broadly as income (and work-related) benefits, which are discussed below in relation to employment and earning, and extra-costs benefits.

Extra-costs benefits for people affected by disability are not generally means-tested. They include Personal Independent Payments (PIP), Disability Living Allowance (which is in part being replaced by PIP) and Attendance Allowance (AA). Eligibility for these disability benefits can increase the amount someone receives on income-related benefits such as Housing Benefit and Pension Credit. Some people may also be eligible for other benefits, such as Disabled Students Allowance and the Disabled Facilities Grant.

As their name suggests, extra-costs benefits are intended to cover the extra living costs associated with disability. Problems exist, however, around both the levels of benefits received and access to them.

> The sums provided by extra-costs benefit fall far short of the extra costs people actually incur

Although the extra-costs benefits people receive are tiered, they

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[10] DWP (2016) 'From welfare state to welfare system'

nonetheless often fall short of the costs disabled people actually incur (Hill et al 2017, Touchet and Morciano 2019). Against the average extra costs for disabled adults in the lowest income quintile of £507, only £58 was received in disability benefits and in the highest quintile the amounts were £609 and £35 respectively (Touchet and Morciano 2019). Despite recent changes to PIP, a cap on domestic fuel cost and guidance to NHS organisations on concessions for parking, the gap has not been addressed (ECC 2015, Touchet and Morciano 2019).

The gap in extra costs benefits is getting bigger

Moreover, the transitions from DLA to PIP has reduced receipt of the extra-costs benefits greatly among many people with disability and MS specifically (e.g. Leonard Cheshire 2017, Wetherly and Erez 2018). Nearly 9,000 people with MS transferring from DLA to PIP since 2013 had their award reduced (or removed entirely; Wetherly and Erez 2018), and at least one in four people with MS are now believed to be losing out on PIP (Erez 2019). In 2016, only 9% of people with MS were receiving PIP (it was higher among those looking for paid employment) while 61% were receiving DLA (higher among those not looking for paid employment; MS Society 2016). By 2019, 39% were receiving PIP and only 26% were receiving DLA (MS Society 2020).

Qualitative research has noted the pressure being placed on DLA for everyday expenses, rather than the extra costs of disability, among disabled people (Snell et al 2014).

Disability-related supplements to means-tested income related benefits have potential to help make up the difference, but these have also been disappearing under UC (Hill et al 2017).

Not everyone with MS is getting the help with extra costs that they should

A part of the problem for people affected by MS is that the benefits system often fails to recognise invisible symptoms like pain and fatigue and the complex, varying and fluctuating nature of MS symptoms (MS Society 2019c, Erez 2019). Two-thirds of people with MS found the application process for PIP difficult to understand as a whole and a similar number had difficulty completing the form, including because it did not allow them to explain how MS affected them (Erez 2019). In 2019, one of the most common reasons people affected by MS called the MS Society benefits helpline was for help with filling in PIP forms and preparing for PIP assessments.[11]

This is evidenced in the assessment criteria for PIP and a failure of assessors to always take evidence provided by professionals into account. People with MS are often under pressure to repeatedly prove they need support and find the claims process as a whole 'humiliating', 'degrading' (MS Society 2019c) and unsupportive (Erez 2019).

Such failures ultimately lead to inaccurate assessments, which means many people with MS end up with 'wrong decisions' (Erez 2019). Calls to the MS Society in 2019 often related to mandatory PIP reconsiderations and

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[11] Provided in direct correspondence, January 2020.

appeals, especially when transferring from DLA to PIP.

Among those transferring from DLA to PIP, more than eight in ten people with MS who take failed PIP claims to appeal win those appeals (Wetherly and Erez 2018). The authors suggest that successful claims on appeal have cost the Government £1m, in contrast to the projected £1.7m it will spend between 2020 and 2023 on processing extra appeals and reassessments, and an extra £90m it cost in lost revenues and increases in benefits from loss of work, increased health care and other costs among people affected by MS. Despite a few attempts to improve PIP in recent years, people with MS are still waiting for PIP to improve (MS Society 2019c).

> Improvements are needed in the way people with MS are supported with their living costs

Addressing the gap in costs could be more important even than means-testing, especially for people with severe disability and very high costs (Hancock et al 2016). Increasing the money available for extra costs payments, such as PIP, can level the playing field (Leonard Cheshire 2017). But other solutions to improve the benefits system that have been suggested include:

- Better matching of the amounts people are entitled to to the costs of disability and the severity of disability (e.g. Hancock et al 2016, Touchet and Patel 2018, Erez 2019).
- Increasing the reach of the benefit system among disabled people (e.g. Hancock et al 2016), including by reforming eligibility for the Warm Home Discount (which is available to people on low incomes; Touchet and Patel 2018, George et al 2013).
- Changes to assessment criteria like the '20 metre rule' and processes that take into account the fluctuating and hidden symptoms and impacts of MS (e.g. Wetherly and Erez 2019, MS Society 2019).
- Improving the way evidence of disability is gathered, assessed and used and increasing the use of evidence from experienced professionals who understand each person's condition (Wetherly and Erez 2019, MS Society 2019c).
- Implementing better control mechanisms through an independent body to oversee PIP assessments (Erez 2019, MS Society 2019c).
- Redesign of the PIP claim form, and changes to assessment criteria, such as the 20 metre rule, and processes that take into account the fluctuating and hidden symptoms of MS and their impact (Wetherly and Erez 2019, Erez 2019).
- Ensuring that people with MS are supported throughout the claim process and in their right to challenge claim decisions (Erez 2019, MS Society 2019c).

Other suggestions have emphasised a need for Government to work with other organisations to provide an Early Intervention and Family Resilience Fund to support disabled children (Touchet and Patel 2018) and to reconsider the under-occupancy rule for people with disabilities (EHRC 2017).

Meanwhile, most families with a disabled person live in homes which are not suitable for disabled people. The provision of Disability Facilities Grants (which are means-tested capital grants for adaptations in the home provided by local authorities) has declined to 'low or very low' in most areas, partly as a result of austerity. The upper limit of the grant has not changed since 2008, even to adjust it for inflation. As time goes on, the problem is likely to become most acute in households who rent privately (Mackintosh 2018).

