

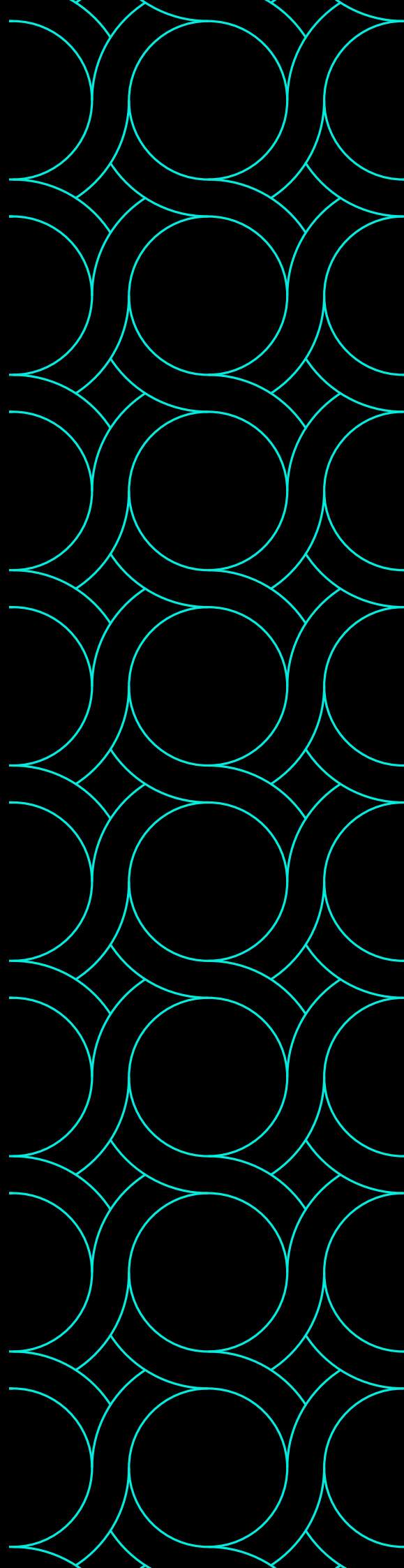


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Briefing document:
**Economic
security and
long-term
conditions**

Hannah Webster and James Morrison



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Author's note

Any errors are the authors' own.

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EXECUTIVE SUMMARY

Health and economic security are co-constitutive. Our research shows that people with multiple long-term conditions experience the greatest challenges in achieving economic security. This briefing document contains six policy recommendations aimed at supporting people with long-term conditions at different stages of their lives.

Executive summary

The Covid-19 pandemic has brought to the fore the intrinsic links between our health and economic security. The virus has both increased the risk posed by our workplaces on our health – particularly for key workers and those unable to work from home – and the reciprocal risk our health plays on our ability to work or earn an income, through the need to self-isolate, shield or care for the health of others around us.

But for many who live everyday with long-term conditions, Covid-19 has only exacerbated tensions that already dictated their economic security. Managing both physical and mental health conditions alongside financial health can be a burdensome and difficult task, and an experience which this research specifically seeks to explore.

A diagnosis, and going on to manage a condition, can be a physical, economic and emotional shock which our systems of support do not currently respond to with the flexibility and integration needed. Through new analysis of Understanding Society data we find that the diagnosis of a long-term condition has both tangible implications for financial health and an impact on an individual's subjective economic security.

Managing a diagnosis

When receiving a diagnosis, there may be both short- and long-term implications for individuals' wider lives and an impact on their economic security. In the immediate term, this might mean taking time off work to manage the diagnosis or any treatment it comes with, whilst in the longer term it might mean leaving employment altogether,

reducing hours or working more flexibly. In each instance those living with long-term conditions in particular move beyond a binary engagement with work or the benefits system and instead often interact with both. But this does not provide a guarantee of economic security.

In our research, we found:

- in the year following diagnosis there is a negative impact on individuals' incomes that lasts into the longer term and worsens over time
- those living with multiple long-term conditions have the highest rate of claiming one or more work, disability or housing related benefits, with a third in receipt of multiple benefits to support them.

Living with long-term conditions

Beyond the point of diagnosis, those living with one or more long-term conditions are faced with an ongoing economic security challenge. For many, economic security is derived from the benefits system as it is no longer possible to work or to find work that meets their needs. In the context of a safety net of state support that has been eroded over the past decade - with increased conditionality for work-related benefits and payment levels trailing inflation across a number of disability related benefits - this makes it extremely hard to maintain economic security.¹

And for those who continue to work (just over a half of those with multiple long-term conditions), the nature of employment options – be that through employers failing to accommodate the flexibility required to manage a long-term condition, the level of income for work that individuals are able to

¹ Personal Independence Payment and Disability Living Allowance each increased by around 0.5 percent between 2020/21 and 2021/22. A full list of annual increases by benefit can be found here: www.gov.uk/government/publications/benefit-and-pension-rates-2021-to-2022/benefit-and-pension-rates-2021-to-2022#disability-living-allowance

access or the use of zero-hours contracts which provide no certainty about income in the coming weeks – can all spell long-term precarity.

In our research, we found:

- those living with multiple long-term conditions face the greatest adversity in achieving economic security across a range of measures
- for those who are unable to work due to their health conditions, two-thirds report low levels of subjective economic security
- that a higher proportion of people in work with long-term conditions than without are employed on zero hours contracts or working part-time
- those living with multiple long-term conditions are the most likely to be in receipt of one or more benefits, and more than a quarter (28 percent) of those in receipt of Universal Credit and living with multiple long-term conditions are also in work.

Looking to the future

In combination, these challenges not only impact the financial situation of those living with long-term conditions in the present, but also speak to confidence in their future. This might be through anticipation of their future health or economic situation, compounded by their access to support or savings.

As we emerge from the Covid-19 pandemic, for many, these questions are top of mind as they look to how they might fit in with a changing working environment and uncertainty about the support from central and local services.

In our research we found:

- Those with multiple long-term conditions have the least optimism about their finances in the future and were the least likely to feel an improvement in their economic security over the first eight months of the pandemic.
- Covid-19 job losses were most acutely felt by those living with multiple long-term conditions, but furlough uptake did not differ by health status.
- Long Covid threatens the future of those with a previous diagnosis of one or more long-term conditions more frequently than those with no long-term conditions.

A recovery that supports those living with long-term conditions

Given the complexity of economic security, there are a range of institutions at both local and national levels and across the public sector, employers and financial systems that can better support those living with multiple long-term conditions to achieve economic security. Addressing a complex challenge like this requires a consideration of a range of avenues for change, and for those living with multiple long-term conditions this means considering the role of work as well as support outside of employment. Such a step change requires us to actively acknowledge the complexity and unique experiential dynamic of economic security, and to align systems of support to actively enhance and support economic security by design.

Recommendations

In light of these findings, we make the following key recommendations to national and local government, employers and integrated care systems (ICS):

- 1** To provide tailored support on economic security for those managing a long-term condition diagnosis, integrated care systems, in partnership with local authorities and job centres and other stakeholders, should establish local economic security hubs. These hubs should include key workers for people managing a diagnosis and operate on a prescription model.
- 2** To ensure that a need for flexibility at work does not undermine economic security, national government should expand eligibility for, and increase the level of, statutory sick pay.
- 3** To support the needs of people with multiple long-term conditions in work, and expand the suitability of employment options for those looking for work, local authorities should encourage employers to specifically support those living with long-term conditions with a commitment to health inclusivity for employers.
- 4** The Department for Work and Pensions must create a safety net that better supports people living with long-term conditions by reforming Universal Credit, Housing Benefit and Carer's Allowance. This should include a reversal of the cut to the £20 Universal Credit uplift.
- 5** With a view to exploring a new model of state support based on stabilising incomes and building security in the future, local authorities, with support from national government, should explore a Universal Basic Income (UBI) trial with a specific focus on health and wellbeing outcomes and those living with multiple long-term conditions. A trial in England would be the first of its kind.

- 6** National government must ensure that any recovery plan from Covid-19 includes a specific consideration of those living with multiple long-term conditions. This should include a risk assessment as furlough comes to a close and an inclusive design for the 'Plan for Jobs'.