Enabling people to be independent for longer in their home calls for more joined-up action across housing, health and social care (Mackintosh 2018). Professionals should explore ways of improving the financial situation of people affected by MS, as well as their strategies to cope with the resulting financial strains (De Judicibus and McCabe 2007). Education and intervention strategies which include therapy targeted at real-life money management problems may have practical benefits to people with MS, especially those experiencing cognitive impairment, and help improve overall quality of life (De Judicibus and McCabe 2007, Goverover et al 2008).

Tackling the care-costs penalty

While central government pays for disability benefits, local authorities manage the provision of social care (Hancock et al 2016). However, social care is rarely completely free,[12] even if people are eligible for a personal budget within a Care and Support Plan. In England, paid for care does not cover personal care (Watt et al 2019).

> There is a significant gap in the public funding of social care

£17.1bn was spent on public provision of adult social care in England in 2015/16 (and a half of this on services for people aged 65 and over). This was £1.1bn lower in real terms than in 2009/10 (Watt et al 2019). Lower real terms spending has led to many local authorities raising their eligibility criteria to reflect severe need, and the funding gap is only set to get bigger (Watt et al 2019).

We have already seen that cuts to social care funding means disabled people are increasingly bearing the brunt of the costs of social and personal care, many are unable to live full and independent lives now and many are worried for the future (Leonard Cheshire 2017). Moreover, the demand for social care is only growing as the population ages and more people are living longer with health problems and disability (Wenzel et al 2018).

When looking across the social care and disability benefit systems Hancock et al (2016) suggest that it uses limited resources comparatively well for older disabled people in poverty, but fails for in protecting the most severely disabled from deep poverty. This is most acute for those who are unaware of, or have difficulty negotiating, the systems for claiming care support.

> Very little evidence points to social care solutions and none relates specifically to people affected by MS

Social care funding must be put on a sustainable footing, for the benefit of disabled people who rely on care and support and their families (CSA 2018). However, the additional funding required for social care is large (Watt et al 2019). Improving access under the current system to the higher levels of 2009/10 would require substantial funding, in the £10s of billions (Watt et al 2019).

Raising funds in a sustainable way could be possible by raising additional

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[12] AgeUk 'Paying for care'

revenue through moderate increases in the taxation system (Watt et al 2019). However, a dedicated tax might exacerbate the current mismatch between the health and social care systems (Wenzel et al 2018). The potential to remove national disability benefits in favour of an expansion of local authority social care funding, would risk many more (older) people missing out on government support completely (Hancock et al 2016).

Major reform may be needed. A joint budget for the newly named Department of Health and Social Care may support progress to the greater alignment of care but it does not in isolation address the funding gap, the need for more revenue or the lack of free personal care (Wenzel et al 2018).

Failures of successive Governments to implement major reform may suggest that small improvements within the current system are more realistic, even if they do not account for the downward trend in funding or the ability to protect people from 'catastrophic' care costs (Wenzel et al 2018). A study of older people with disabilities suggests that the bigger source of failures in the current system comes from failures in targeting those with the most severe need effectively, rather than spending resources on the wrong people in the first place (Hancock et al 2016).

Based on a small-scale qualitative study in 2011 (including one family with a person with MS), it was also suggested that the now abolished Community Care Grants and Crisis Loans be maintained, and the inclusion of DLA as a contribution to social care funding removed (Wood and Grant).

It is suggested that, most importantly, there needs to be urgent investment in social care to fill the current funding gap (MS Society 2019c). More generally, there needs to be more integrated and person-centred care (Bajorek et al 2016).

Tackling the employment and earnings penalty

There are two main dimensions to the employment and earnings landscape which are relevant to people affected by MS: the benefits that are intended to support work or replace income from earnings; and other policies which support people in finding, maintaining and staying in suitable employment.

> Employment and Support Allowance (ESA) is the main working-age income-replacement benefit for people with disabilities

Employment and Support Allowance (ESA) is the main income-related benefit relevant to disabled people of working-age struggling to find or do paid work. People with MS who can no longer work as a result of their symptoms can apply for it (MS Society 2017c). It is means-tested, and eligibility is assessed through a Work Capacity Assessment (WCA, normally within 13 weeks of the claim).[13]

In 2016, eight in ten people with MS entitled to ESA (or income support) were claiming it (MS Society 2017c). The majority are placed in the Support Group (92%).[14] Around two-thirds of these are not expected to return to

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[13] https://www.scope.org.uk/advice-and-support/employment-and-support-allowance/

[14] This group is not required to take any work-related activity.

work within two years or longer (MS Society 2017c).

A smaller group is placed in the Work-Related Activity Group (WRAG), requiring them to undertake some work-related activity and prepare for employment (6%). However, for people with MS, committing to work-related activity could be impossible due to the severity or fluctuating nature of their conditions (MS Society 2017c). In a 2015 survey, WRAG conditionality was reported to be problematic in about half of cases (MS Society 2017c). Moreover, appointed 'work coaches' are rarely seen as supportive by people with MS, because they are neither disability specialists nor attuned to the symptoms people with MS can face (MS Society 2017c).

In addition, concerns have been raised about the effectiveness of WCAs in accurately identifying barriers to employment in MS (APPG for MS 2016). This includes failure to adequately consider high-quality and specialist medical evidence and results in poor assessment outcomes for people with MS; an increase in successful appeals is testament to this. Many have had to undergo repeated WCAs (MS Society 2017c). While government efforts focus on supporting disabled people to re-enter employment, people with MS more typically cannot look to re-enter work because of their symptoms (MS Society 2017b) and out of work support is very important for people with MS in these circumstances (MS Society 2017c).

People with MS are losing out as a result of the benefits system

The WRAG-related benefit was cut (by £30 per week), ostensibly as an extra incentive to find work, and this further disadvantaged people with MS whose complex and varied conditions results in multiple barriers to work (MS Society 2017c, APPG for MS 2016). Some have experienced significant hardship as a result (MS Society 2017c). Even before the cut to financial support (WRAG), people with MS have been telling us that they struggle to afford essentials such as food, gas and electricity (MS Society 2017c).

Possibly due to a lack of awareness, but also stigma, one in five people entitled to ESA are not claiming it. They lose out on around £4,500 each per year. An eligible person who does not claim ESA also loses out on National Insurance credits for State Pension entitlement (MS Society 2017c). Organisations of all kinds should help improve awareness of ESA and its gateway role (MS Society 2017c).

The benefits system also acts as a gateway to statutory government services, such as the former Work Choice programme. Those who avoid claiming benefits may therefore inadvertently miss out on further support (MS Society 2017b). Other services are simply not attuned to the fluctuating nature of the symptoms people with MS often face; referrals to Fit for Work (now only a support line and online service) could only be made after four weeks of unemployment and only once in 12 months (MS Society 2017b).

People affected by MS need sufficient support (financial and non-financial) to help them achieve the right work outcomes for them without impacting their financial security adversely (MS Society 2017c). In a recent study of people with MS, those needing support to help stay in employment and not getting it ranged from 1% among those with advanced MS, to 7% of those described as 'living well' and 13% among the newly diagnosed (MS Society 2019a).

To increase the effectiveness of the available benefits, organisations of all kinds should help improve awareness of ESA and its gateway role (MS Society 2017c). But intervention must extend further than this. The MS Society recommends that:

- Government should make access to employment support voluntary rather than conditional for people with MS.
- Government should recognise that some people with MS cannot work and provide them with adequate financial support (2017b, APPG for MS 2016). This includes reinstating previous levels of payments for those in the WRAG (2017c).
- Occupational health services should signpost people to ESA.
- The descriptors used in the WCA should be reviewed and simplified to better capture fluctuating conditions, such as MS with hidden impairments. Assessors should be supported to understand and consider the implications of these, including in reference to the evidence, and people with MS who face very little prospect of recovery should be exempted from future reassessments (a policy now implemented).[15]
- The requirements placed on people under WRAG be performed by neurology specialist assessors and based on appropriate evidence and specialists.
- Assessors should be legally bound to provide a copy of the assessment and any medical evidence they obtained at the decision stage (MS Society 2017c).
- Provide employers with guidance for good transitions out of work (APPG for MS 2016).

We have already noted that most people with MS wish to stay in employment, however some people withdraw from employment because of the barriers they face (MS Society 2017b).

> Staying in work for as long as feels right is often more important for people with MS

Current services are not effective enough at keeping people in employment, with significant costs to them and the economy (Bajorek et al 2016). Greater focus is needed on helping people with MS stay in work for as long as possible and adapting their working lives as their condition changes (APPG for MS 2016). They need timely and joined up interventions, especially to offset lost support as UC rolls out (MS Society 2017b, Touchet and Morciano 2019). Workplace strategies focused on job retention are critical to reducing the high economic burden of MS (Stephens 2019), jobs that provide for flexible or part-time working are especially important (MS Society 2017a).

Government services which help people to remain in work for longer are (or have previously been) available. They include Access to Work, and formerly Fit for Work and Work Choice; however levels of awareness of them has been

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[15] See House of Commons Library (2019) 'ESA and PIP reassessments'

low both among people with MS and employers. Government should pilot new interventions to help people stay in work (MS Society 2017b).

Employers can sign up to the Government's Disability Confident scheme, which provides employers with guidance and resources about employing disabled people. However, there is currently no evidence on its take up and Government support of it (and the Work and Health Programme) should be strengthened and extended (APPG for MS 2016, MS Society 2017a, Leonard Cheshire 2019).

The employer is critical and many are still failing staff with MS

A majority of people with MS disclose their condition to their employer and have discussed the support they need, such as adjustment in the workplace (MS Society 2017a). Research has nonetheless highlighted a lack of understanding among employers and colleagues, and people with MS can still find it difficult to get the adjustments they need (especially in smaller organisations; APPG for MS 2016, MS Society 2017a). In a survey of people with MS, many employers had waited to be prompted to have the conversation about people's needs and then to arrange the support (APPG for MS 2016).

Employers generally report low confidence knowing where to find relevant information and advice. However, is has also been asserted that some employers refuse to implement Access to Work recommendations for people with MS, even where grants are available to support the adaptations they need (MS Society 2017a).

A substantial minority of people said they had experienced MS-related stigma or discrimination at work in the past five years (APPG for MS 2016). Cultures which reinforce long working hours or a lack of awareness of the help that is available, may explain why some people with MS do not disclose their condition (MS Society 2017a). Some, but not all, employers allowed people time off for MS-related medical appointments (MS Society 2017a).

Recommendations identified in the literature for employers include:

- Ensuring compliance with the Equality Act.
- Increasing awareness of the information and guidance available and adopting policies and practices which promote inclusion and opportunity for disabled employees, including on disability absence and normalising reasonable adjustments.
- Reviewing and promoting working cultures which are supportive and deal quickly with bullying, harassment or discrimination.
- Sharing good practice with each other.
- Supporting employees as they leave employment, possibly through a coordinated advice service (APPG for MS 2016 and MS Society 2017a).

External employment support services should also ensure that they engage with employers as much as possible to encourage them to support people with MS actively (APPG for MS 2016). A multi-disciplinary approach to treating MS leads to improved health, wellbeing and work outcomes (Bajorek et al 2016).

Health professionals can also play a critical role in employment outcomes

People with MS also need to help self-manage their condition at work and consider early disclosure (Bajorek et al 2016). While early diagnosis and more effective therapeutic interventions for the management of early MS symptoms are important for employment outcomes (Stephens 2019, Bajorek et al 2016), inadequacy of referrals from health professional to employment service has also been identified as an issue (APPG for MS 2016).

Employment should be considered an important health outcome for people with MS (APPG for MS 2016, Chiu 2015) and should even be adopted as a clinical outcome in health service measurement frameworks (APPG for MS 2016). NHS England's Five Year Forward View commits to supporting people to get and stay in employment (Bajorek et al 2016). In the meantime, only 27% of people with MS in the 2016 survey said they had spoken to a health professional about their employment situation in the last year, and referrals were often slow (APPG for MS 2016).

Measuring MS & poverty

Measuring poverty well among people affected by MS means being able to measure poverty accurately using a definition which reflects the experience of poverty among people with MS and being able to capture MS as a distinct condition.

Measuring poverty

Although studies are consistent about the disproportionately high exposure of people with disabilities to poverty, the different definitions they use nonetheless affect the headline rates of poverty that are observed. Some definitions are especially likely to underestimate poverty among disabled people (e.g. Hancock et al 2016).