We hope that this briefing and the supporting evidence acts as a catalyst for change and that as we emerge from the Covid-19 pandemic we place a specific focus on the needs of those living with long-term conditions.

Box 1: Defining economic security

The RSA defines economic security as "the degree of confidence that a person can have in maintaining a decent quality of life now and in the future, given their economic, financial and social capital".¹ This is a definition which includes critical components that contribute to economic security:

- It includes the subjective and cannot be predicted by objective circumstances alone.
- It is dynamic, related to the past, present and anticipation of the future.
- It is not binary, whilst security and insecurity are used in this work as opposites between them sits a multi-dimensional scale of experiences.

In this report we will refer to economic security and economic insecurity, which describes a low or absent degree of confidence.

We will make reference to 'subjective economic security', which we have derived from Understanding Society data. To create a measure of subjective economic security, we combined responses to two questions about subjective assessments of respondents' current and future financial situations within the main Understanding Society data. Together these take into account how they are managing now and in a years' time. Specifically, respondents are asked:

1. How well would you say you yourself are managing these days?

- a. *Living comfortably*
- b. *Doing alright*
- c. *Just about getting by*
- d. *Finding it quite difficult*
- e. *Finding it very difficult*

2. Looking ahead, how do you think you will be financially managing a year from now?

- a. *Better off*
- b. *Worse off than now*
- c. *About the same*

Combinations of responses were then categorised into four levels of economic security groupings: high, medium, low, and very low. This approach is outlined in full in the technical appendix and reference to subjective economic security in the data will be used to refer to this measure.

Box 2: Research hypotheses

This briefing is informed by data analysis conducted by the RSA of Understanding Society. Our analysis sought to quantitatively explore the prevalence and nature of economic security amongst those living with one or more long-term conditions.

In particular, we set out with three key hypotheses:

1. The experience of economic insecurity is acutely felt by those living with single or multiple long-term conditions.
2. The factors contributing to economic security vary from those living with no long-term conditions.
3. Covid-19 has added to the scale of insecurity for the general population and specifically for those living with long-term conditions.

We address these hypotheses by exploring a chronology of experiences for those living with one or multiple long-term conditions, including at the point of diagnosis, going on to live well with long-term conditions and looking ahead to the future.

We place a particular focus on those of working age who are navigating work, their health and preparing for the future. We also acknowledge that those living with one or more long-term conditions are not a homogenous group. The nature and implications of a long-term condition will vary depending on the diagnosis and a number of wider factors, and additionally, some may or may not have a registered disability. This will relate to their ability to receive certain kinds of support.

As set out in the supporting data for this briefing, our analysis suggests that each of these hypotheses are evidenced. For more detail, see our accompanying data deep dive.

More information on the methodology for this work can be found in the appendix of this briefing.

A DIAGNOSIS

MANAGING

Managing a diagnosis

The diagnosis of a first or additional health condition can be an emotional, physical and financial shock in an individual's life. Improving economic security, through the systems of support that surround us and tailored guidance at the point of diagnosis, can help those experiencing a period of uncertainty with their health to remain confident in their finances.

Our analysis shows the point of diagnosis is also a particular moment of financial precarity, with incomes directly impacted (see Figure 2). By looking over a series of successive years we see that those with no long-term conditions who remain in good health experience the highest growth in income, whilst those newly diagnosed with a condition over this period, or continuing to live with a condition, on average have lower income growth.

This might be due to a range of reasons, many of which interact. Specifically, for those navigating a diagnosis and any treatment that might follow, they may require a much more flexible working pattern, reduced hours or indeed to move out of work altogether. In each of these instances, individuals risk losing income and the offer of support from employers or the state tends to fall short of the income employment can bring. For example, for those moving onto statutory sick pay (SSP) their income will fall to £96.35 per week. By contrast, someone working full-time on minimum wage would earn £267.²

Though only one in four (26 percent) of employees in the UK with sick pay rely on SSP (as opposed to additional employer contributions), they are concentrated in certain kinds of work.³ Government data indicates that three quarters of managers are covered by non-mandatory sick pay, compared to just 43 percent of workers in caring, leisure and other

service occupations.⁴ We find that people with multiple long-term conditions are more likely to work in these sectors – and specifically health and social care - making exclusion from SSP a particular concern for this group.

Depending on their diagnosis, those unable to work in the longer-term, or unable to find work, might be eligible for a range of benefits, such as Universal Credit, Employment and Support Allowance (ESA), Personal Independence Payment (PIP) or others. Our research shows that over half (54 percent) of working age people living with multiple long-term conditions are in receipt of one or more work, housing or disability related benefits, compared to less than a third of those with no long-term conditions (29 percent) (see Figure 2).⁵ Of those with multiple long-term conditions, a third (34 percent) are in receipt of multiple benefits. Diagnoses can, therefore, lead to greater interaction with the Department for Work and Pensions at a time when individuals might also be increasingly engaging with a range of health professionals and institutions.

Our recommendations here seek to specifically mitigate the risk of an income loss, and to create a cultural shift in policy to reduce the burden on individuals. Instead, we should strive to create a forum for collaboration across systems, with a shared ambition of improving economic security.

- For an adult over 25 years old working 30 hours at a minimum wage of £8.91. UK Government (2021) *National Minimum Wage and National Living Wage rates*. [online]. Available at: www.gov.uk/national-minimum-wage-rates
- O'Connor, S. (2020) Threadbare sick pay is a false economy. *Financial Times*, [online] 27 October. Available at: www.ft.com/content/51aea217-4da7-423a-9e77-50eea30fe903
- Department for Work and Pensions and Department of Health and Social Care (2019). *Health in the workplace: patterns of sickness absence, employer support and employment retention*. [pdf]. Available at: www.assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/817124/health-in-the-workplace-statistics.pdf
- Specifically, one or more of: Income Support, Jobseekers Allowance, Child Benefit, Universal Credit, Incapacity Benefit, Employment and Support Allowance, Carer's Allowance, Disability Living Allowance, Personal Independence Payments, Attendance Allowance, Industrial Injury Disablement Benefit, Sickness and Accident Insurance, Foster Allowance, Maternity Allowance, In-work Credit for Lone Parents, Return to Work Credit, Working Tax Credit, Council Tax Reduction, Rate Rebate, Housing Benefit, Rent Rebate, any other disability related or state benefit.

Figure 1: Subjective economic security by health conditions, national

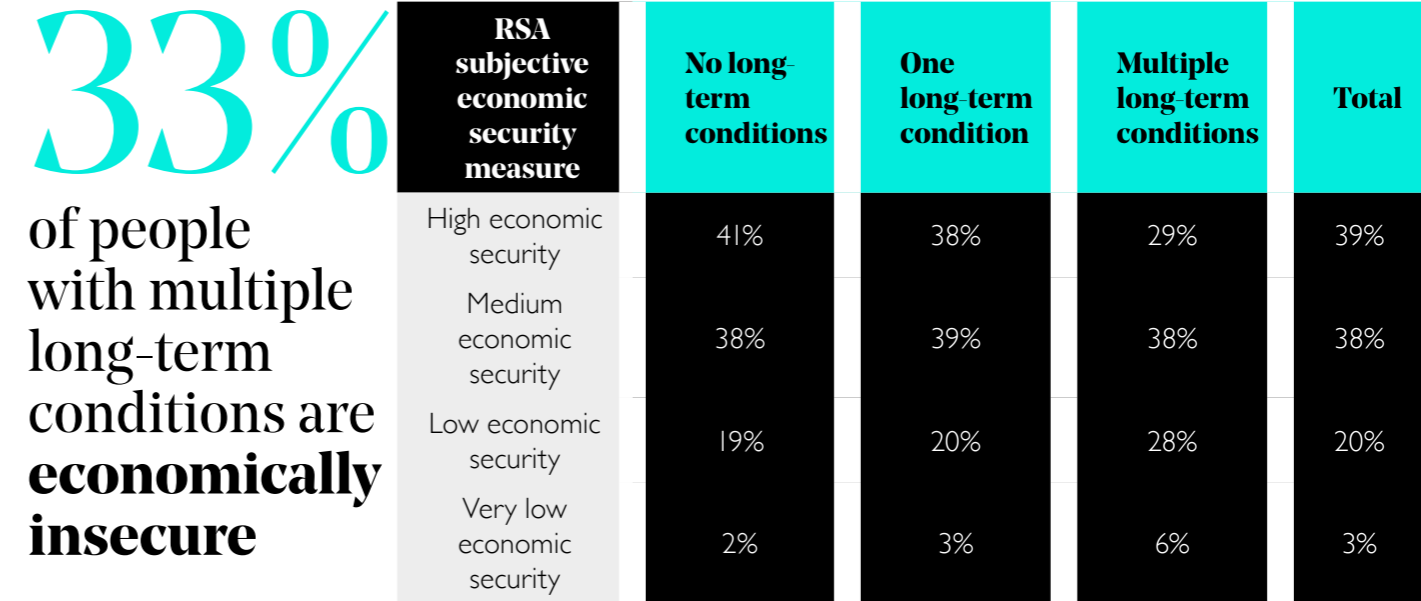
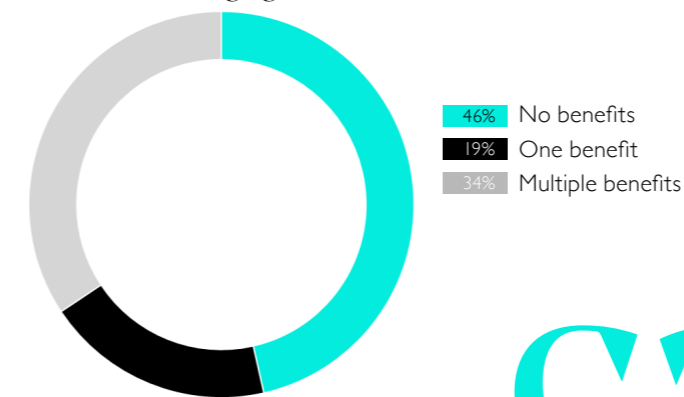


Figure 2: Number of benefits claimed by health condition status, national, working age



One in three working aged people with multiple long-term conditions are in receipt of **multiple benefits** - compared to 10 percent of people with no long-term conditions.

£2,323

The difference in mean gross annual income between people with multiple long-term conditions and the national average

Average annual income increase	Had long-term condition in previous wave	Did not have long-term condition in previous wave
Has long-term condition in current wave	£530	£757
Does not have long-term condition in current wave	£801	£1059

Year-on-year income increases are lowest for those who have been diagnosed with a long-term health condition

Recommendations

1 Provide tailored support on economic security for those managing a long-term condition diagnosis through local economic security hubs.

To ensure that people with long-term conditions are comprehensively and holistically supported to maintain economic security.

We recommend the remit of integrated care systems, defined in the Health and Social Care White Paper, to include a hub of services and support for their economic security, with tailored support for those managing a new diagnosis. This would include:

- A new role – an economic security advisor - designed to act as a designated point of contact for those living with long-term conditions, with outreach at the point of diagnosis.
- Collaboration between integrated care systems, local authorities, housing providers, Jobcentres (including Access to Work teams), employer representatives and local residents to design the necessary service offer within each local place.
- An offer of pooled local resources, referrals and advice for those living with long-term conditions and in need of additional support or information in relation to their current and future financial situation.

The period following a diagnosis is often stressful and navigating the complex system of support risks a detrimental impact on an individual's wellbeing. With commissioned services such as Macmillan welfare rights advice for those navigating a cancer diagnosis and local authority welfare rights offers unevenly provided across the country, the economic security hub would be an opportunity to ensure that all people managing a diagnosis have access to the same level of support.⁶

The Health and Social Care White Paper sets out a departure from Clinical Commissioning Groups (CCGs) and towards ICS, offering a timely opportunity to build infrastructure around economic security as a public health outcome.⁷ In particular, ICS Health and Care Partnerships have a remit to 'address the systems' health, public health and social care needs and action 'place based joint working between the NHS, local government, community health services and other partners such as the voluntary and community sector'.⁸ Given the interconnection of economic security with a range of health and public health needs, such a hub could be supported as part of this remit.

Individuals would be connected with this support on diagnosis through a prescription model, mirroring how social and medical prescriptions work and meaning that the service referral is built into existing systems. A hub would bring together opportunities for a range of local stakeholders to collaborate around service provision or information sharing according to the needs of the local area. By engaging those in receipt of such support and residents more widely, hubs can work to meet the needs of the population they serve by design.

Our recommendation for the establishment of economic security advisors would ensure those with long-term conditions are able to access the benefits they are entitled to following a diagnosis and help to navigate the labyrinthine welfare system. As a person's

6 Macmillan (2021) Welfare Rights Advice. [online]. Available at: www.macmillan.org.uk/cancer-information-and-support/get-help/financial-help/welfare-rights-advice

7 Department for Health and Social Care (2021) Working together to improve health and social care for all. [pdf]. Available at: www.gov.uk/government/publications/working-together-to-improve-health-and-social-care-for-all

8 Department for Health and Social Care (2021) Integration and Innovation: working together to improve health and social care for all. [pdf]. Available at: www.assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/960548/integration-and-innovation-working-together-to-improve-health-and-social-care-for-all-web-version.pdf

relationship with their diagnosis changes, the advisor would be able to refer them to employment or volunteer services and, where relevant, collaborate with Jobcentres.

Crucially, this would not be the end of the relationship. Recognising that a person may move in and out of work as their condition develops or things just don't work out at a job, the advisor would be on hand to offer support in accessing benefits once again. An advisor would be in place to offer as much or as little support needed to ensure their economic security and would span the breadth of contributory factors that affect an individual's economic security including – and not limited to – income, debt, housing and employment.

2 Ensure that statutory sick pay is sufficient and supports economic security at the point of diagnosis and beyond.

To smooth the transition in and out of work and reduce instability.

We recommend that central government reviews statutory sick pay to account for the following expansion of provision and rise in payment level:

- Eligibility to start from the first day of need (ie no waiting days).
- Removal of lower income limit for eligibility.
- Available for up to 52 weeks with a gradual taper across this period.
- Change payment to hourly and increase to 70 percent of pay with a lower limit of minimum wage and to a maximum of £2,500 per month.
- For those working on zero-hours contracts, pay should represent average hours worked in the last three months and, for all contract types, SSP should flexibly cover any hours not worked.

For those on low pay, or those who might experience more frequent bouts of leave due to a health condition, the system offers very little financial support and at the statutory level can equate to a loss of income. This increase to the level of statutory payment is suggested under the principle that loss of work due to sickness or ill health should not be a barrier to achieving economic security. For this reason the minimum payment level we recommend is a level of payment equated to the minimum wage as a lower limit and 70 percent of income otherwise. This would equate the UK's policy to the average across OECD countries.

Removing wait days should support people to take the time they need to manage a new diagnosis and the financial and personal implications this might bring, whilst the removal of the lower income limit should mean that there is no complete loss of income due to ill health. As an example, last year, RSA research found that 11 percent of all care workers (an estimated 79,000 people) earn less than £118 per week and are therefore ineligible for SSP.⁹ In this research we found that those living with multiple long-term conditions are more likely to work in the health and care sector than others.

Last year, the Resolution Foundation calculated that increasing SSP from £96 to £160 would entail a cost of £2bn, under the assumption that half of eligible employees were taking two weeks leave due to Covid-19 related sickness or isolation.¹⁰ Our recommendation to 70 percent of average earnings (£224) would represent a cost of closer to £4bn under these conditions, though this is likely to be the upper end as we move away from the pandemic and far less than half of eligible employees taking such leave. The government is currently running a

9 Jooshandeh, J. and Lockett, A. (2020) All clapped out? Key workers living through lockdown. [pdf]. Available at: www.thersa.org/reports/clapped-out

10 Resolution Foundation (2020) *Doing what it takes: Protecting firms and families from the economic impact of coronavirus*. [pdf]. Available at: www.resolutionfoundation.org/app/uploads/2020/03/Doing-what-it-takes.pdf

SSP rebate scheme for small and medium enterprises which offers a potential mechanism for support for employers to meet this cost.