Parckar (2008) proposed that disability poverty be recognised as a unique form of poverty because it is about more than having a low income. Instead, a wide range of potential indicators would be used, including relative poverty, employment status, savings and goods and services accessed (in Heslop 2013). This closely reflects the findings of this review; that the financial impacts of MS extend well beyond narrow definitions of income poverty.

Nonetheless, being able to represent the financial resources someone has available is important, and measuring income remains a logical place to start. It is also the basis for most alternative measures (e.g. SMC 2019, Hill et al 2017).

> Income poverty measures should take account of housing costs

Previous authors have noted the particular role of housing costs in the measurement of poverty, with high poverty rates for disabled renters (Tinson et al 2016) and the rising costs of rents (EHRC 2017). This emphasises the importance of measuring income poverty after housing costs, and the SMC's new measure of poverty addresses this directly (2019).

> Income poverty measures should exclude benefits which are designed to offset the extra costs of disability

The role of benefits is also important (and these interconnect with the role of other costs which disabled people face). Excluding certain disability benefits (DLA – now partly replaced by PIP – and AA, which are designed to meet some of the extra costs of disability) from income measures has been shown to result in higher rates of poverty among people with disability (McInnes 2014).

The DWP's 2013 figure, of 20% of disabled people living in poverty increased to 23% when excluding these benefits from income, and McInnes (2014) identified an extra 1m people living in poverty. In analysis of the over 65s, including disability benefit in income while failing to make any allowance for the higher living costs that disability brings, disabled people appear better off (Hancock et al 2016).

This makes sense when the income from these benefits is offset by the extra costs recipients incur which the benefits are intended to cover. These benefits are often treated as 'income', even though a disabled person with £100 extra income and £100 extra needs is as poor as someone without a disability (McInnes 2014).

The extra costs people incur as a result of disability are often larger than the benefits they receive

In the UK, benefits for disabled people are generally set at arbitrary fixed levels within broad ranges (Heslop 2013). However, the extra costs disabled people incur are normally larger than the benefits available to them (McInnes 2014). Despite more recent attempts to measure these extra costs, most notably by Scope, there is no consensus about how best to measure these costs or their size and previous estimates have varied wildly as a result (Heslop 2013).

In one study, the average disabled person had extra costs amounting to 24-35% of their income (Zaidi & Burchardt 2003, in McInnes 2014), and the corresponding rate of poverty rose from 25% to 30-32% (McInnes 2014). Another author suggested that the income needs of a disabled person should be weighted to be 1.56 times that a non-disabled person when calculating poverty thresholds (Kuklys 2005, reported in Heslop 2013).

The recent innovation of the SMC's definition of poverty was, in part, to capture the extra costs people incur as a result of disability. However, their early estimates used the disability benefits people received to capture this element. They are seeking ways to address this limitation (SMC 2019).[16]

The extra costs people incur depend on the nature of their disability

Moreover, estimates of poverty and the extra costs disabled people face also vary widely because of the different nature of different disabilities and how costs are attributed to them (Heslop 2013). These can only be measured properly in national data if the nature of someone's disability is also captured well. The standardised (so-called harmonised) definition of disability for UK surveys (such as is used in the Family resources survey) asks about 'any physical or mental health conditions or illnesses lasting or expected to last for 12 months or more' and the impact of these on people's ability to carry out day-to-day activities. It also asks about types of impairment, also using a harmonised approach, but not specific conditions (such as diagnosed conditions).

The SMC's approach also has the advantage of addressing the issue of persistent and severe poverty; and it takes account of housing and other fixed costs well. In time, it is intended to account for debt repayment and the costs of social care.

Towards a recommended approach to measuring poverty in the context of MS

Building only slightly on the SMC's model, and emphasising the need for more multi-faceted measures of poverty, Figure 2 shows how the experience of poverty may be more adequately captured in the context of MS.

This simple model has lived experiences at its heart, taking into account the SMC's focus on financial outcomes as they are reflected in the ability of

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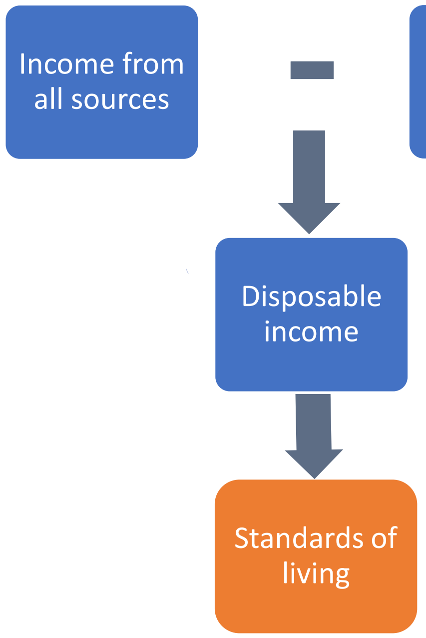
[16] The DWP is currently undertaking analysis of this measure to see whether and how it might be developed or improved: [DWP 'New poverty statistics developed to help government target support' (2019)].

Figure 2: Measuring poverty in MS



someone to make ends meet, rather than 'poverty' as a measure of income in a purely numerical sense. In this case, concepts of making ends meet are combined with key elements of material and social deprivation, and may be combined further to incorporate quality of life indicators to capture notions of 'standards of living' more broadly. And at its very simplest an adequate range and type of standard of living indicators may well be sufficient to capture the experience of poverty as a whole in the context of MS. These measures have potential to be developed and reported at the level of individuals and their households, for both people living with MS and their (non-family) carers.

In keeping with the approach used previously by Scope (e.g. Touchet and Patel 2018), there is potential to produce a Standards of Living Index as the overall measure of the experience of poverty among people with MS. This might further be informed and reviewed in a consensus-based approach among people who are, and those who are not, affected by MS which would consider acceptable living standards.[17] Statistical modelling may be used to test, refine and validate an Index (e.g. after Touchet and Patel 2018).

Measurement of 'poverty' may still to be undertaken according to this model and it may be reported in relation to people's disposable incomes as a headline rate (against a relative threshold as before). Use of alternative thresholds would enable the depth of poverty to be assessed as well. Rather as an end in itself, however, low disposable income by these definitions would be intended to explain some of these more meaningful financial outcomes which relate to someone's standard of living.