Box 3: Sick pay in other countries

In recognition of the importance of financially supporting people to isolate and contain Covid-19, many members of the OECD (Organisation for Economic Co-operation and Development) have strengthened sick pay provision since the outbreak of the pandemic.¹¹ Across the OECD, sick pay covers on average 70 percent of an eligible employee's wage during a four-week spell of illness with Covid-19.¹² In many countries in Northern and Central Europe including Austria and Germany, the replacement rate is 100 percent. Though often supplemented by non-mandatory employer contributions, statutory sick pay in the UK only covers an average 10 percent of wages for a four-week Covid-19 illness. This is the third lowest rate among OECD countries, behind the US and South Korea. In fact, only a minority of countries' sick pay policies cover less than half of person's last wage, including most Anglophone countries, Italy, South Korea and Colombia.

¹¹ OECD (2020) Paid sick leave to protect income, health and jobs through the COVID-19 crisis. [online]. Available at: www.oecd.org/coronavirus/policy-responses/paid-sick-leave-to-protect-income-health-and-jobs-through-the-covid-19-crisis-a9e1a154/#figure-d1e652

¹² This is calculated for a full-time private-sector employee earning an average wage.

Living well with long-term conditions

Living well with long-term conditions

The experience of living with long-term conditions is not static and can mean navigating changing symptoms, treatment and the development of additional conditions. A life-long approach to elevating economic security for those living with long-term conditions therefore must include a flexible system that supports individuals to live well and according to their needs.

Our analysis shows how living with long-term conditions, and multiple long-term conditions in particular, can mean navigating complex economic circumstances. As Figure 4 shows, an individual's subjective economic security is closely related to their main economic activity, with a quarter (26 percent) of those in paid work (employed or self-employed) experiencing low economic security compared to two thirds (64 percent) of those who are long-term sick or disabled. We know (from Figure 3) that a quarter of people living with long-term conditions are out of work as a result of their health. Clearly, their conditions play a role in the determination of such differences and place a limiting factor on the ability of an individual to achieve a sense of economic security.

For those managing long-term health conditions and able to work it might not be possible to work full-time and our analysis shows that those living with multiple long-term conditions are more likely than those with no long-term conditions to work on zero hours contracts or part time hours. More is needed to understand to what extent this is the preference of those in this position and the reciprocal impact on their health and wellbeing.

We have already seen in Figure 2 that to make ends meet, those living with multiple long-term conditions are in receipt of benefits more commonly than those with one or no long-term conditions, and for one in three this means claiming multiple work, housing or disability related benefits. Amongst this group there is also a higher claimant rate of Universal Credit.¹³

The impact of this insecurity and financial strain means that those living with multiple long-term conditions report the highest levels of material deprivation (see Figure 5). Half (49 percent) of those living with long-term conditions say their household would be unable to replace worn out furniture and 42 percent to replace electrical goods. Crucially, their reported material deprivation reflects the whole household, showing the wider impact of a diagnosis on those they live with or support.

Our recommendations to support those living with long-term conditions are designed to ensure that regardless of the balance between work and state support an individual requires, all are able to achieve economic security. This requires both employers, local systems and national government to take action with this specific objective. It also requires us to move beyond an assumption that all work is good, and specifically consider how the conditions of work might actively support the health and wellbeing of those living with multiple long-term conditions. We take a household approach in acknowledgement of the interconnectedness of the personal and financial circumstances of those within the same home.

¹³ Note that the data collection period for this analysis of Universal Credit spans 2018-2020 during which time the Universal Credit roll-out is ongoing. Therefore we estimate the overall claim rate for Universal Credit at the point of publication to be higher amongst all groups.

Figure 3: Current economic activity among people with multiple long-term conditions (inner ring) and total population (outer ring)

Among working age people with multiple long-term conditions, a quarter are out of work due to long-term sickness or disability, but over half are in work.

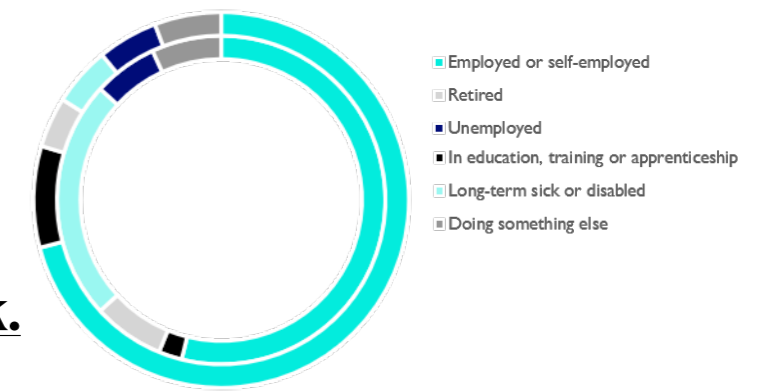
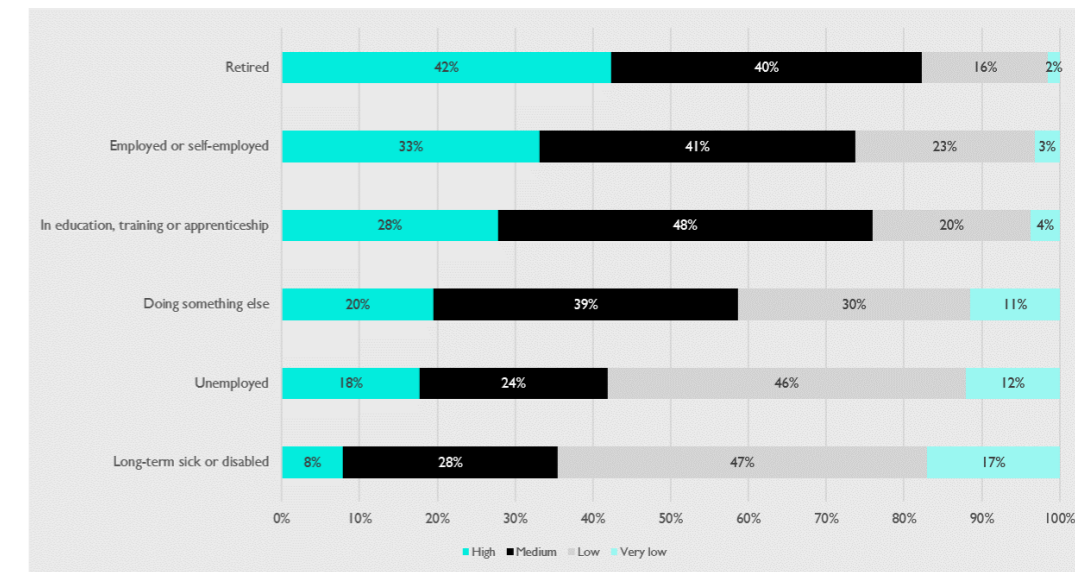


Figure 4: Subjective economic security by economic activity

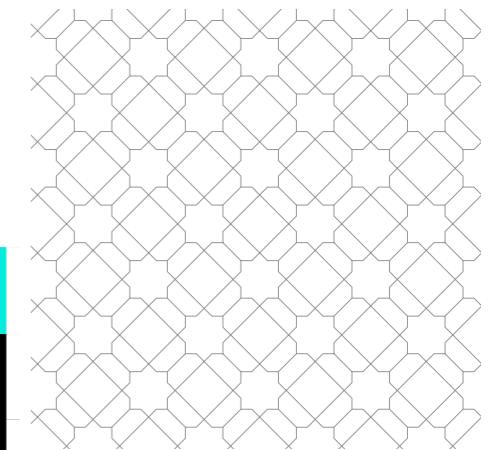
Those who are out of work due to employment or long-term sickness or disability report the lowest economic security.



Of those in work, people living with multiple long-term conditions are more commonly on zero-hours contracts or working part time.

Figure 5: Proportion of people unable to afford basic outgoings

Basic outgoing	Multiple long-term conditions	Total population
Replace any worn out furniture	49 percent	33 percent
Replace or repair major electrical goods	42 percent	27 percent
Save £10 per month regularly	38 percent	25 percent
A holiday away from home	40 percent	32 percent
Keep home in decent state of repair	27 percent	17 percent
Keep up with bills and repayments	12 percent	8 percent



People with multiple long-term conditions are less able to cover basic outgoings compared to the general population.

3 Encourage employers to specifically support those living with long-term conditions with a commitment to health inclusivity.

To make sure all employers recognise the value of their employees and meet their health and wellbeing needs.

As part of support for those with long-term conditions and our proposal for economic security hubs, integrated care systems should consult on and establish best practice commitments for local employers to specifically support those living with long-term conditions or periods of ill health and create an inclusive working environment where all employees can benefit from good work.¹⁴ These might include:

- Flexible working, including working from home.
- Hour guarantees, including a right to move away from zero-hours contracts.
- Leave to manage long-term conditions or to support someone you care for.
- Working conditions that meet the needs of current and future employees and actively support physical health, mental health and wellbeing.
- Wellbeing support for employees that might include independent employee assistance programmes.
- Greater guarantees that roles will be held for those returning from an extended leave of absence.

A number of local areas have good work charters or standards which seek to encourage employers to positively impact on the lives and health of employees. Many of these, including the London Mayor's Good Work Standard, consider the direct impact of work and employment on health and wellbeing.

However, a further consideration of the reciprocal impact of long-term conditions and periods of ill health on the ability to engage in work is needed in such standards

to ensure that work is inclusive, regardless of health considerations. We recommend a locally led employer commitment to best practice to support current and possible future employees living with, or recently diagnosed with, long-term health conditions.

This process might be managed through economic security hubs recommended in this report or through partnership between ICS, Jobcentre Plus and Access to Work schemes.

Such a commitment should draw on government guidance on employing disabled people and people with long-term conditions and opportunities supported by Access to Work schemes, but specifics should be informed by local employers, employees and prospective employees.¹⁵

Employers would benefit from a more inclusive working environment and increased capacity outcomes as employees are supported to continue in work. Such a working environment that actively supports the health and wellbeing of all employees could see benefits in productivity and reduced absence.¹⁶

More generally, commitments would give confidence both to those living with long-term conditions and those who do not have a diagnosis but might need support or flexibility in the future. In return, employers can reference their commitment and local Jobcentre Plus and Access to Work schemes could recommend these employers to job seekers.

¹⁴ The RSA and Carnegie Trust's Measuring Good Work identifies eight measurable dimensions to good work; that is work which meets the needs of those taking part in it and which actively supports their health and wellbeing. Namely; terms of employment, pay and benefits, health and wellbeing, job design and nature of work, social support and cohesion, voice and representation, and work-life balance. More can be read at: The RSA (2018) Measuring Good Work. [pdf]. Available at: www.thersa.org/reports/measuring-good-work2

¹⁵ Department for Work & Pensions (2020) Employing disabled people and people with health conditions. [online]. Available at: www.gov.uk/government/publications/employing-disabled-people-and-people-with-health-conditions/employing-disabled-people-and-people-with-health-conditions

¹⁶ HM Government (2005) Health, work and wellbeing: caring for our future. [pdf]. Available at: www.gov.uk/government/publications/health-work-and-wellbeing-caring-for-our-future

In this way such a commitment would encourage working environments that meet the needs of those with long-term conditions, and support those out of work to find appropriate and supportive workplaces.

4 Create a safety net that better supports people living with long-term conditions.

To ensure that nobody falls into poverty as a result of their health.

To support those living with one or more long-term conditions to take confidence that the state support offered to them will meet their needs, we recommend that the Department for Work and Pensions:

- Increase Universal Credit and Housing Benefit to:
 - Increase Universal Credit to at least make the £20 uplift permanent.
 - Return Local Housing Allowance to the median local rent.
 - Adjust Broad Market Rental Areas to smaller boundaries to account for local variation.
 - Begin from the point of application and not after a mandatory five-week wait.
- Reform Carer's Allowance to:
 - In the short term, introduce a taper to Carer's Allowance based on hours worked or income earned over the current cap.
 - In the long term, conduct a cost benefit analysis of an expansion of Carer's Allowance to a universal payment to all providing care to someone in their household and reviewing the level of payment.

Our research shows that two-thirds of working age adults living with multiple long-term conditions derive income from a range of work-, housing- and disability-related benefits. In combination, the above recommendations would help to provide

those living with long-term conditions with confidence that the benefits system will adapt to support them during a financial shock such as a diagnosis or a temporary or long-term progression of a diagnosed condition. This would support those with long-term conditions that do not meet the necessary requirements to claim for disability-related benefits.

Increasing Universal Credit and Local Housing Allowance payments should support those new to receipt of the benefit towards improved economic security. However, this alone will not guarantee the financial needs of those in receipt of such benefits are met. The Joseph Rowntree Foundation sets their Minimum Income Standard, that is the amount a household needs to earn to be able to meet a decent standard of living, at £325 per week for a single adult household.¹⁷ The benefit cap currently prevents those reliant on state benefit from an income greater than £258 per week. Clearly the system cannot support the economic security and wellbeing of those in receipt. The above recommendations relate to a minimum needed to step towards improved economic security. In the next chapter we will explore what a longer-term reform might look like.

Within the current system, in principle Universal Credit should accommodate for variable income through the tapering payment system based on previous monthly earnings. However, this is undermined by the initial five-week wait which requires recipients of Universal Credit to either go a month without income or to take out a loan to cover an advance payment. Neither of these alternatives support economic security and therefore we recommend the removal of the five-week wait. This would be possible by replacing the initial loan system with a grant system.

¹⁷ Minimum Income Standard (2021) Minimum Income Calculator UK. [online]. Available at: www.minimumincome.org.uk

Our research has shown that people living with multiple long-term conditions are the most likely to live in households that experience material deprivation. This data does not just reflect the experience of the individual, but rather shows how a whole household is affected by the economic implications of living with long-term conditions.

For those who are supported by unpaid carers within their household, the system disincentivises household economic security as the entire benefit is lost at a certain income and working hours cap. Moving to a taper system, whereby any income earned above this limit is matched with a gradual decrease in Carer's Allowance would reduce the disincentive for those providing care to engage in work to increase their household income.

In the longer term, a review of Carer's Allowance is needed to ensure that the design of the benefit is fit for purpose. We recommend an exploration of a more universal system for those providing unpaid care including the potential impact on the economic security of households in receipt. Specifically, this would mean removing the conditionality related to the number of hours of care provided and income earned.¹⁸ This would acknowledge the increased costs associated with providing care and the societal value of unpaid care work whilst supporting the ability to work flexibly.¹⁹