The measurement of disposable income in turn would be dependent on the comprehensive measurement of the income someone has available. This would take account of income from all available sources, including from earnings, benefits and other liquid assets which can reasonably be made available. These should ideally be calculated net of tax, housing costs and other fixed costs, as previously discussed.

It would also be dependent on adequate, representative measures of the extra costs someone with MS faces, from the extra costs of daily living to the costs of personal and social care incurred by the individual and their family. This adopts the approach used by Scope (e.g. Touchet and Patel

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[17] Following e.g. Mack 'Consensual method' and JRF 'Minimum Income Standards'

2018); however, it would extend the SMC's approach by ensuring that these costs are calculated on the basis of lived experience, rather than relying on proxies. A robust approach to identifying the appropriate costs for measurement should start with focus groups with people affected by MS.[18]

At each successive level of the model, measurement would need to be made in the household unit as a whole. This reflects both that incomes tend to be pooled at household level, but also that the financial impacts of MS (whether from the extra costs of living, costs of care or reduced earnings) may be incurred by the individual or their family members. The model can be applied in each case to the households of people living with MS, and/or outside informal carers. As noted, at the final stage, a mixture of personal and household measures can be captured.

Measuring MS

In order to measure poverty among people with MS, MS also needs to be captured adequately as a distinct condition or disability.

In 2013, Heslop recommended that MS should be mentioned explicitly in official definitions of disability, and this has since happened. The Equality Act 2010 makes explicit the inclusion of MS as a disability from point of diagnosis, as an exception, in a list of three potentially progressive and life-threatening conditions (cancer, HIV and MS).[19]

However, harmonised measures of disability disregard this exception and may therefore inadvertently exclude people with MS from their disability indicators.[20] Those which combine MS with the conditions noted in the Act's exception prevent disaggregation by MS as a specific condition.

Instead, some surveys – such as the latest Annual Population Survey for 2018 – asked about 'progressive illness not covered elsewhere', which includes MS and other conditions in a list of examples. Others, including the Family Resources Survey, use a harmonised definition of impairment type (as noted above).[21] This includes impairments such as problems with mobility, vision and hearing, but also includes problems with dexterity, memory and learning, understanding or concentrating which may also be of relevance to MS. Still they do not collect information about 'MS' as a diagnosed condition.

The exception to this is Understanding Society, which is a major longitudinal social survey of UK households. Understanding Society is funded by the Economics and Social Research Council and a consortium of government departments. As well as capturing a range of measures relating to the financial wellbeing of households (some of which are asked every year, others being rotated onto the survey every few years), Understanding Society does collect specific health conditions which have been diagnosed, including MS. Understanding Society also usefully collects other health and disability-related information, as well as information on care needs and caring responsibilities.

As it stands, Understanding Society represents the best source for understanding levels and the

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[18] Following e.g. Davies et al (2016): 'The Poverty Premium'.

[19] The Equality Act 2010 covers Great Britain. See also acas advice on the Equality Act.

[20] GSS (2019) 'Measuring disability for the Equality Act 2010'.

[21] GSS (2019) 'Impairment'.

experience of poverty among people affected by MS. Nonetheless, the calculation of a new measure of poverty which takes account of the extra costs of MS would not be possible with Understanding Society because it does not capture expenditure in sufficient detail.

Therefore, it is recommended that MS should be explicitly included in disability measures in studies as a distinct condition or diagnosis. This includes in official national surveys, but should also be made routine in smaller bespoke surveys carried out by other organisations which relate disability to poverty, hardship and other wellbeing outcomes. Understanding Society provides a model for measuring this well.

Whether in the absence of, or in addition to, an explicit measure of MS, the inclusion of the harmonised measure of impairment type should also be included as a minimum. This will allow for the complexity and nuanced nature of MS to be understood in relation to poverty and hardship.

In international literature, the Expanded Disability Status Scale (EDSS) has been used effectively to quantify disability among people with MS (e.g. Kobelt et al 2017, Stephens 2019). The Multiple Sclerosis Severity Score (MSSS) is an algorithm which measures relative disease severity and progression in MS (Svendsen et al 2018). There is also a 23-item Multiple Sclerosis Work Difficulties Questionnaire (MSWDQ-23) which captures MS-related work performance. While more complex to administer (and sometimes requiring clinical examination), these scales provide further options for the measurement of MS-related impairment. Moreover, they have been found to be predictive of the types of financial impacts considered in this report.

Still, it should be noted that social surveys may tend to underrepresent people with MS in their samples, and especially those with severe symptoms or cognitive impairment. People with disabilities are among the so-called ‘hard to reach’ in surveys. This is likely to be mitigated to some extent in household surveys (as opposed to surveys of individuals), in which other household members may act as the main respondent, providing key information about others in the household; although this will tend to underrepresent people with MS in single-adult households. Established longitudinal surveys, such as Understanding Society and the Wealth and Assets Survey, may go further still in mitigating the difficulties reaching people with MS, because a relationship with the survey is more likely to have been established before the onset of MS symptoms (and especially severe symptoms).

Conclusions

If poverty is a consistent lack of resources which leads to deprivation, then there is a distinct lack of evidence about the experience of poverty among people affected by MS. There is nonetheless clear evidence of higher levels and deeper experiences of poverty among disabled people (and their families), including for people with cognitive and visual impairments.

Estimates vary but suggest the poverty rate is around 1.5 times higher where disability is present than when it is not and is higher still in relation to deprivation. There are similar differences when severe or persistent poverty are considered. Other risk factors which compound the experience of poverty further among people with disabilities includes those with comorbidities (especially where mental health problems are also present), living on one’s own and living in a home that is rented.

It is reasonable to ask what is driving this pattern and to draw inferences in doing so about the picture for people with MS. MS is a complex neurological condition with often multiple and fluctuating or progressive impairments. Some of the symptoms, such as fatigue and cognitive impairment, are hidden. Others can be more obvious, such as problems with mobility and sight. It is the complex and unique nature of the condition for individuals which can make adapting to, and living with, MS especially difficult financially.

These difficulties translate into extra living costs, extra care costs and reduced capacity for employment and earning for people affected by MS. These factors represent intermediary financial impacts of MS which themselves lead and contribute to poverty. The implications of MS specifically and disability more generally on these financial impacts are strongly supported in the research literature.