Box 4: Building the evidence base

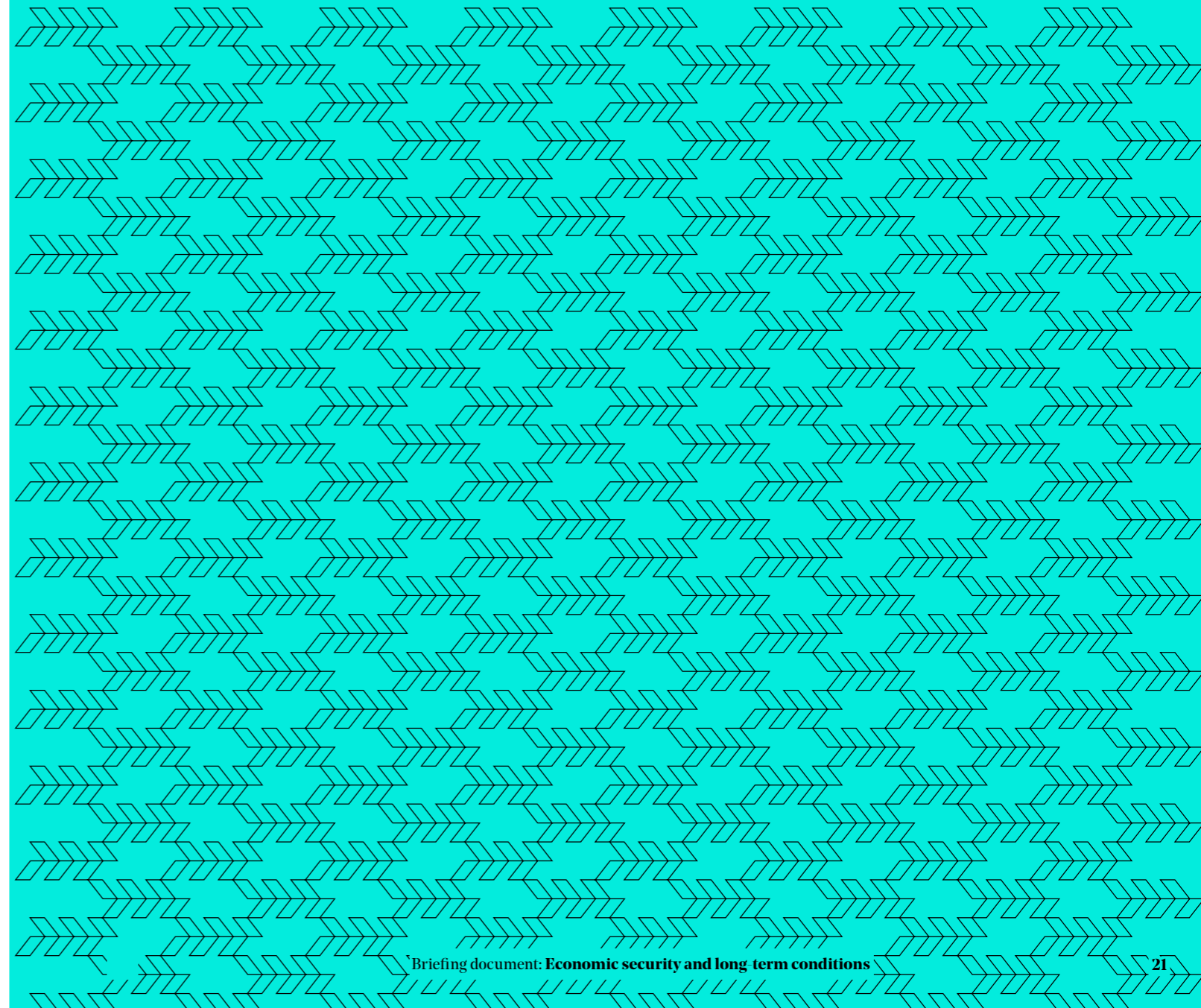
Our quantitative analysis of the experiences of those living with one or more long-term conditions suggests employment on zero-hours or part-time contracts is higher amongst those in work with multiple long-term conditions. The implementation of our recommendations around living well with long-term conditions should include a consideration of this group but to fully support their needs we need to know more about the experience of these contracts in combination with managing one or more health conditions. For example, Understanding Society does not allow us to explore the motivations for engaging in this work, whether individuals feel they have a choice or what their preferred working pattern and hours would be.

Further research on these areas would ensure that economic security hubs and a commitment to health inclusivity as recommended would be able to support individuals across different working patterns.

¹⁸ Currently Carer's Allowances is provisional on supporting someone in the same household with at least 35 hours of care and an income of no higher than £128 per week.

¹⁹ Department for Work & Pensions (2020) DWP benefits statistical summary, February 2020. [online]. Available at: www.gov.uk/government/statistics/dwp-benefits-statistics-february-2020/dwp-benefits-statistical-summary-february-2020#:~:text=The%20total%20number%20of%20people,have%20contributed%20to%20this%20rise

LOOKING TO THE FUTURE



Looking to the future

Economic security is defined by its relationship across time horizons. In order to derive confidence in the present, individuals must feel positive about their future and their ability to support themselves and those dependent on them over time and across changes in circumstances.

Our analysis shows that those living with multiple long-term conditions are the least optimistic about their financial future, with 13 percent reporting a sense that they will be better off financially in a years' time (half the rate of those with no long-term conditions at 27 percent).

The idea of the progression of a health condition might play a role in this group's anticipation of the future as well as their experiences of economic security and financial health to date. Balancing financial or work-based opportunities with enhanced confidence that they will receive the support they need from our health and social care systems is critical to improving the economic security of this group and an area we feel needs more consideration.

Our central recommendation in this chapter speaks to the volatility that plays out for those who feel limited in the types of work they can carry out, or where managing a health condition into the long term can mean needing to take time to focus on this throughout the course of someone's working life. By embedding more universal support and hoping to stabilise incomes, we hope that those living with long-term conditions will feel more confident in their economic futures.

This is more pressing now than ever. As we look to a recovery from the Covid-19 pandemic, we need to ensure that those living with multiple long-term conditions

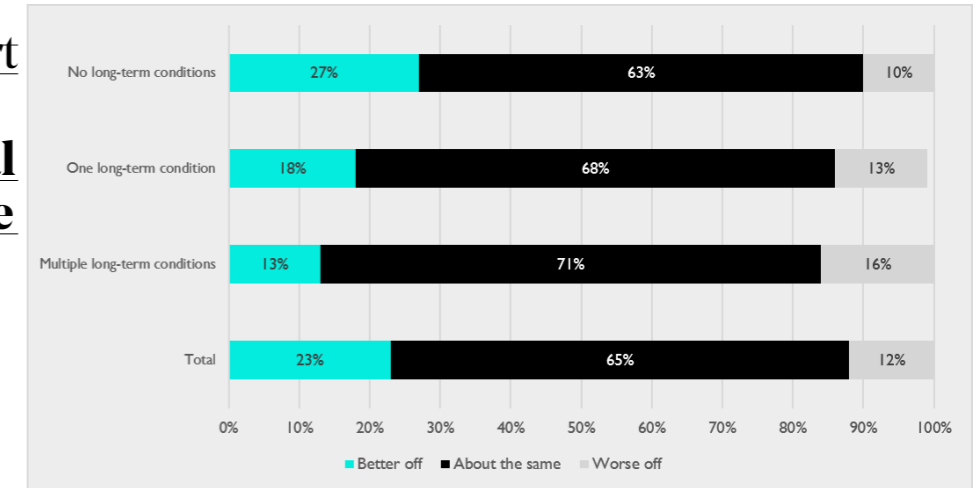
are actively supported to improve and sustain their economic security. Particularly as this group are just half as likely to have seen their economic security improve over the early months of the pandemic compared to their counterparts with no long-term conditions (see Figure 7).

With our analysis showing that the groups are facing increased risk to their work – with the highest loss of work during the pandemic, see Figure 8 – and their health – with the highest rates of Long Covid, see Figure X.X – over the course of the Covid-19 pandemic it is essential that we seek innovative new opportunities that support them to live well.

Our recommendations attempt to overcome these specific challenges, but to truly support the economic security of those living with long-term conditions, a cultural shift is needed to reframe what state support looks like and the opportunities it provides.

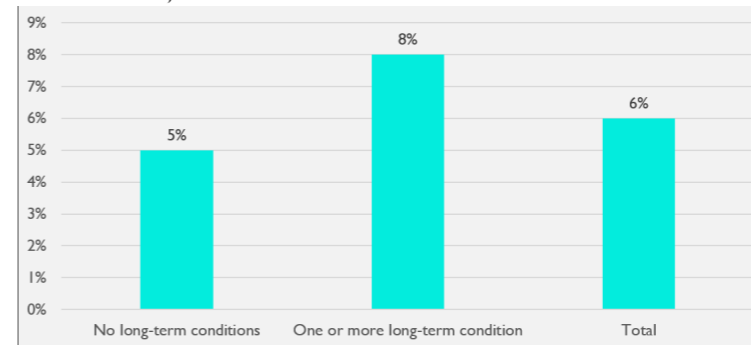
Those with no long-term conditions report optimism about their future financial situation at twice the rate of those living with multiple long-term conditions

Figure 6: Expectation of financial situation in one year by health conditions, national



62% of people with multiple long-term conditions are **unable to save regularly** compared to 52 percent of the total population.

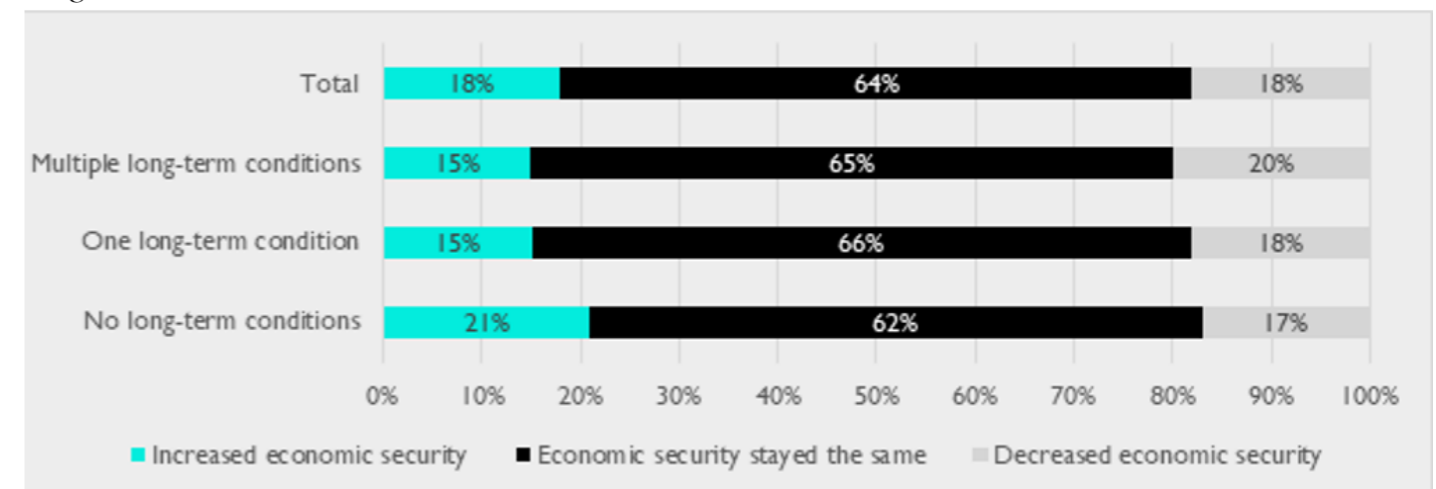
Figure 8: Percentage of those in paid work in April 2020 no longer in paid work by November 2020 by long-term conditions, national



One in five

(21 percent) people with no long-term conditions have increased their economic security in the pandemic, compared to 15 percent of people with multiple long-term conditions.

Figure 7: Change in economic security April to November 2020 by number of ever diagnosed long-term conditions



1 in 12

people with one or more long-term conditions reported leaving paid work in the first six months of the pandemic.

5 **Stabilising incomes for those managing health conditions and their economic security to build confidence in the future.**

To develop security and stability now and in the future.

We recommend that a Universal Basic Income trial is explored in England, with a view to ensuring state support keeps apace with a changing landscape of employment and complex individual needs. We recommend that the Department for Work and Pensions:

- Collaborates with a small number of local authorities to design and trial a Universal Basic Income which:
 - Is designed with input from those experiencing low economic security, including specifically those living with multiple long-term conditions to ensure that the trial is inclusive and accessible.
 - Specifically recruits those living with multiple long-term conditions from a range of economic activities including in work, out of work due to long-term sickness or disability and unemployed, and spanning intersection with a range of current benefits.
 - Explores a liveable income with the potential for supplementary payments for those living with specific needs, such as those currently covered by disability related benefits.²⁰
 - Includes at least three locations to account for place-based differences in context and allows for comparative analysis of impact, with at least one of these locations being an inner-city region.

Universal Basic Income, or guaranteed income, is an acceleration of institutional changes discussed elsewhere in this report which aim to create a flexible system which accounts for complexity over the longer term.

A UBI offers a number of points of differentiation from the current system of benefits. In particular, for those living with one or more long-term conditions, the lack of conditionality and the universality of its design means that individuals can derive greater confidence in their future compared to a system which includes complex evidence of circumstances and sometimes sanctions. Universality means that a UBI or similar would be available to all residents, regardless of citizenship status. Most UBI models, including previous designs from the RSA, see universal payments sitting alongside needs-based benefits such as disability support.²¹

A UBI has the potential to simplify the system, and in doing so, to reduce the harm to wellbeing that is derived from managing multiple benefit payments and having to repeat difficult circumstances to a range of different people and institutions. The absence of conditionality would also mean that those living with multiple long-term conditions, but not able to adequately provide evidence to receive support through disability-related benefits, would have more autonomy over the kinds of work they enter in to. Getting a bad job is often worse than having no job for this group, and a UBI could provide the security and freedom to only take on work that works for them.

20 The poverty line is calculated to be 60 percent of the median equalised net household income. Using Understanding Society data, we calculated the national poverty line to be £1010 per month and the London specific poverty line to be £1142. These figures were calculated using the OECD household equivalence scales.

21 Painter, A., Cooke, J., Burbidge, I. and Ahmed, A. (2019) A basic income for Scotland. [pdf]. Available at: www.thersa.org/globalassets/pdfs/rsa-a-basic-income-for-scotland.pdf

22 Ibid.

6 **A recovery from Covid-19 that supports those living with long-term conditions to rebuild and sustain economic security.**

To recognise that the needs of people with long-term conditions must be at the centre of economic development during the recovery from the pandemic.

In addition to the recommendations already explored in this report which should help those living with multiple long-term conditions in the emergence of the Covid-19 pandemic, central government should:

- Conduct a risk assessment to inform tailored support for employers and employees after the end of the furlough scheme. Specifically, such an assessment should seek to understand:
 - Which roles and sectors are at the greatest risk as furlough comes to an end.
 - The intersection of furlough with existing and Long Covid related health conditions.
 - Ensure that all stages of the Chancellor's Plan for Jobs programme are designed inclusively to support people living with long-term conditions.
 - Explore a care-led approach to the economic recovery, underpinning a social care recruitment drive with a review of economic security in the sector.

With government support packages – such as furlough and the Universal Credit uplift – coming to an end, it is essential

In addition to the benefits associated with unconditionality, there is evidence that shows a fiscal benefit to individuals under such a reframing of the system. For example, previous research from the RSA suggests that a basic income of £5,000 per annum would eradicate destitution in Scotland.²² Going further, a UBI payment calculated according to a minimum income standard would be more generous than existing benefits and, though the direct impact on health, wellbeing and poverty requires further research, has the potential to lift many people with multiple long-term conditions out of poverty by providing a comprehensive safety net for people who may have to move in and out of work more frequently. Our research shows that 15 percent of people with multiple long-term conditions live below the poverty line, rising to 35 percent of those in receipt of Universal Credit.

We therefore recommend exploring a range of payment levels and their impact on those living with multiple long-term conditions in the design of any trial.

While there have been a number of international UBI trials, a trial with the principles outlined here would be important for a number of reasons. It would be the first UK UBI trial and would have a focus on the impact of payments on the intersection of health and economic security. The potential benefits of this have already been modelled theoretically and the multidisciplinary challenges mapped.²³ Furthermore, it would be the first local authority based UBI trial in England and including areas with different characteristics (eg urban, rural, peri-urban) would offer insights into how UBI might be more effectively deployed at a national level. Lastly, exploring a range of payment options in the trial design allows us to understand the potential of an ambitious scheme on people's economic security.

23 Lancaster University (2021) The health case for UBI. [online]. Available at: wp.lancs.ac.uk/healthcaseforubi/; Johnson, M, Johnson, EA, Nettle, D and Pickett KE (2021) Designing trials of Universal Basic Income for health impact: identifying interdisciplinary questions to address, Journal of Public Health. Available at: doi.org/10.1093/pubmed/fdaa255.

24 Department for Work & Pensions (2021) 'Plan for Jobs' skills and employment programmes: information for employers. [online]. Available at: www.gov.uk/guidance/plan-for-jobs-skills-and-employment-programmes-information-for-employers#skills-bootcamps

25 Department for Education (2021) List of Skills Bootcamps. [online]. Available at: www.gov.uk/government/publications/find-a-skills-bootcamp/list-of-skills-bootcamps

that there is not a cliff-edge for those at risk of losing their jobs or income. By conducting a risk assessment of roles and sectors, support into the longer term can be designed to ensure that viable jobs are supported. Any such risk assessment should include a consideration of how roles have been impacted for those living with long-term conditions during the pandemic, including the relationship with Long Covid, shielding and other diagnoses over this past year.