The implications for the extra costs of living for people affected by MS could amount to several £1,000s annually, on average, although precise figures are unknown. Perhaps more than a half of people with MS pay for all or some of their social and personal care needs, which may cost as much as several £10,000s over someone's lifetime. The impact of MS on earning capacity is highlighted by significantly lower rates of employment among the economically active and higher rates of part-time over full-time working. What this amounts to in lost earnings over the lifetime is not known.

The corollary for people with MS is evidence of serious difficulties making ends meet day to day, including difficulties paying for food and fuel. There is also greater risk of exposure to debt problems, reduced capacity to build savings and wealth and clear evidence of negative impacts on quality of life outcomes, including worry about the future financially and impacts on family relationships and perceptions of self-worth.

Based on the available evidence, MS is linked both to the drivers of poverty and its outcomes. Although there is no direct evidence of MS as a specific risk factor for poverty, it is nonetheless reasonable to conclude that it is a major risk factor and leads to both higher levels of poverty overall and more severe and persistent poverty among those with MS.

Moreover, there is patchy, if consistent, evidence where it does exist that these impacts are felt beyond people with MS to their families and carers. Around two in five people with MS need informal care from friends or family, at an estimated cost of between €5,000 and €11,000 annually depending on symptom severity and the lifetime cost of MS to families has been estimated at substantially over £100,000.

Costs of MS to the NHS and society more broadly are indicated as being substantial but are rarely linked to issues of poverty. The closest available estimate for the effects of MS on poverty and on society relates to the indirect cost of MS to the UK among the working-age population, of £0.65bn, which derives from productivity-related and welfare-related costs.

A life-course view

The existing research has tended to focus on adults. We found very little research relating to children with MS even where poverty and hardship among families and households were considered. Among adults, a lot of the research has distinguished working-age and pensioners. This makes sense in relation to poverty and employment because income patterns and needs are different after pension-age; and the impacts are consistently found to be greater among people of working-age. Among disabled people generally the rate of poverty is particularly high among the under 45s.

The financial impacts which we have conceived of as outcomes of poverty are likely to be more acute among disabled people of working-age. This corresponds to life-cycle models of economics which predicts that borrowing as an investment in lieu of future income will tend to occur before and during child-rearing years, while net savings and wealth will tend to peak in early retirement.[22]

Where the role of MS is considered, there may tend to be a greater legacy of prior borrowing and for more mooted accrual of savings and wealth, flattening the curve of life-cycle models. This is because of the earlier typical onset of MS than many disabilities, leading to greater disruption to earning capacity over the lifetime. Additionally, there will be a tendency for the financial outcomes of working-age and older people with MS to diverge from each other more markedly where MS onset is late in life compared with typical onset in peoples 20s and 30s; since people who are diagnosed later will have been able to accrue more wealth.

In other words, employment and loss of employment are crucial intervening factors in the financial (and wider) wellbeing of people affected by MS. Differential impacts arise depending on when the onset of MS is felt and how well people with MS are then supported in their health and their employment.

Compounding factors

Financial wellbeing among people with MS is related to the severity and progression of the disease, its onset and duration, its complexity and comorbidity with other illness (including mental health problems). People with progressive, advanced and more severe MS typically incur greater financial impacts, especially via the impact of MS on employment (accessibility of work and working hours), and therefore on

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[22] E.g. Pettinger (2019) 'Life-Cycle Hypothesis'

levels of income. Early onset and long duration result in more significant financial costs to individual and their families, in part through the accumulation of disadvantage over longer periods of people's lives.

Neurological symptoms (and specifically cognitive impairment), mobility problems and visual impairment – all characteristic of MS – are especially linked to additional financial impacts. The finding that comorbidity adds to the financial impacts of disability is important for a condition like MS which is typified by multiple impairment types and higher incidence of depression and anxiety. Income-related and extra costs benefits disadvantage people with MS, in part because of the complexities of the condition and its often more hidden or fluctuating symptoms.

Financial wellbeing among people with MS is also likely to be influenced by other aspects of their circumstances. Based on findings for disabled people as a whole, poverty is higher among those living on their own and renting their homes. They are also more likely to be renting, and paying more for their accommodation as a result, and their homes are likely to be unsuitable or unsatisfactory.

Implications for policy and practice

Overall, people with MS need timely and joined-up interventions, which address their living, care and income 'costs'. This means linking Government support to what employers and health professionals do, but also setting benefits and support for care, and access to these, at a level that acknowledges the nature, complexity and severity of MS symptoms. It also means joined-up support across the health, social care and housing sectors to enable people to live independent lives for longer, including in their own homes, and protects them from rises in food, energy and rental prices, and urgent investment in social care.

The findings highlight the need for professionals to consider the direct costs of MS on individuals and families, but also the financial strain which results from it and the contingent impacts on people's quality of life.

A particular focus is needed in the first instance on supporting people to stay active in work for longer, which means ensuring early diagnosis and therapeutic intervention and enabling people to adapt their working lives as their symptoms change or progress. Employment should be an important health outcome for MS. More generally, support is needed to help people affected by MS (whether as individuals, families or carers) to achieve the right work outcomes for them, which may be to continue in work, reduce or even transition out of work, or to find fulfilling activities through non-paid work.

Some of the greater problems may reflect where people affected by MS are unaware of, or have difficulty negotiating, the sources of support that are available; across the Government, employer and third sectors. Even so, welfare benefits play a special role in the financial impacts of MS. The literature suggested that a reliance on benefits is both a key financial outcome of MS, and of poverty itself, and can help to alleviate poverty. However, the inadequacy of the current benefits system also appears to compound the experience of poverty.

Changes to the welfare state (including streamlining through UC), removal of some benefits and moving people between and reducing the sums provided by others may disadvantage people with MS. This is compounded where the system places importance on employment but fails to provide the support or opportunities for people with MS to benefit from employment.

Gaps in the research

Gaps in the research to date, as they relate to MS specifically, include key gaps in the measurement of poverty levels specifically among people affected by MS. We simply do not know how many people with MS, their families or their carers are income-poor or materially deprived or the nature and depth of their experiences. There is also nothing which tells us directly about how poverty is differentially felt by people at different life stages or the factors associated with MS and people's demographic and socio-economic circumstances which may increase (or mitigate) their poverty risks.