Even with tailored support, there will be job losses still to come. But the government's flagship jobs recovery programme, Plan for Jobs falls short of providing the needed support for those living with multiple long-term conditions, despite their disproportionate job loss over the pandemic. For example, the only dimension of the plan directed at those seeking work and not specifically for young people is the Skills Bootcamp proposal.²⁴ Currently, an emphasis is placed on construction, engineering and digital skills.²⁵ But our research shows that those living with multiple long-term conditions are less likely to occupy roles in the construction sector than their counterparts with one or no long-term conditions. As this plan continues to be implemented, government should outline how the interventions included are appropriate for and can be tailored to support those with multiple long-term conditions.

An expansion of bootcamps to the health and social care sector is one way that the plan might better support those with multiple long-term conditions. We know from this research that this is a sector more heavily populated by those with multiple long-term conditions (see accompanying data dive). Additionally, given the strain on current services and a need to reform the sector (see accompanying data dive), a care-led recovery plan for skills and jobs would support those living with multiple long-term conditions both through increased service provision and job creation.

In order for a care-led recovery to fully support economic security of those employed in the sector or potential employees, reforms will be needed. A commitment to health inclusivity for good work (see recommendation 3) would be a start, and in particular a review of the use of minimum wage and zero-hours contracts.

Box 5: Building best practice

Across our recommendations we are asking a range of stakeholders at the local and national level to make changes to the level or nature of their support for people living with long-term conditions. In order to do this effectively and sustainably it is important that the voices of those with experiences of living with one and with multiple long-term conditions are able to participate in such changes. Underpinning each of these recommendations, therefore, we recommend opportunities for participation to support the design of new process, practice or payments from a diverse group of residents living with long-term conditions. This should include those currently in work, in receipt of a range of benefit payments and those who are not currently in work. By working collaboratively with those affected by these policy and practices, actors in the system of support can be confident that they are taking steps to genuinely support the economic security of this group and are accounting for different experiences.

Appendix: About the data

This enquiry into the economic security of those living with long-term conditions is largely based on RSA analysis of the most recent data publications from the Understanding Society study. Namely, this includes wave 10 of the main study (2018-2020), and wave 1-6 of the Covid-19 study (April - November 2020).^{26,27}

The data collated considers a range of dimensions of economic security, defined across wider work from the RSA, and explores these experiences for those living with no, one or multiple long-term conditions. A case study focus is placed on the case study area Lambeth and Southwark which offers an insight into the particular experiences in an urban, inner-city context.

To support the data analysis from Understanding Society, this report also makes reference to wider contextual statistics. Each of these are referenced as they appear in the report.

About Understanding Society

The Understanding Society study is funded by the Economic and Social Research Council and is led by a team at the Institute for Social and Economic Research at the University of Essex.

The principal data source for this research is Understanding Society. Understanding Society is an annual household longitudinal study with over 34,000 respondents. This includes an ethnic minority boost sample to enable subgroup analysis for ethnic minorities. The study covers all ages, though in our survey we restrict our analysis to those over 16 years old. The

study also covers the whole of the UK. When we refer to national data, therefore, we mean the data of England, Scotland, Northern Ireland and Wales.

Limitations of the data

When reading and interpreting the data there are a number of considerations and limitations it is important to remain mindful of. Some of these have been covered in earlier sections of this Appendix but are reiterated here for the sake of being explicit.

- Base sizes

Whilst at the national level the size of the survey affords us with usable minimum base sizes across most data points, naturally this decreases when looking at smaller geographical areas for analysis or specific subgroups. Unweighted base sizes are always listed in the charts in this report and the accompanying data tables and base sizes under 50 should be taken with caution.

In particular, caution should be taken in interpreting the data specific to Lambeth and Southwark. A minimum base size of 50 respondents is not met for the Covid-19 Understanding Society data and therefore only main survey analysis is conducted for these local authorities. Further, for data representing these areas we have pooled the local authorities to ensure a necessary minimum base size.

²⁶ University of Essex, Institute for Social and Economic Research, NatCen Social Research, Kantar Public. (2020) Understanding Society: Waves 1-10, 2009-2019 and Harmonised BHPS: Waves 1-18, 1991-2009. [data collection]. 13th Edition. UK Data Service. SN: 6614, Available at: doi.org/10.5255/UKDA-SN-6614-14.

²⁷ University of Essex, Institute for Social and Economic Research. (2020) Understanding Society: COVID-19 Study, 2020. [data collection]. 4th Edition. UK Data Service. SN: 8644, Available at: doi.org/10.5255/UKDA-SN-8644-4.

We recommend interpreting the data for Lambeth and Southwark as a case study group of respondents and do not make direct comparisons with the national data due to the vastly differing base sizes.

- Missing or new long-term conditions

Due to the approach taken to defining multiple long-term conditions there are some limitations in what conditions are named and therefore potential undercounting of the number of conditions. For example, anyone with two or more unlisted long-term health conditions will only be coded once as having an 'other' health condition. In this instance, they would be counted as having a single long-term condition and not the multiple conditions they may have.

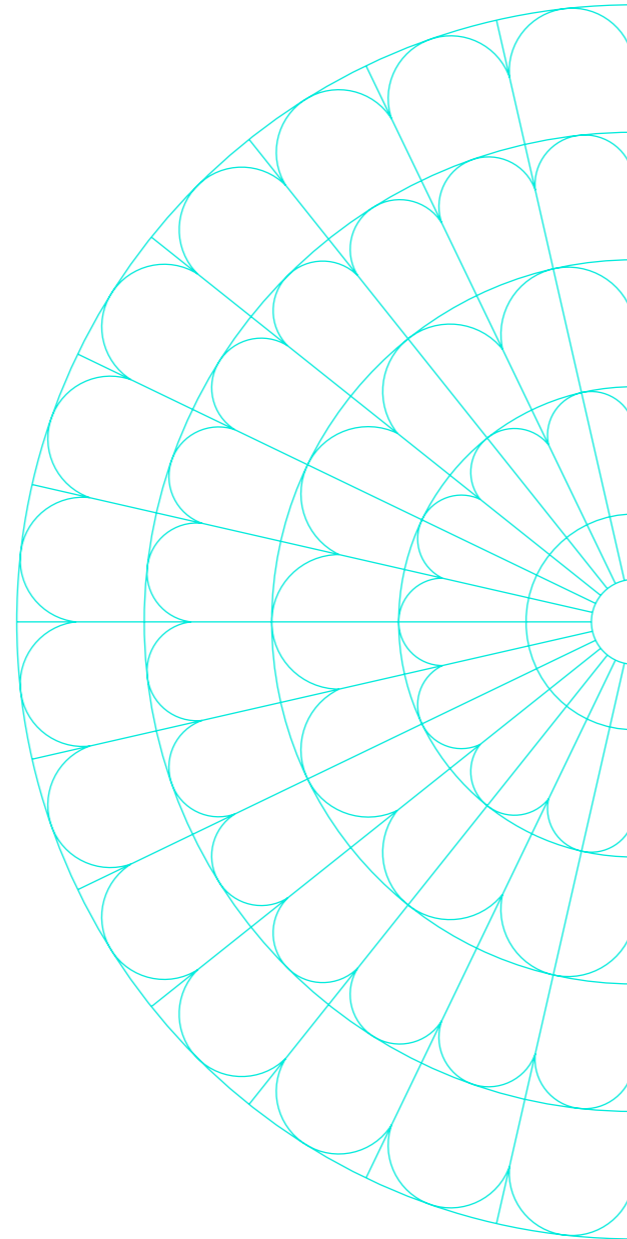
The definition of long-term conditions used does not account for how long ago a condition was diagnosed meaning that recent diagnoses are considered alongside diagnoses that have been known for longer.

- Differences across survey stages

As outlined in the discussion of the definition of multiple long-term conditions, there are some differences in the wording or inclusion of questions between the mainstage and Covid-19 Understanding Society surveys.

Most critical to this work is the omission in the Covid-19 data to confirm whether an individual still has a diagnosed health condition and therefore the two surveys are not directly comparable in this data. We therefore only consider trends within the mainstage data or within the Covid-19 data but not between the two. This means that there appears to be a higher reported incidence of single or multiple long-term conditions in the Covid-19 data as opposed to the mainstage.

More information on the data and approach taken in this report can be found in the technical appendix.



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RSA

8 John Adam Street
London WC2N 6EZ
+44 (0)20 7930 5115

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