There is as yet no research which has estimated the extra costs of living to people with MS and their families in the UK. Given the significant impacts on employment observed among people with MS, an important gap relates to scale of earnings and incomes that are consequently lost, and this should extend to families (especially partners) and carers. There is patchy evidence at best in relation to the financial impacts of MS on social and personal care provision, and among carers (the latter being most acute in relation to poverty specifically); and the extra living costs which carers incur as a result of their caring responsibilities (formal or informal) are missing from the literature.

We also found no evidence about the financial impacts of MS in childhood, whether on those children, their families or their carers. And we need to know more about the availability, adequacy and impacts of other types of benefits – beyond PIP, DLA and ESA – on people affected by MS. Finally, an important gap appears to be in our understanding of the living arrangements of people with MS, especially in relation to their housing and housing costs.

Measurement recommendations

Levels of poverty are volatile, in part because of the specific definitions studies employ. Moreover, the measurement of poverty *per se* appears abstract; it fails to account for the *experience* of poverty itself.

This report suggests that the experience of poverty is more meaningful than any arbitrary threshold of income. These experiences are observed better through measures of someone's (and their household's) standard of living (strictly the outcomes of poverty), incorporating measures of material and social deprivation, and other aspects of the ability to make ends meet day to day. There may also be value in including quality of life measures in the assessment of standards of living, especially those that reference subjective measures of current and future financial wellbeing and strain.

Still, there are options for calculating and reporting an income-related poverty measure, based on disposable income. Recent innovations in measurement, and those of the SMC and Scope in particular, also emphasise the lived experiences of poverty. Within this, they advocate the measurement of the extra costs of living individuals and their households experience, although this has not yet been undertaken in detail. Moreover, there is a strong case for identifying and measuring the specific costs associated with MS. In keeping with the SMC's approach, these costs, along with care costs, would need to be subtracted from total incomes and other readily available resources (such as liquid assets).

The survey Understanding Society represents the best currently available source for understanding levels and the experience of poverty among people affected by MS. However, this report also recommends that MS should be included explicitly in disability measures in other major studies as a distinct condition or diagnosis. This includes in official national surveys, but should also be made routine in smaller bespoke surveys carried out by other organisations which relate disability to poverty, hardship and other wellbeing outcomes. This will increase the scope for measuring and understanding the experience of poverty in people with MS, particularly as a dynamic experience.

Whether in the absence of, or in addition to, an explicit measure of MS, the inclusion of the harmonised measure of impairment type should also be included as a minimum. This will allow for the complexity and nuanced nature of MS to be understood in relation to poverty and hardship. Consideration might also be made of extending measurement to the severity and progression of MS.

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Appendix: Methodology

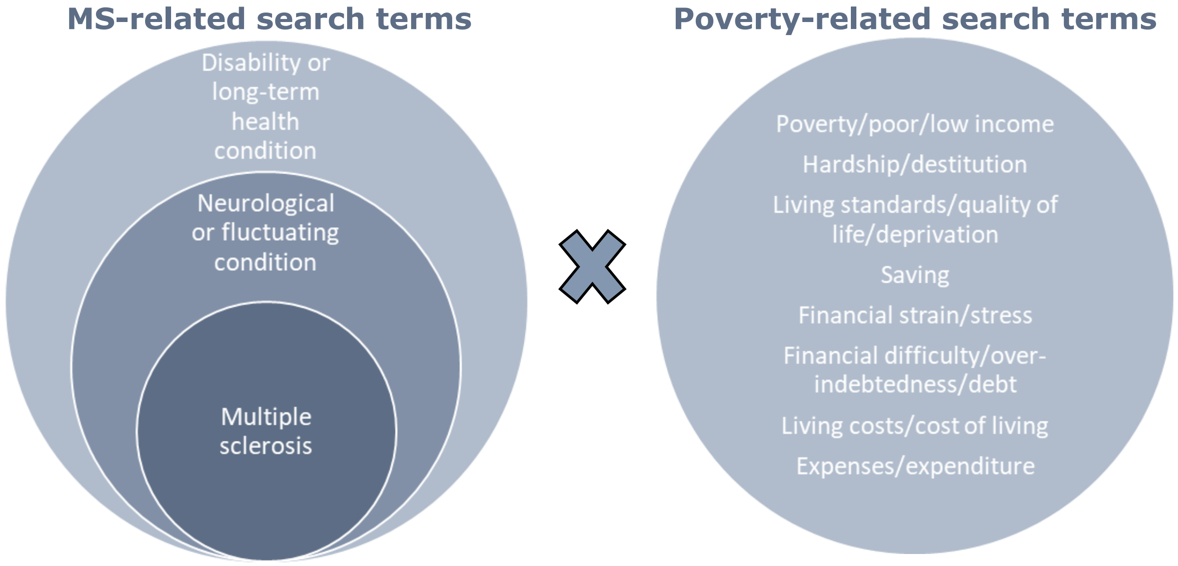
A rapid evidence assessment provides a framework to structure the literature search and data extraction and appraisal processes. This ensures that the review is robust and reduces the biases associated with traditional narrative reviews by adapting techniques from the systematic review methodology. In particular, it also allows for (and encourages) an assessment of the quality and validity of the literature, and ensures that appropriate weight is given to each piece of evidence.

Searching and screening the literature

The search was intended to be expansive but not exhaustive. Searches were limited to literature published from 2005 to 2019 inclusive (with the search undertaken in December 2019) and the main focus was on literature based on the UK context. Sources and search terms were agreed in discussion with the MS Society.

Academic and "grey" (i.e. non-academic research literature) were expected to be important and empirical and non-empirical (e.g. think-piece, campaign literature) was included. The search therefore encompassed a number of sources of literature, including online mixed (academic and grey literature) repositories, the publications webpages of government and sector (e.g. charity and research organisation in the health or poverty field, government) and other organisational sources including those of university and non-university research centres and think-tanks. I undertook a separate search of the Web of Science: Core Collection; one of the most comprehensive bibliographic databases of the social science and economics academic literature. A final search was made using Google to capture any other items.

Figure A1: Search terms



MS-related search terms

Poverty-related search terms

For each source, a series of systematic searches were made which prioritised 'multiple sclerosis' (and 'MS') and 'poverty' and then broadened these search terms out, as shown in Figure A1.[23]

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[23] The Web of Science search was more targeted than other searches, focussing on 'multiple sclerosis' (and MS), 'neurological' health conditions and 'fluctuating' health conditions.

Table A1: Initial search sources by source

Source type	Source	Initial returns
MS Society research brief	Literature review and items snowballed from these	30
Academic and non-academic mixed (23)	Personal Finance Research Centre library	12
	SRS library (my own)	1
	Financial Capability Evidence Hub (MAPS)	10
Government sources (23)	Department for Work and Pensions	11
	Department for Health and Social Care	3
	Government Statistical Service: Health and care statistics	3
	NHS England Statistics	1
	All-Party Parliamentary Groups (APPGs) for MS; Disability; Carers	✓ see*
	Parliamentary Briefings	5
Sector sources (e.g. health, financial wellbeing) (84)	*MS Society	14
	*Scope UK	4
	*Carers UK	5
	Health Foundation	0
	Health Poverty Action	0
	Kings Fund	3
	Joseph Rowntree Foundation	6
	Eaga Charitable Trust	2
	Bristol Poverty Institute (BPI)	5
	Poverty and Social Exclusion (PSE UK)	0
	Christians Against Poverty	0
	Financial Services Consumer Panel	1
	Money Advice Trust	0
	Trussell Trust	4
	Parkinson's UK	2
	Reform	5
	Demos	8
	Leonard Cheshire	3
	US National MS Society	8
	US National Disability Institute	5
	Disability Law Service	1
Other organisational sources (e.g. research centres, think-tanks) (22)	Institute for Fiscal Studies (IFS)	5
	ESRC Evidence briefings & Themed reports	0
	Institute for Public Policy Research (IPPR)	4
	Policy Studies Institute (PSI)	1
	Institute for Policy Research (IPR)	0
	Centre for Analysis of Social Policy (CASP)	1
	Centre for Research in Social Policy (CRSP)	2
	Centre on Household Assets and Savings Management (CHASM)	0
	CitA	9
Academic bibliographic databases (6)	Web of Science: Core Collection (which includes the Social Sciences Citation Index and many others)	6
Web search	Google	13

Adjustments were made to the search protocol to reflect where a source had a specific focus and only a partial search was needed (i.e. where a more specific search would have been redundant). Searches were made of full content wherever possible, and otherwise by topic, tag or title, to ensure as broad a search as possible. Duplicates were excluded as much possible prior to recording the initial returns.

Table A1, above, shows the sources searched and the number of initial returns identified as potentially in scope from each source. A total of 193 items of literature were initially screened-in and recorded. A first sift of these items identified 54 for exclusion as duplicates, inaccessible or because they were superseded by later report editions or were out of scope (by date, geography, content).

Sifting, sorting and classifying the literature

With too many items still to include within the constraints of the review, the remaining 139 items were subjected to a more detailed second sift. This identified the focus of each item in relation to MS and the emerging poverty topic (or definition; shown in Table A2). The items were sorted by poverty topic and items were selected as priorities for review within each topic based on providing good representation of each topic and having a stronger MS-focus. This second sift resulted in 89 items being selected. This included all 27 with a specific MS-focus, an additional eight which specifically mentioned MS (totalling 35 with specific mentions of MS) and three more which mentioned related conditions (e.g. chronic, fluctuating or neurological impairment). Table A2 shows how the final items were distributed by broad topic.

Table A2: No. of items reviewed by topic

Topic (an item could be in multiple topics)	No. of items reviewed	No. of items with specific MS mention
Poverty (e.g. low incomes, material deprivation)	18	6
Benefits	21	8
Costs of care	11	6
Costs of living	12	5
Debt	3	1
Employment	23	13
Equality	2	0
Financial capability	4	1
Financial exclusion	2	0
Making ends meet (e.g. ‘struggling’, financial difficulty, food and fuel poverty)	20	9
Quality of life	1	1
Saving and wealth	2	0
None or not categorised	2	1
Total	89	35

It is noteworthy that a portion of the literature addressed the relationship between poverty *per se* and disability/long term health conditions directly, and less still addressed the relationship between poverty *per se* and MS, despite this being the priority in the search and screening. Separately, only a handful of items (9) made specific reference to persistence (5) or severity (5) of poverty or hardship; and none of these referred specifically to MS. Items which covered *only* the measurement of poverty and were not counted in the final 89, but were considered in the review.

Data extraction and recording

For each of the final 89 items, key details of the literature were extracted, recorded and appraised. This was undertaken systematically using a standardised data extraction form. Details recorded included the methodologies and samples (to assess the robustness and reliability of the results) and what topics the research covers, summarising details of the findings or observations of the source. The data extraction form is provided in Table A3. Most of the items were extracted in full. However, for about a third of items – which had more peripheral relevance to the research questions – information was instead recorded 'in brief' (for key fields, shown shaded in Table A3, and based as much as possible on executive and other summaries).

Table A3 Data extraction template

Field	Sub-field
Reference	Author and date
	Sponsor/funding body
Aims	Research aims, questions and scope
Context	Definition of poverty/financial hardship
	Comments/critique of definitions
	Flag for persistent or severe poverty
Findings All information in this section is to relate to people with or affected by MS	Extent of poverty/financial hardship
	Groups most likely to be affected
	Factors driving poverty
	The influence of policy and funding changes/contexts
	Impacts of poverty on people and their families/carers
	Impact of poverty on NHS (inc. costs)
	Impact of poverty on wider society (inc. costs)
	Policy solutions for tackling poverty
Coverage	Unit of analysis
	Geographical coverage
	Population focus by life-stage
	Population focus by income
	Population focus by health
	Population focus by subject
Methodology	Research type
	Study design (if primary research)
	Study method (if primary research)
	Sampling (methodology, size and response rate where applicable) (if not lit review/think-piece)
	Year of study (if primary research)
	If secondary analysis, give survey name and year
	Study method (if literature review)
	Reviewer comments on methodology (biases, likely reliability and robustness)
Reviewer assessment	Limitations of the study, including definitions
	Any additional comments on relevance/quality
Reviewer rating	Relevance
	Quality
	Classification
Measurement	Considerations for future measurement

Author credits and acknowledgements

This report was written by Andrea Finney, an independent social researcher and applied statistician (www.socialresearchandstatistics.wordpress.com) and Honorary Senior Research Fellow at the University of Bristol's Personal Finance Research Centre (www.pfrc.bris.ac.uk).

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